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FALL 2011 FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE VOL. 4 NO. 2

Understanding and Addressing the Unique Needs of Individuals With Asperger's Syndrome and High Functioning Autism

An Autism Spectrum News Interview With New York State OPWDD Commissioner Courtney Burke

By David H. Minot, BA
Publisher
Autism Spectrum News

It has been six months since Courtney Burke was appointed Commissioner of the New York State Office for People With Developmental Disabilities (OPWDD). Among the many things she has accomplished since that time, Ms. Burke has completed a statewide Listening Tour focused on issues concerning individuals in her agency's care and their family members, as well as those of OPWDD's 23,000 employees. She has also made protecting the health and safety of individuals with developmental disabilities the top priority, and is enacting systemic reforms to this vast system that serves the needs of over 126,000 individuals in New York State.

Autism Spectrum News is pleased share our recent interview with Commissioner Burke to familiarize you with her background and her immediate and long-term plans for OPWDD, an agency vital to the ever-growing needs of the autism community in New York State.

Courtney Burke

Q: How does your background prepare you to serve as Commissioner of OPWDD?

A: A great deal of my background relates to my new duties as Commissioner of OPWDD. My entire career has been devoted to improving how government services are delivered, with a great deal of experience working in health and disability policy.

I received my Master's Degree in health policy and management from the School of Public Health at the University of Albany, where I worked on a project of the Department of Health aimed at refining the processes for improving durable medical equipment for people with disabilities through the Medicaid program. This project was designed to revamp how Medicaid was executed.

After that, I worked at the New York State Office of Advocate for Persons with Disabilities, which later merged into the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD). I spent seven years working on a wide range of issues for people with disabilities including early intervention, school services, employment, Medicaid, Medicare, and health care. My time at the Office of Advocate for Persons with Disabilities provided me with a global view of the various issues concerning how agencies often have difficulty working together.

From 2007 to 2011, I served as Director of The Nelson A. Rockefeller Institute of Government's New York State Health Policy Research Center (HPRC), where I oversaw all health policy research. I directed projects involving the administration of long-term care under the Medicaid program, health reform implementation, Medicaid financing, Medicaid waivers, Medicaid funding for nonprofits, policies for expanding private insurance coverage, and looking at what states were doing that was innovative in terms of delivering care. This experience is helping me here at OPWDD, as we are now moving forward with an 1115 Demonstration Waiver. My national research on different types of demonstration waivers is applicable for my work at OPWDD. NYS Governor Andrew Cuomo was looking for

see Interview on page 28

Educational Rights and Legal Considerations for Your Young or Adult Child with Asperger's or High Functioning Autism

By Sheryl R. Frishman, Esq and
Amy C. O'Hara, Esq
Littman Krooks, LLP

Over the last several years in our Special Needs Planning and Special Needs Advocacy practices, we have seen a significant increase in clients having a family member with high functioning Autism or Asperger's Syndrome. Although not exhaustive, this article is intended to provide an overview of the common legal issues these families face.

School Age Services

If a school aged student is diagnosed with high functioning Autism or Asperger's Syndrome (hereinafter referred to collectively as "Asperger's") and has special needs that rise to the level of requiring special education services, he or she would be classified and receive an Individualized Education Plan ("IEP").[1] The Individuals with Disabilities Education Act ("IDEA") requires that the school district provide a classified student with a "Free and Appropriate Public Education" designed to meet the student's "unique needs and prepare them for further education, employment or independent living." Due to the unique nature of Asperger's, these students are usually functioning at or well above their "typical" classmates academically. Thus, students with Asperger's would most likely not be appropriate for many of the self-contained programs school districts offer for students with Autism. Consequently, students with Asperger's are typically educated either in a mainstream or collaborative (also known as "integrated" or "co taught") classroom settings. Nevertheless, students diagnosed with Asperger's typically function well below the norm both functionally and socially. Commonly, this is also coupled with extreme anxiety in social situations and changes in routine, attention issues, and/or sensory dysfunction. This requires the school district to tailor a student's IEP to emphasize the specific social and/or emotional needs, which impede the student's ability to learn and to make meaningful progress. Without that specific tailoring, the student, at times, could become oppositional, be isolated from their peers, and/or perceived as a discipline problem. Regardless of the

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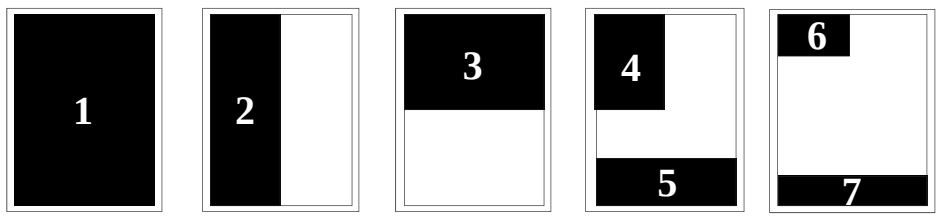

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Accepting and Embracing Individuals with Asperger's Syndrome

By David H. Minot, BA
Publisher
Autism Spectrum News

This issue of *Autism Spectrum News* represents a collaboration of over fifty individuals and organizations who are dedicated to improving the lives of children and adults with Asperger's Syndrome. I am so excited and motivated by the incredible response we have received to this issue's theme, "Understanding and Addressing the Unique Needs of Individuals with Asperger's Syndrome and High Functioning Autism." I wish to thank everyone involved in this Fall 2011 issue of *ASN* for not only volunteering your time to contribute to *Autism Spectrum News*, but also for your tireless devotion to improving the lives of individuals with autism spectrum disorders.

David H. Minot, BA

Imagine a utopian society that accepted the idiosyncratic personality traits often associated with Asperger's Syndrome (AS) without question or judgment. Just as different cultures and their differences are acknowledged, accepted, and accommodated in school, the workplace, and in everyday life, so would individuals with AS. Educators, peers, emergency first responders, employers, etc. would all be trained and educated about what makes individuals with AS unique, and how their brains function differently than those who are not diagnosed with AS. Social interactions where someone comes off as strange, off-putting, or perhaps rude would not be judged or stigmatized. Instead, these individuals would be accepted and appreciated for what makes them special.

Unfortunately, this world-wide acceptance and understanding is still a dream. However, with each passing day, many aspects of society are slowly adapting and becoming more accommodating and accepting of both children and adults with Asperger's Syndrome. With our ever-increasing awareness and understanding of how to best accommodate this special group of individuals, it is essential to implement and put into action what we have learned.

It is inevitable that teachers and support staff in our children's schools will at some point in time be working with children with AS. Treatment professionals and First Responders in the community must understand how to properly communicate with children and adults with AS. Employers must be made aware that, rather than being a burden or something to avoid, the employment of individuals with AS can offer many benefits to the workforce with a minimal amount of accommodation and understanding. With this combined effort, individuals with Asperger's Syndrome will be offered a much better chance at the full life they deserve as contributing members of society.

By devoting an entire issue of *Autism Spectrum News* focused on the needs of individuals with AS, it was our goal to highlight the many issues confronting the autism community and to increase awareness and education across all aspects of community life. For example, parents and educators can learn about the unique legal issues individuals with AS face by reading our front page article, "Educational Rights and Legal Considerations for Your Young or Adult Child with Asperger's or High Functioning Autism," by Sheryl R. Frishman, Esq and Amy C. O'Hara, Esq, of Littman Krooks, LLP. Also, first responders and public safety officials will greatly benefit from reading "The Impact of Bullying on Individuals with High Functioning Autism and Asperger's Syndrome" on page 12, written by Charles N. Cartwright, MD, and Victoria Bein, MA, MS of the YAI Network.

I urge you to share the articles in this issue of *Autism Spectrum News* with your professional colleagues and personal friends. The more informed and educated we are, the better we can serve and understand individuals with Asperger's Syndrome. You can view the entire issue on our website, www.mhnews-autism.org, and you can connect with us on Facebook to share and collaborate with our growing online family of readers at www.facebook.com/AutismSpectrumNews.

We have an exciting lineup of themes for the coming winter, spring, and summer issues of *Autism Spectrum News.* Our upcoming Winter 2012 issue (Deadline: December 5th) will be devoted to the theme, "Science Matters: The Latest Advances in Autism Research." Next spring we will take an in-depth look at "Transitioning into Adulthood: Navigating the Complex Changes Ahead." Next summer we will take a compelling look at "Vital Supports and Services in the Community."

As always, I look forward to reading your articles and hearing your comments, suggestions, and ideas. Please feel free to call me at (508) 877-0970 or write to me at dminot@mhnews.org.

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Winter 2012 Issue
"Science Matters: The Latest Advances in Autism Research"
Deadline: December 5, 2011

Summer 2012 Issue
"Vital Supports and Services in the Community"
Deadline: June 5, 2012

Spring 2012 Issue
"Transitioning into Adulthood: Navigating the Complex Changes Ahead"
Deadline: March 5, 2012

Fall 2012 Issue
"The Importance of Early Intervention After Diagnosis"
Deadline: September 5, 2012

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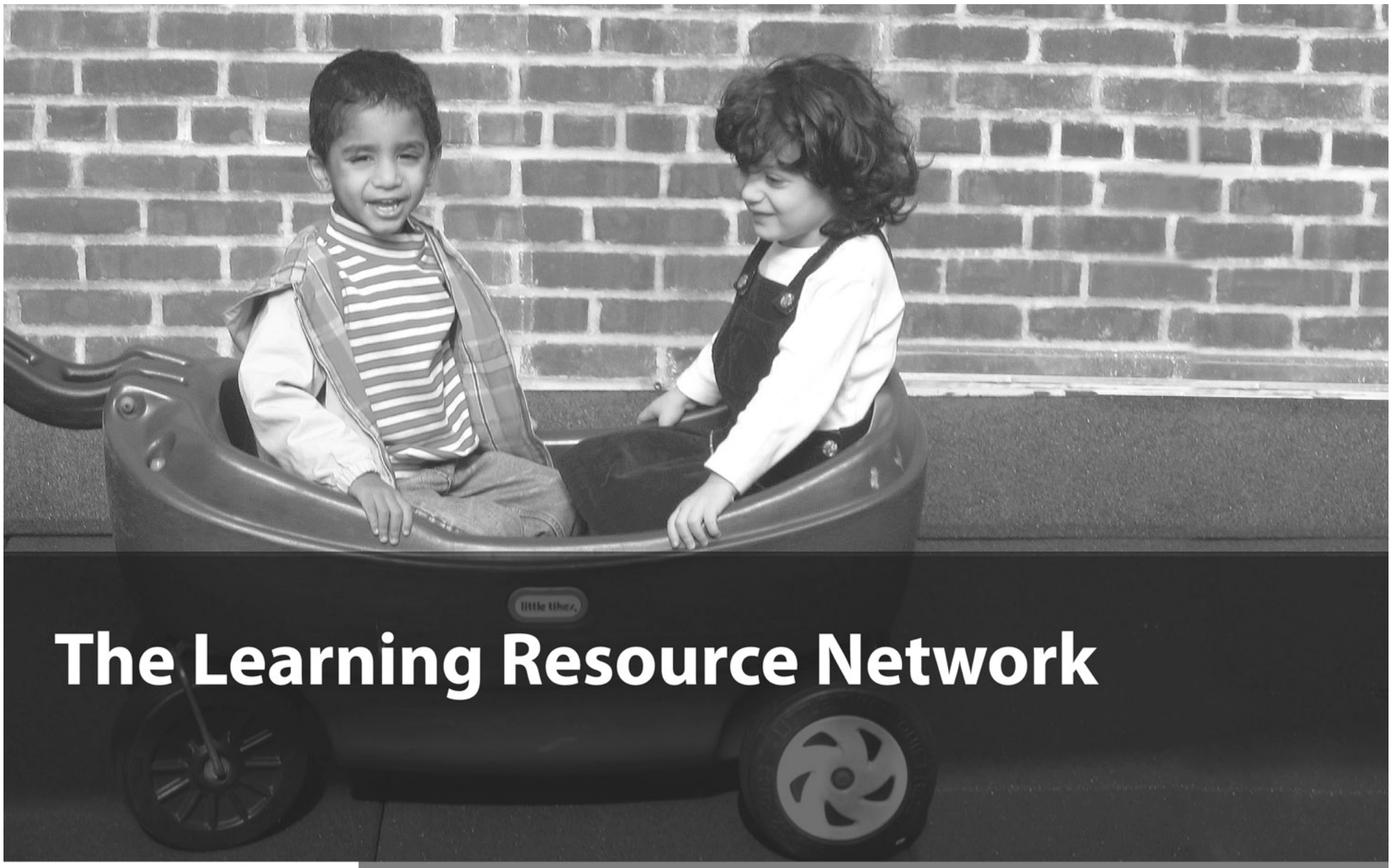

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AUTISM SPECTRUM NEWS DESK

Balance Towards Environment as Heritability Ebbs in Autism

Non-Inherited Genetic Factors Also a Consideration

By The National Institute of Mental Health (NIMH)

The largest and most rigorous twin study of its kind to date has found that shared environment influences susceptibility to autism more than previously thought. The study, supported by the National Institutes of Health, found that shared environmental factors - experiences and exposures common to both twin individuals - accounted for 55 percent of strict autism and 58 percent of more broadly defined autism spectrum disorders (ASD) (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml). Genetic heritability accounted for 37 percent of autism and 38 percent of ASD. Random environmental factors not shared among twins play a much smaller role.

Earlier twin studies had estimated the genetic heritability of autism to be as high as 90 percent, due to much lower estimates of concordance - both members of a twin pair having the disorder - in fraternal twins. The new study found such concordance to be four to five times higher.

"High fraternal twin concordance relative to identical twin concordance underscores the importance of both the environment and moderate genetic heritability in predisposing for autism," explained Joachim Hallmayer, M.D., of Stanford University, Palo Alto, Calif. a grantee of the NIH's National Institute of Mental Health. "Both types of twin pairs are more often concordant than what would be expected from the frequency of autism in the general population. However, the high concordance among individuals who share only half their genes relative to those who share all of their genes implies a bigger role for shared environmental factors."

Hallmayer, senior co-investigator Neil Risch, Ph.D., of the University of California, San Francisco, and colleagues report on findings of the California Autism Twins Study (CATS) in the July 2011 issue of the Archives of General Psychiatry.

"These new findings are in line with other recent observations supporting both environmental and genetic contributions to ASD, with the environmental factors likely prenatal and the genetic factors highly complex and sometimes not inherited (www.nimh.nih.gov/about/director/2011/autism-spring.shtml)," said NIMH director Thomas R. Insel, M.D.

Studies are under way to determine if autism may be traceable, in part, to environmental exposures (www.niehs.nih.gov/health/topics/conditions/autism/index.cfm) early during pregnancy.

The new study is the first to analyze a large sample of twins drawn from the general population; previous twin studies have been based on more limited samples, such as patients in treatment. It is also the first to employ the latest standard in diagnosing autism, which requires structured clinical assessments based on interviews with the parents as well as direct observation of the child.

see Environment on page 39

Early Motor Experiences Give Infants a Social Jump Start

Study Indicates Infants at Risk for Autism Could Benefit from Motor Training

By Klaus Libertus, PhD
Research Scientist
Center for Autism and Related Disorders
Kennedy Krieger Institute

In a new study published on September 9, 2011 in the journal *Developmental Science* (Epub ahead of print), researchers from the Kennedy Krieger Institute and Vanderbilt University found that early motor experiences can shape infants' preferences for objects and faces. The study findings demonstrate that providing infants with "sticky mittens" to manipulate toys increases their subsequent interest in faces, suggesting advanced social development.

This study supports a growing body of evidence that early motor development and self-produced motor experiences contribute to infants' understanding of the social world around them. Conversely, this implies that when motor skills are delayed or impaired – as in autism – future social interactions and development could be negatively impacted.

"Our results provide us with a new way to think about typical, and also atypical, development," said Klaus Libertus, PhD, the study's lead author and a research scientist at Kennedy Krieger Institute's Center for Autism and Related Disorders. "The mind is not independent from the body, especially during development. As motor skills advance, other domains follow suit, indicating strong connections between seemingly unrelated domains. Such connections have exciting implications, suggesting that interventions could target the motor domain to foster social development."

Klaus Libertus, PhD

Previous research has found that infants diagnosed with autism spectrum disorders (ASD) show less interest in faces and social orienting. While the current study was conducted with typically developing infants, it indicates that infants who are at risk for ASD or show signs of abnormal social development may benefit from motor training as early as 3 months of age.

"For parents, this means that early motor development is very important and they should encourage motor experiences and active exploration by their child," said Dr. Libertus. "Fostering motor development doesn't have to be complex or require sticky mittens. Any interactions or games that encourage a child to develop independent motor skills are important."

In the study, the researchers divided 36 typically-developing 3-month-old infants into two groups – one receiving active motor experiences and the other receiving passive experiences. Infants in the active group were given mittens affixed with strips of Velcro, known as "sticky mittens." The researchers observed as infants in the active group played with the "sticky mittens" for 10 minutes each day for two weeks. While wearing the mittens, a brief swipe of the infants' arm made toys, also covered in Velcro, "stick" as if the infant had successfully grasped the object. Parents first demonstrated this by attaching the toy to the mitten, but then the toy was removed and the infant was encouraged to independently reach for the toy again.

In the passive group, infants were fitted with aesthetically similar mittens and toys, but without Velcro. Passive infants also played with the mittens and toys for 10 minutes each day for two weeks, but were only passive observers as parents provided stimulation by moving the toy and touching it to the inside of the infants' palms.

After two weeks of daily training, the researchers tracked the infants' eye movements while they watched images of faces

see Motor Training on page 30

AUTISM SPECTRUM NEWS DESK

Risk of Recurrence of Autism in Younger Siblings Higher Than Thought

Risk Among Male Children Greater Than 25 Percent - Over 30 Percent for "Multiplex" Families

By The UC Davis MIND Institute

The risk that an infant with an older sibling with autism also will develop the disorder, previously estimated at between 3 and 10 percent, is substantially higher at approximately 19 percent, a large, international, multi-site study led by researchers at the UC Davis MIND Institute has found. While the study found a combined estimated risk for all participants of nearly 19 percent, it found an even more elevated risk of recurrence of over 26 percent for male infants, and over 32 percent for infants with more than one older sibling with autism.

The study is the largest prospective investigation of autism spectrum disorder and sibling recurrence to date. It is published online today and will appear in print in the September issue of the journal Pediatrics.

The study has important implications both for genetic counseling for parents and for referral to early intervention for the infant siblings of children with autism if concerns arise about their development, said Sally Ozonoff, professor of psychiatry and behavioral sciences at the MIND Institute and the study's lead author.

UC Davis MIND Institute researcher Sally Ozonoff with infant Cooper Stuart and his mother, Laurisa Stuart, during an evaluation for autism

"This is the largest study of the siblings of children with autism ever conducted," Ozonoff said. "There is no previous study that identified a risk of recurrence that is this high," she said.

Autism is a complex disorder that affects a child's ability to think, communicate, interact socially and learn. The U.S. Centers for Disease Control and Prevention places the incidence of autism at 1 in 110 children born today.

The participants in the study were enrolled in separate studies that are part of the Baby Siblings Research Consortium, an international network supported by Autism Speaks that pools data from individually funded research sites to facilitate the study of infants at high risk of developing autism because they have an older sibling with the condition. There is strong evidence that genetic factors play a critical role in vulnerability for developing autism.

Twelve consortium sites located in the United States and Canada participated in the study, with additional sites as far away as Israel engaged in analyses and interpretation of the data. The study included 664 subjects, infants whose average age at enrollment was 8 months, with two-thirds recruited prior to 6 months of age. The researchers followed the participants' development until 36 months, when they were tested for autism.

The study subjects were tested using the Autism Diagnostic Observation Schedule (ADOS), an autism diagnostic tool, and the Mullen Scales of Early Learning, which measures nonverbal cognitive, language and motor skills. Of the 664 participants, a total of 132 infants met the criteria for an autism spectrum disorder.

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Autism Science Foundation Named Number One Nonprofit Startup

"A Shining Star to Those Interested in Real Science and Evidence Based Interventions"

By Staff Writer
Autism Spectrum News

The Autism Science Foundation has been named the number one startup nonprofit in the "Disabilities" category by Philanthropedia/Guidestar.

GuideStar is a nonprofit organization working to help donors make smarter donations by connecting them with some of the highest impact nonprofits in a cause. The rankings are based on the recommendations of over six dozen experts in the field.

"We are thrilled to be recognized as one of the nation's most promising nonprofits" said Alison Singer, president of the Autism Science Foundation. "We are committed to funding critically needed autism research. The Guidestar designation should help all existing and potential donors feel very confident about supporting our organization, knowing that we use every dollar wisely, where it will have the greatest impact for families and individuals with autism."

Alison Singer

The Autism Science Foundation was founded in 2009 and began funding research grants in its first year of operations. It has increased its funding levels each year. Since 2009, it has funded nearly half a million dollars in autism research.

Guidestar reported the following about the Autism Science Foundation on its website:

- ASF has made a great contribution to empirically valid information on autism spectrum disorders.
- This group funds outstanding autism research that is totally science based. They are a shining star to those interested in real science and evidence based interventions.
- We find this group to operate with the highest level of integrity. They also have extremely low overhead. Every dollar possible is put toward autism research.

All the information collected and research used by Guidestar to compile the rankings are available at www.myphilanthropedia.org/startups/national/people-with-disabilities/autism-science-foundation.

In August, the Autism Science Foundation issued a Request for Applications for 2012 Pre- and Post-Doctoral Fellowships (www.autismsciencefoundation.org/applyforagrant.html). In September, ASF will co-sponsor the KIDA Autism Summit in Irvine, California. Former First Lady Rosalynn Carter will give the keynote address. In October, ASF will sponsor the Rockland County Autism Symposium in Pearl River, New York. Dr. Temple Grandin is the featured speaker at this annual event.

The Autism Science Foundation is a 501(c)(3) public charity. Its mission is to support autism research by providing funding to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization 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's programs visit www.autismsciencefoundation.org.

Support For Parents in Teaching Emotional Regulation Skills

By Lisa Guy, PhD
Psychologist and Senior Scientist
Center for Autism Research at
The Children's Hospital of Philadelphia

In addition to the defining features of an autism spectrum disorder (ASD), many individuals with Asperger syndrome (AS) and high functioning autism (HFA) also have difficulty with both awareness of their own emotions and their ability to regulate emotional expression. They may overreact in a negative manner to relatively minor events or fail to show emotions such as sympathy or excitement for someone else's success. This can lead to significant problems in their behavioral functioning and in their relationships with others. There are likely biological causes for the deficits in emotional processing seen in individuals with ASDs, such as impairments in the amygdala (a brain structure involved in processing emotions), which have been found in many persons diagnosed with ASD (Baron-Cohen et al. 2000). Although the cause may be biologically based, behavioral interventions aimed at teaching emotional regulation strategies can be very helpful. Including a focus on emotional regulation in the intervention plan is particularly important for those individuals who also demonstrate signs of an anxiety or mood disorder in addition to ASD, which can be common. Some studies have

Lisa Guy, PhD

reported that as many as 42% of individuals with ASDs also have an anxiety disorder (Simonoff et al., 2008).

Parent involvement is vital for successful interventions with children with ASDs (Reaven, 2010) and two sources of information may be very helpful for parents as they are thinking of ways to improve their child's emotional awareness (Clark, 1998). These include the concept of emotional intelligence and strategies from cognitive behavioral therapy. The term emotional intelligence was popularized by Dr. Daniel Goleman several years ago, and it includes the following skills: knowing our emotions, managing our emotions, motivating ourselves to achieve our goals, recognizing emotions in others, and managing relationships with others. The concept of emotional intelligence is independent from general intelligence or IQ (cognitive thinking and reasoning skills). Many individuals with AS and HFA have high IQs and do very well academically but seem to be lost when navigating the world of emotions.

A good beginning point is to teach individuals with AS or HFA to identify emotions and to be able to give them a name. At first, parents may have to label the emotions for the child based on how they think the child is feeling. As the parents do this, they role model for the child the skill that is being taught. Parents can use images of facial expressions that illustrate different emotions and provide their child with a written list of emotion words. It is important to teach positive as well as negative emotions. Giving a feeling a name helps the child to talk about his or her experience, which is an adaptive coping strategy. Parents can also talk about their own emotions as another way to role model emotional awareness.

A cognitive behavior therapy (CBT) perspective is also a very useful way of understanding emotions and has lead to highly successful treatments for mood disorders, some of which have been adapted for the unique needs of individuals with ASDs (Reaven, 2010). According to CBT, emotions are closely related to our thoughts and self-statements. Often our thoughts about a negative event can create more emotional upset than the actual event itself. The thoughts and self-statements often occur automatically and below our conscious awareness. There are common cognitive distortions that serve to worsen our emotional response to a situation, including using the words "always," "never," or "should." This may be a particular problem for individuals with ASDs due to their cognitive rigidity and tendency to focus on rules. They may perseverate on negative interpretations of events and have difficulty moving on to a more adaptive view. Therefore, it is important to help individuals with AS and HFA to become aware of their negative self-talk and to replace those thoughts with more adaptive ones. Parents can provide their child with a verbal script of positive self-statements to use when upset. It is important to practice these self-statements at a time when the child is calm so that he or she can use them more effectively during a time of emotional

see Regulation on page 27

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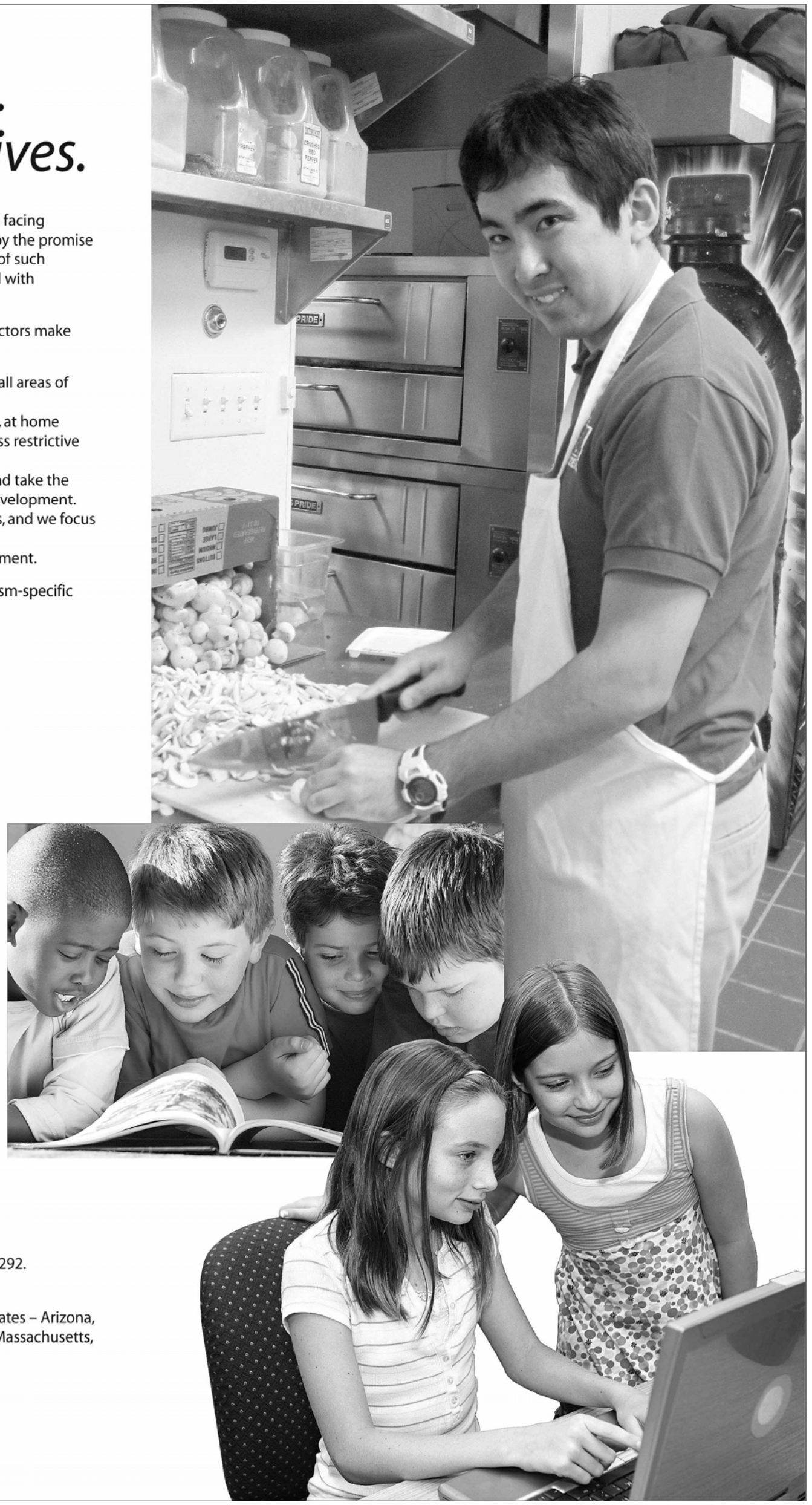

The Impact of Bullying on Individuals with High Functioning Autism and Asperger's Syndrome

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

Individuals with Asperger's Syndrome (AS) and high functioning autism (HFA) often report being bullied at some point in their lives. Many describe in great detail the experience of being bullied, and some appear traumatized by the experience. In my clinical experience, individuals with AS and HFA appear to develop post-traumatic stress symptoms as a consequence of bullying. Parents, teachers, and clinicians should be alert to this possibility.

What is Bullying?

The pioneer of bullying research, Dan Olweus (1993), has defined bullying as the experience of being exposed, repeatedly and over time, to negative actions by one or more other persons, and having difficulty defending oneself. Olweus described nine types of bullying behavior including verbal and physical aggression, isolation, lies, false rumors, threats, and racial, sexual and cyber bullying. Bullying may be overt or subtle but in all cases involves an interaction where there is an imbalance of power.

Charles Cartwright, MD

Victoria Bein, MA, MS

Bullies generally victimize individuals who appear or act different from the group. Individuals with AS and HFA are particularly vulnerable in school and work settings, given their social and communication challenges. Their behavior may be viewed as unusual, annoying or socially clumsy. If they show anxiety, this may be perceived as a weakness that can be exploited. Individuals with AS and HFA may be socially isolated, and lack the supports that would protect them from being bullied.

Unfortunately, individuals with AS and HFA may not recognize bullying when it occurs. Baron-Cohen et al., (1985) have described how autism spectrum disorders are associated with deficits in "theory of mind" abilities, namely they have difficulty attributing mental states (beliefs, intents, desires, and feelings) to themselves and others, and understanding that other people have mental states that are different from their own. This makes it challenging to recognize and interpret subtle social cues and social signals of threat and sarcasm. Credulity and gullibility are important factors in our understanding of why individuals with AS and HFA are often victims of bullying (Sofronoff et al., 2011).

Credulity is defined as the ability to determine whether something is believable; gullibility refers to the experience of being vulnerable to being tricked or manipulated. Individuals with AS and HFA tend to interpret verbal exchanges and social cues literally, and may therefore be more vulnerable to bullying, and have fewer resources to combat the bullying when it occurs.

The Effects and the Neurobiology of Bullying

Victims of bullying have been shown to be at risk for depression and suicidal thoughts. In addition, we should consider the possibility that individuals with AS and HFA who have experienced bullying may be at risk for developing Post-Traumatic Stress Disorder (PTSD). As a result of the bullying they may develop traumatic memories that are sufficiently intense to lead to the re-experiencing of the trauma, avoidance of situations that bring up these memories, and a chronic

see Bullying on page 37

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Do Parents and Teachers "Get" Children with AS/HFA?

These Children Lack the Insight or Social Skills to Explain Themselves

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

Many teachers and parents miss the connection between the diagnosis of children with Asperger's Syndrome (AS) or high functioning autism (HFA) (and nonverbal learning disabilities) and the behaviors of the child in day-to-day life. When adults don't get this connection, they can't communicate understanding to the child. Children usually react negatively to feeling misunderstood, and a cycle of misinterpretation, anger and hurt can result. Parents and teachers often label these behaviors as rude, oppositional or "attention seeking."

What are the symptoms of Asperger's Syndrome that are often misunderstood? Concrete thinking is typical of these children, yet many adults misinterpret concrete thinking because children with Asperger's Syndrome, HFA or nonverbal learning disabilities (NLD) are often quite bright and verbal. Their apparent verbal skills set unrealistic expectations for their level of comprehension and behavior. The comments of the child are often seen as due to rudeness or a "bad" attitude.

I was called into a school to observe a 7th grade boy whom the staff feared was

Marcia B. Eckerd, PhD

"pre-Columbine." He was described as withdrawn and hostile. The staff shared one story in particular to illustrate his negative attitude. His science teacher had decided to take a break by showing a short funny film. The class enjoyed it, but this boy raised his hand and asked, "What does this have to do with science?" His teacher saw this comment as rude and inappropriate. I observed this boy during the day. He thought an "electric car wash" was a wash for electric cars. His question was simple and authentic. He didn't understand what the movie had to do with science. His poor social judgment did not warn him that his comment would be out of place. Children with AS may ask many apparently inappropriate questions, much to the annoyance of their teachers, who don't believe that a "bright" child would miss the point.

Another boy I evaluated was frequently "melting down" at home. He described to me how much he enjoyed his mother's homemade cookies. As we were talking, I was trying to describe to him how unexpected things happen, and used the example of a time when his mother's cookies might not come out right. He yelled, "That can't happen!" and burst into tears. Eventually I figured out that he thought I meant that his mother couldn't open the oven door so the cookies could "come out."

This concreteness and failure to grasp ideas especially interfere with inferential thinking and generalization. Children with AS usually have excellent rote memories and remember facts well, but they can completely miss a main idea. These children fail to see the forest for the trees; they focus on details and miss the "big picture." History can be easy to understand if the material is factual, but open-ended questions can stump even bright students with AS. Literature in which information is implied can be completely confusing. "Huck Finn" is a great example of literature that is incomprehensible to some children with AS, since so much information has to be inferred from details. Writing is a huge problem if details aren't prioritized and connected to main ideas. Parents often don't understand why their bright children can't produce a paper, and are pressured by teachers to have their children get homework completed.

This focus on details can make it very hard to generalize, whether in math problems or in behavioral rules, because if you focus on details, each situation seems unique. Frequently, when I'm testing child with AS, he will ask about the directions, which he had already followed successfully, but in a new section of the test - he won't know if the same rules apply. A 3rd grade boy often made truthful (for him) but inappropriate comments that were critical of his peers, such as, "That's an ugly sweater." He was finally told, "If you don't have something nice to say, don't say it, so don't say something is ugly." The next day, he asked a girl why she was eating a yucky bologna sandwich.

see Children on page 34

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Key Components of a Social Skills Group

By Nancy Weiss, MS, CCC/SLP
Speech Language Pathologist
Fay J. Lindner Center for Autism

During a therapy session a few weeks ago one of my clients said, "Learning how to be social is easy for everyone except me, I have to learn how to do everything." It was at that moment I began to wonder about what I would do if I felt that way about anything, much less socializing with others. So, I thought, what could I say that would help her to recognize her own social language strengths and that she was not alone in her feelings? At that moment I did share with her that every day, each and every one of us makes some type of social mishap. It is human given the complexity of socialization. It is not only what the speaker does, but there are also so many factors influencing successful social interactions. These factors include, but are not limited to: the communication partner, specific situation, how each person is feeling, and the nature of the relationship. I hope that my words provided some encouragement and awareness that she is not alone in making "social mistakes," and that despite her own personal challenges, she recognizes the progress she has made in therapy and that she has become a very competent social thinker and has developed several very solid conversational skills.

Nancy Weiss, MS, CCC/SLP

Autism is a spectrum of disorders characterized by pervasive impairments in social interactions and communication, as well as the presence of restricted interests and repetitive behavior. Individuals with High Functioning Autism (HFA) and Asperger's Disorder (AS) tend to experience increased levels of frustration by their social difficulties due to an overall awareness of their deficits and not knowing what to do about them. Further exacerbating these individuals' frustration levels, their social deficits often lead to repeated negative social experiences (i.e. rejection, bullying). In my professional experience, I have yet to work with an adult who does not have multiple stories to tell about being "bullied," and from these experiences many individuals are afraid to engage in unfamiliar social situations.

In the last issue of *Autism Spectrum News – Summer 2011* (www.mhnews-autism.org/back_issues/ASN-Summer2011.pdf), there were many articles outlining a variety of treatment approaches and different perspectives on how to address the social deficits experienced by individuals with HFA and AS. Additionally, these articles shared the question many families and professionals struggle with: "What type of professional can best teach social skills?" As a speech-language pathologist, I wish I could say "speech pathologist," but the truth is many different professionals are capable of providing social language/social skills training. The critical component is to understand how each professional views social deficits, his/her ability to teach skills, and then to ultimately facilitate the individual's ability to generalize these skills into to real world.

As I tell everyone I work with, even "neurotypical" people (including their families) have some type of social mishap daily. Why is this? It is because of the complexity of social interactions. It is important to understand that the success of communication is not one-sided, but by the nature of social relatedness there is always at least one other person involved, and successful communication requires both people to communicate their messages effectively. What does this mean? To be successful socially one must to be aware of the individual(s) with whom he/she is interacting with, the rules of the situation, and an understanding of his/her own communication style, which includes having an awareness of the type of impression he/she is making.

Social skills programs are almost always conducted within a group. It is important to be aware that there are times when a client may require individual social skills training, in order to develop some basic social skills, which will allow him/her to maximize success within a group setting. These basic skills include: desire to communicate with others, functional means of communication, basic understanding that others have thoughts and feelings (basic Theory of Mind) and the ability to attend for at least half of the session time (e.g. if the session is one hour, the individual should be able to focus for at least 30 minutes). When families and professionals seek a social skills program, it is essential to gain an awareness and understanding of the needs of the

see Social Skills on page 32

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Tackling the Unemployment Crisis for Adults with Asperger Syndrome

By Marcia Scheiner
President and Founder
Asperger Syndrome Training and Employment Partnership (ASTEP)

Those of us who are touched by autism – either personally or professionally – are all too aware of the statistics for this population. In its most recent estimates, the Center for Disease control projects that 1 in 110 individuals in the U.S. are born with an Autism Spectrum Disorder (ASD). These prevalence numbers jumped in 1994, and have been climbing ever since, when the diagnostic criteria for Asperger Syndrome were included in the DSM-IV as an ASD. According to data published by the Data Accountability Center (which was funded in October 2007 by the Office of Special Education Programs, U.S. Department of Education) the number of children ages 6-21 diagnosed with autism and receiving services under the U.S. Department of Education *Individuals with Disabilities Education Act* (IDEA) Part B and C increased on average 43% per annum from 1997-2006. During this same time period, the average growth rate for children with all disabilities receiving services under the IDEA grew at an average annual rate of .4%. It is also estimated that 80% of individuals diagnosed with an ASD are under the age of 20.

Marcia Scheiner

Many professionals agree that these statistics greatly underestimate the overall number of individuals with an ASD, as today many adults on the autism spectrum have never been diagnosed. Underestimated or not, these statistics foreshadow a wave of individuals on the spectrum entering adulthood over the next ten years. Yet, for adults on the spectrum, employment statistics are dismal.

In a 2008 study of 200 families with transition-age and adult children with an ASD, conducted by the University of Miami/Nova Southeastern University CARD, 74% of the respondents were unemployed and 74% of those employed worked less than 20 hours a week. Most studies indicate that 75-85% of adults with Asperger Syndrome do not hold a full-time job. Federal and state vocational programs are underfunded and overwhelmed by requests for services. The Federal Department of Health and Human Services reports annual average staff turnover rates of 50% for programs serving adults, with staff vacancy rates of 10-12%. Yet we all know that gainful employment is a proven factor in improving self-esteem, reducing instances of depression and promoting financial independence.

So how do we address this crisis for adults in the Asperger community and the young people who will soon face adulthood? Websites, social skills classes, job coaches and books instructing the adult with Asperger's how to behave in the workplace abound. Increased awareness and sophisticated interventions have resulted in many individuals with autism spectrum disorders, particularly those with Asperger Syndrome, successfully completing post-secondary education. However, as a hidden disability, Asperger's is not understood in the workplace, and support systems for adults on the job are virtually non-existent. This leaves individuals with Asperger's – who often have unique talents and capabilities - as a largely untapped workforce.

To date, the responsibility for fitting into the workplace has fallen largely on the shoulders of the individual on the spectrum. As a result, many of the resources for individuals with Asperger's focus on what they need to do to "fit in," with little or no attention given to what the employer can do to accommodate the individual, and why they should. It is important to recognize that the road to successful employment for individuals with Asperger's is a two-way street. The need to educate employers on how to hire and retain employees with Asperger Syndrome is as critical as educating individuals with Asperger's on how to seek employment and meet their employer's behavioral expectations.

The first thing to accept in addressing the employment crisis among adults with Asperger's is that employers' decisions are largely driven by the bottom line impact. As a result, all decisions, whether they are to hire an individual, buy from a particular vendor or produce a specific product, must result in a benefit – usually economic - to the company. So with already high unemployment rates in the U.S., and a readily available supply of potential employees without an ASD, why should an employer seek out these individuals as a part of its

see Unemployment on page 32

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Asperger Center for Education and Training is a virtual center that disseminates information about AS and has nonclinical services available such as coaching, coaching supervision, educational consultation, and series of workshops and courses. www.aspergercenter.com

Asperger Syndrome Training & Employment Partnership (ASTEP) has the mission of creating and supporting programs that promote employment for adults with AS in the corporate sector and training employers about their special talents and needs. Marcia Scheiner, CEO, Michael John Carley, Executive Director, and Susan Lesco, Director of Program Partnerships, will be working to raise awareness about the benefits of hiring adults with Asperger Syndrome and the challenges they face in the world of employment. www.asperger-employment.org

Asperger Syndrome and High Functioning Autism Association (AHA) provides support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. www.ahany.org

Career and Employment Options, Inc., CEO is an award winning service providing transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities. www.ceoincworks.com

The Unique Needs of Students with ASDs Transitioning to College

By Paul K. Cavanagh, PhD, MSW and Ernst O. VanBergeijk, PhD, MSW
New York Institute of Technology
Vocational Independence Program

Paul K. Cavanagh, PhD, MSW

Ernst O. VanBergeijk, PhD, MSW

It has been clearly established that individuals with Autism Spectrum Disorders have difficulty with transitions. One major transition for a young person is the transition from secondary educational settings to the college environment. It can be overwhelming for any college freshman, but it is particularly stressful for a student on the spectrum.

In high school most courses and sources of support are contained in one building. Classes are regularly scheduled and transitions between classes are clearly denoted by bells to tell students when to go to their next class. Classes meet generally every day at the same time and location. Only one meal is eaten at school. Students can escape social pressures at the end of the school day by returning home and can socialize as they see fit. They are not expected to do their own laundry, pay bills, and regulate their free time. During high school, if a student on the autism spectrum needs help, his or her parents can advocate for the student at school or with health professionals. The parents are monitoring the student's sleep patterns, medication, computer usage, and socializing. In fact, parents are often a major source of scaffolding and support. They often keep track of the student's assignments and deadlines. The parents motivate the student to complete the assignments and supplement the student with an ASD's impairments in executive functioning.

Most college campuses are contained in multiple buildings spread over acres of land. Classes are not held on a daily basis. Some classes are even held in the evenings and weekends. Support services are contained throughout the campus in a variety of buildings. No bells ring to tell students when they are supposed to go to the next class. The student on the autism spectrum has to be able to read a schedule full of abbreviations for the course name, time and day of the class, and the building name and room number. A student on the spectrum must be able to decode all of this information and must know that they should consult a map to find the class. Classes instead of being potentially down the hall from each other can now be spread all over campus. The student must be able to factor in travel time in order to reach class. Structure is at a minimum and a student is left to his or her own devices regarding when to eat, bathe, do laundry, take medication, allot time for research and other assignments, etc. No one is there to tell them when to go to class, or to sleep, what and how much to eat, or when to exercise.

A student with a disability who is enrolled full time in a college degree bearing program presumably has graduated from high school. After years of being in the special education system and being protected by the Individuals with Disabilities Education Act (IDEA), the student with an ASD is no longer guaranteed a Free and Appropriate Public Education (FAPE). Parents may not advocate for the student to receive special education services in college. Special education does not exist in this environment. Under IDEA, a student's school district is required to provide FAPE until he or she graduates from high school or through the student's 21st birthday. The law that governs colleges in relation to people with disabilities is the Americans with Disabilities Act (ADA). Here, the law is designed to prevent the individual with autism, or any "otherwise qualified individual" with a disability, from being denied the opportunities the

see Transitioning on page 29

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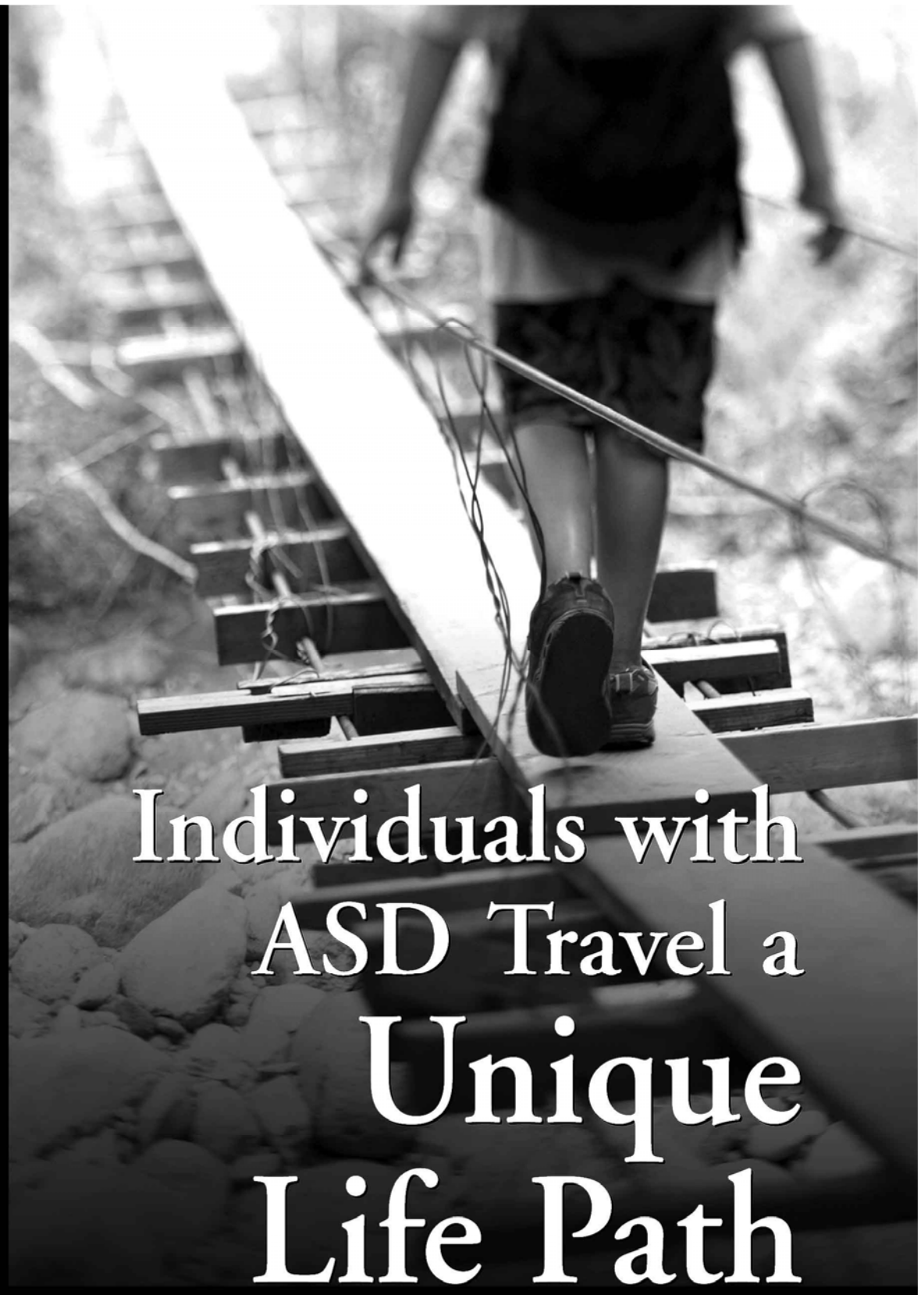

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It Takes a Village: Westbrook Preparatory School Opens

New York's First Approved Therapeutic Residential Secondary School for AS/HFA

By May-Lynn Andresen, RN
Co-Founder and Project Director
Westbrook Preparatory School
A Program of SCO Family of Services

"Despite my district and the team's best efforts, my son is winning the battle but losing the war. He can handle the academics of whatever program he has been in but can't manage his own behaviors, doesn't have any real friends and spends all of his time outside of school alone in his room, he is acting out more and more at home (although he can usually hold it together in school). It is a fight to get him to bathe, brush his teeth, or get off the computer. He becomes extremely anxious when faced with change or any social situation at all."

"She is bright but lacks daily living skills, the ability to regulate her own emotions and behaviors, and the basics of communicating on a social level with most anyone. She has no idea how to appropriately get the help she needs, she is depressed, developing school phobia and she is already 15."

"How is he going to be able to get through a job interview, hold down a job, attend college, live on his own, and lead a happy and fulfilled life?"

"When she was evaluated, we were told that the appropriate placement for her was a residential therapeutic school that works on all of these critical skills sets across all environments, but that doesn't exist in our state."

May-Lynn Andresen, RN

These are just a few comments, common to parents of those diagnosed with high functioning autism/Asperger syndrome. Nearly six years ago, six parents/professionals impacted by this condition vowed to change that final statement and create an environment that not only could serve students exemplified above, but also be a model that could be replicated elsewhere in part or in its entirety.

This group of parents reached out to SCO Family of Services, a large New York based human services organization that works to meet the needs of underserved New Yorkers - together they opened Westbrook Preparatory School in February of 2011. Westbrook, located in Westbury, Long Island, is the first residential therapeutic school (in New York State and fully-approved by the New York State Education Department) specifically designed for students in grades 7 - 12 with complex learning difficulties and average/above average IQs who have an autism spectrum disorder and/or other related neurobiological condition (s). Westbrook's students have experienced failure in local education settings and often come to Westbrook from out of state placements, home instruction or hospitalization. This program has repatriated New York students as well as prevented others from having to leave the state.

Often we are asked, "Why residential?" There are several explanations for why a student might need a residential setting:

- Some students with autism spectrum and related conditions with average/above average IQs require a more intensive or differently structured behavioral and adaptive skills training approach than most supportive 6-1-1 day programs, and/or a full time aide can provide.

- Although families benefit from parent training and in-home autism/behavior consultant support, in some cases youngsters develop significant maladaptive coping strategies coupled with significant anxiety, and adequate supports and consistency are not available across all environments.

- Supportive efforts can prove insufficient to reverse the challenging behaviors, anxiety, regression and dysregulation of emotions, mood and impulse control necessary for success. Many also struggle with attentional and severe executive function deficits as well.

- Others suffer from the effects of bullying, rendering them school-phobic, clinically depressed and sometimes even having the desire to end their lives.

see Westbrook on page 35

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Emergencies Happen - You Must Plan Ahead

By B. Madeleine Goldfarb, MA
Founder and Executive Director
Noah's Ark Institute

At the time of this article's publication, many of us will have been affected by Hurricane Irene. In light of this weather emergency we can look at this event and learn some valuable lessons.

For those of us involved with children on the spectrum, the challenges on a daily basis can be overwhelming. When there is a weather event or other emergency, those challenges can become acute.

It is very important to put plans in place for yourself and especially for your loved one with high function autism or Asperger's. Though there have been pundits out there remarking on how non-eventful this weather event ended up being and are crying about the overhyping of the danger…I can tell you as a family who is living through the aftermath: if that was overhype I certainly do not want to go through anything worse.

Noah's Ark Institute and our partner's at the New Jersey Office of Emergency Management have collaborated on some helpful suggestions for families caring for individuals with special needs. Some of the information is adapted here, as it is especially helpful at this time after Hurricane Irene and can be useful for future planning.

B. Madeleine Goldfarb, MA

Emergency Planning

Change - After a disaster, the physical environment (your home, neighborhood and other familiar places) can be altered significantly. It is important to anticipate this and extra effort may be needed to help all family members feel safe through the process of disaster response and recovery. Preparedness and talking about it is one way to mitigate the stressful impacts that change can bring. Your loved one's routine will be disrupted. There may be large scale power outages caused by downed power lines or trees falling. If your loved one has a certain show which they watch on TV or cable program, this will be disrupted. Consider buying a portable DVD player with copies of the program or programs handy.

If you are sheltering in place, you should consider a backup generator. If so, ensure you have a power source, such as extra gasoline if the generator is gasoline powered. Remember to keep all dangerous substances in a secure place.

Ensure your car's gas tank is also full. Make a habit of not letting your gas tank go below half full at any time. If power is out, the gas pumps at the local gasoline station will not work. If you must evacuate, you do not want to be stuck in a tremendous line for gas.

Communication - For those with high functioning autism and Asperger's, disaster communication can be particularly challenging. Emergency responders may or may not immediately recognize that a person has autism or Asperger's, or they may have varying levels of experience in dealing with this. In New Jersey, first responders are now required to complete awareness level training on working with individuals with developmental disabilities during emergency responses. That said, the more proactive we are at preparing ourselves and our loved one's ahead of time the better the outcomes will be for everyone.

Though our loved ones with high functioning autism and Asperger's are verbal, it is very important to remember that in times of great stress and the associated anxiety that the stresses of the emergency situation will create, our loved ones may become less able to express themselves effectively to you or to emergency personnel. A card or information sheet about how to best interact with your family member is a good tool to have on hand during emergencies. This is especially important, in light of a situation when many community members all need help at the same time. As you begin to prepare, you may want to consider some sort of social story and/or role playing scenarios with your family member.

Evacuation - The NJ Office of Emergency Management and the Noah's Ark Institute NAI support the efforts of our Red Cross partners regarding mass care operations. However a mass care shelter environment can be noisy and chaotic. Think about alternatives to mass care shelters, if you need to evacuate. Staying with a family member or friend might be a better alternative. Taking all necessary

see Plan Ahead on page 37

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Turning 18? Social Security Offers Options for Teens with Special Needs

By Stephen A. Ehrens, CPA, CLTC
Financial Advisor
Northwestern Mutual Financial Network

For parents of a teenager, watching a son or daughter grow into adulthood can be a bittersweet time. For parents of a teenager with special needs, this time takes on even greater meaning. In addition to helping their loved one transition to young adulthood, parents are challenged with meeting the financial needs of their now "grown up" yet dependent adult child.

In terms of access to all government benefits, age 18 is also a significant milestone. That's because once a teen reaches age 18, he or she is considered an adult, regardless of disability.

This means a child who has received Social Security benefits prior to age 18 will need to have his or her case re-determined at age 18. In many cases, this involves providing documentation verifying the child's personal income and assets as well as continued disability status. In the case of a child who has not previously applied or qualified for benefits, turning age 18 may provide welcome financial relief. That's because at age 18 access to Supplemental Security Income (SSI) is determined solely by the child's disability status and his own income and resources, without regard to parental income or assets. Keep in mind: SSI eligibility does not necessarily preclude employment for young adults with special needs as long as earned income does not exceed the allowable limit per month.

Stephen A. Ehrens, CPA, CLTC

Regardless of the age of the individual, SSI eligibility also confers another important benefit: access to Medicaid health insurance**.** This can be especially important for families whose health insurance does not cover a child with special needs past age 18. But even for those with such coverage, it makes sense to evaluate the cost and benefits of Medicaid versus private health care insurance relative to their child's special needs. Medicaid and SSI can provide significant resources for the adult child with special needs, which can ease a family's financial challenges.

Reaching the age of adulthood brings joy and challenges. For those with special needs, proper planning can help ensure that this transition will take advantage of resources that may be helpful to open up new opportunities.

Article prepared by Northwestern Mutual with the cooperation of Stephen A. Ehrens. Stephen A. Ehrens is a Financial Advisor with Northwestern Mutual, the marketing name for the sales and distribution arm of The Northwestern Mutual Life Insurance Company (Northwestern Mutual)(NM), Milwaukee, Wisconsin, its affiliates and subsidiaries. Financial Advisor is an insurance agent of NM based in Fairfield, CT. To contact Steve, please call 203-256-2162, e-mail him at stephen.ehrens@nmfn.com or visit his website at www.stephenehrens.com.

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THANKS to the families who so generously participated in the Simons Simplex Collection, a five-year, nationwide study of autism spectrum disorder. The data collected during this study have created a unique and lasting scientific resource that will enable many new autism studies, far into the future.

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Most families who took part in the study will continue to contribute to and benefit from autism research by joining the Simons Simplex Community at the Interactive Autism Network (SSC@IAN). SIMONS SIMPLEX COMMUNITY @interactive autism network

For more information about SSC@IAN, please visit iancommunity.org/cs/simons_simplex_community.

THANKS also to the more than **150** clinicians, investigators, counselors and administrators who contributed to the study.

This partnership of families and research teams has yielded:

- *more than 185 requests for biospecimens by scientists; 136,000 samples have been shipped.*
- *more than 112 new studies of autism spectrum disorder to date, and the number of studies will grow with time.*

For information about the Simons Simplex Collection and other advances in autism research, please visit SFARI.org.

SFARI SIMONS FOUNDATION AUTISM RESEARCH INITIATIVE

Focus on Video Modeling Techniques for Inexpensive, Fast and Customized Solutions for Improving Social Skills

By Laurie Jacobs, MA, CCC-SLP
Co-Founder
Social Skill Builder

When my sister and I began Social Skill Builder in 1999, we were looking for a way to bridge the social language gap to help kids with ASD, Asperger's and other learning disabilities achieve success in social situations. Social Skill Builder has created a series of learning tools that use videos of real kids in computer assisted programs to help teach social understanding. As the video scenarios unfold, the child or adolescent user steps inside familiar social situations to make choices, predict outcomes and problem-solve. With the attraction of the computer, motivating reinforcements and games, the task of learning social skills becomes fun and entertaining. This unique training software provides a reference for language, behaviors and interactions that the children learn to carry into their natural environments.

Users of Social Skill Builder software have exhibited increased confidence and acceptance of transitions in different social scenarios, increased expressive language skills, and decreased anxiety and negative behaviors have been noted in situations that once caused problems.

Laurie Jacobs, MA, CCC-SLP

Often, social learning opportunities occur so quickly that the teachable moments of body language or a glance are gone before they can be identified, but with Social Skill Builder software each scenario can be paused, with the opportunity to replay scenarios and study the different layers of social cues for greater understanding. Such practice provides children with more intuitive insight into social interactions and increases their confidence as they try out new skills in their real-world environments.

Why Social Skills Training?

Unlike their peers, children who struggle with social language do not acquire basic social skills through general experience and observation, usually because of the complexity of the interaction and all of the "unwritten" and situational-dependent rules. In social skills instruction, each individual skill is broken down into a series of steps that students are taught in order to master (Cumming, 2001). Social skills training uses problem-solving techniques to actively teach children the skills they need to be successful and to cope with challenging situations in their social environment. Research has demonstrated that video social skill training using real peer subjects (as opposed to drawings or cartoons) is one of the most effective treatments for helping children with ASDs and other learning disabilities succeed in their interpersonal and social awareness.

Additionally, research has established that many students with pragmatic learning disabilities, particularly those with ASDs, are drawn to visual stimulation and are often visual learners. Because of this visual inclination, video modeling of social skills meets these students where they learn best. As Dr. Temple Grandin, a professor, author and researcher with autism explains, "I think in pictures. I do not think in language. All my thoughts are like videotapes running in my imagination. Pictures are my first language, and words are my second language" (Grandin 2002).

We have found great success and seen lasting improvement using teaching strategies that capitalize on the visual learning strengths of children on the spectrum and allow for repeated evaluation of targeted social behaviors. Social Skill Builder products provide a great outline and guide to start you on your way to using video training techniques by providing the foundational social videos situations typically seen in a preschool, elementary school or middle school or out in the community and pairing them with systematic levels of understanding, question probes and scoring.

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see Video Modeling on page 36

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Sensory Processing Difficulties - Dressing For Success

By Susan Donohoe, OTR/L
Founder
Prince's Sensory Delights

Many Children with Aspergers experience sensory processing difficulties or sensory processing disorder (SPD). Sensory Processing is the neurological processing and interpretation of sensation within one's own body and from the environment. In short, it is the brain's organization and interpretation of the sensory input from everyday use. This is a complex interrelationship of processes, hence the term sensory integration. Modulation is a term you may hear describing the neurological process which the child's central nervous system appropriately regulates (continually adjusts) behavior responses to continually changing external and internal sensory stimuli. If this modulation is not working well the child may seem under responsive, over responsive (seeking stimuli), or both, or may be overwhelmed to sensory stimuli. When this behavior interferes with a child's "occupation" in life (social, emotional, play, school, attention, body mechanics, self-care, etc.), then it is termed a disorder, hence sensory processing/integration disorder. It is important to note that anyone and everyone has some sensory processing or integration problems from time to time because any kind of sensory stimuli can temporarily disrupt ones

Susan Donohoe, OTR/L

normal functioning. The three main sensory systems we are referring to are tactile/touch (influencing motor control and emotional development), proprioception (sense obtain through one's own muscles, ligaments, deep pressure to the skin - therefore giving a sense of body position, organization, and calibration of movement), and Vestibular (sense of movement and gravity specifically postural control, muscle tone, coordinated use of both sides of the body, coordinating eye movements, etc.). Other sensory systems include olfactory (smell), auditory, visual, and gustatory (taste).

Sensory processing disorder and sensory processing difficulties are individual to each child. Some may be mildly affected while others have greater difficulty functioning in life. It is important to note that symptoms vary and not all are present. Also it is a marker of neurological dysfunction that a child may show symptoms one day or with one activity and not the next. The main type of therapy for SPD, with a trained Sensory Certified Occupational Therapist, includes a safe and challenging level of sensory stimulation encouraging movement to focus the child on tolerating and integrating sensory input, which is driven by the child's interests and the "occupation" of play. Other therapy focuses on making environmental adaptations (such as in the home and school).

Common symptoms of SPD include: clumsiness (tripping, bumping, falling); poor fine motor skills; delayed self-care skills; poor muscle tone; difficulty initiating tasks; poor timing; poor posture; poor hand-eye coordination; learning disabilities; poor handwriting; poor organization skills; becomes easily frustrated; difficulty with social relations; constantly touching objects; doesn't like to be groomed (hair, teeth, etc.); difficulty with clothing seams, socks, waistbands; seeks only soft clothes; likes tight clothing, small spaces, weight of blankets; opposed to being touched, would rather be the one to touch; hates being tickled or cuddled; often touches people or objects too hard; difficulty with eye contact; often smells objects; poor attention skills; picky eater; stuffing food or objects into mouth; difficulty with transitioning; hypersensitive to noise (things are too loud); hyposensitive to noise (doesn't seem to notice); Hypersensitive to touch (certain fabrics, surfaces, etc.); little awareness to pain and temperature; hyposensitive to touch (may not notice when clothes are twisted or on improperly); hypersensitive to light; movement produces an anxious reaction (swinging, roller coasters, bike riding, spinning, rolling); over-seeks movement (swinging, spinning, rolling); takes excessive risks in movement, extreme activity levels; walking on tiptoes.

Dressing for Success!

As mentioned above, making adaptations within the child's everyday life is also a part of understanding the child. Every child deserves to feel comfortable and adorable in their clothing. What if that same clothing could offer qualities that address sensory discomfort and therapeutic input? The child's image of themselves and how they feel in their environment can enhance the social and emotional quality of life when that child feels organized and

see Sensory on page 30

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To Be or Not To Be (Autistic)

The New Generation of Kids Who Are Almost Autistic, But Not Quite

By Jacqueline Aidenbaum, MA
Autism Advocate

Parents of children diagnosed on the high functioning side of the Spectrum confront the quandary of whether concealing their kids' diagnoses in avoidance of discrimination, or disclosing them to educate others on the many layers of the Autism Spectrum Disorders (ASDs).

There is, however, a third alternative which would involve pursuing classifications related to Sensory Integration Dysfunctions (SID). The presence of multiple sensory input and output difficulties is an appropriate way to easily explain many of the challenges faced by children under the so-called High Functioning Autism (HFA) category. Furthermore, terms such as "sensory processing" and "functional integration" sound less stigmatizing than the word Autism, and the fact of the matter is that behind many of the Autistic traits in high-functioning children, there is a sensory integration dysfunction that can often explain such behaviors.

There is undeniably an emerging group of children that are initially diagnosed as Autistic (mostly to allow them to receive Early Intervention services) who, as they grow up, start falling under what the American Psychiatric Association calls

Jacqueline Aidenbaum, MA

sub-groups - the "almost but not quite" Autistic; those who either don't manage to fully present the Autism criteria, or who show traits of Residual Autism. Should they continue being called Autistic?

Furthermore, there are children who seem Autistic merely because their brains have a hard time in processing sensory information, those who are over- or under-sensitive, who present inadequate vestibular or proprioceptive systems. Should they also be called Autistic? These disorders cannot be officially recognized as "…many psychiatrists, pediatricians, family doctors and school officials fear that if validated, sensory processing disorder could become rampant - a vague diagnosis that could stick insurers and strapped school districts with enormous bills for unproven therapies" (*The Disorder Is Sensory; the Diagnosis, Elusive*, The New York Times, 6/5/07).

The fact remains that to receive therapeutic services, and in order to be placed in appropriate schools, many of these children must still be called Autistic; a strong and heavy label that will accompany them throughout their entire life.

In New York City, the best public schools (see *Nest* below) that serve the educational needs of high functioning children require that the students are labeled as Autistic. A label that, ironically, parents (in this instance) receive as a blessing, as the confirmation of such diagnosis is pivotal to get their kids into this outstanding school program.

Conversely, some of the sought-after non-public schools (funded through the Department of Education) that host a population of HFA children will categorically reject any application if the word Autism or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is ever mentioned in a private psychoeducational evaluation (which, by the way, will cost a parent between $4,000 to $8,000). The information about the right wording needed for each school is unofficially shared and passed on from older to younger parents via blogs and support groups. Well informed parents applying to private (though funded) schools know when to openly flaunt their kids Autism or PDD-NOS diagnoses, and when to disguise them under terms such as "learning disabilities" or "sensory integration dysfunctions" to effectively tailor the language in accordance to the schools' tacit preferences.

The lack of unified criteria between private-funded and public institutions adds a burden onto the parents, who end up shopping for a diagnosis given the educational vacuum that exists for the higher functioning population - in particular the kids who are not Autistic enough and do not quite have Asperger's Syndrome either. Nevertheless, their ordeals might be invisible to the untrained eye, but remain strong throughout their academic years.

The United Nations took notice of the

see To Be on page 35

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Fay J. Lindner Center for Autism Welcomes New Psychiatrist

Staff Writer
Autism Spectrum News

Katherine Cody, PsyD

The Fay J. Linder Center for Autism is proud to welcome Katherine Cody, Psy.D to its staff. Dr. Cody received her doctorate in clinical Psychology from the American School of Professional psychology at Argosy University located in Washington, DC. She completed her Postdoctoral Fellowship at the Mount Sinai School of Medicine, Seaver Autism Center through a community partnership with F•E•G•S Health and Human Services Day Habilitation in their Bronx and Manhattan locations. Dr. Cody is also a member of the American Psychological Association and the New York State Psychological Association.

Dr. Cody has a breadth of experience working with child and adolescent populations from the underserved in community mental health populations, to the developmental disabilities population, to an autism-specific population. Dr. Cody has also had extensive experience providing developmental, psychological and neuropsychological assessments for both children and adolescents. Dr. Cody's experience includes outpatient, day service, and research settings.

The Fay J. Lindner Center for Autism, an affiliate of the North Shore-LIJ Health System, was formed to meet the needs of children and adults with autism and related developmental disabilities and their families. The Center is located in a state-of-the-art facility on AHRC Nassau's Brookville campus. The Center offers a wide range of programs, clinical services, professional training, community education, specialized program consultation and research, to individuals, families and schools. Visit us online at www.FayJLindnerCenter.org.

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

By Carrie Cariello

Angels

As a mother of an autistic boy, I've been fortunate enough to meet all kinds of extraordinary people who have touched our lives. In addition to the beautiful network of supportive teachers, family, and friends, I've encountered many people – sometimes strangers – who share their compassion and love for my son Jack. Like shining lamp-posts along a back road, they often light my path in what could otherwise be a dark, lonely road with a sometimes misunderstood child. They are my earthly angels.

It's the saleswoman who gives me a meaningful look of support when Jack is mid-tantrum over buying gum. Or my sister-in-law, Elaine, who takes my hysterical phone calls in stride and checks in each evening to hear about Jack's day at school. It's the man in the lobby at Bertucci's who pauses an extra minute to thoughtfully answer Jack's question about his Toyota Prius.

To me, angels are people who see not only what Jack has, but who he is. They take the time to glimpse the little boy hiding behind his preoccupations about cars and birthdays, radios and dogs, and can see a child struggling to socially connect despite his disability. They don't set out to change our lives but instead make small changes to my heart with little - usually unintentional - acts of kindness. Although we've had many, many angels over the past seven years, three special people come to mind.

Kristin and Jack

About a year ago we did a major renovation to the entire downstairs of our house. The noise, disruption, and overall chaos put Jack into a tailspin, and every day after school I had to coax him back up the driveway and into the house. Matt, our general contractor, became a permanent fixture and a familiar face amongst the endless stream of construction people in and out of the door each day. Childless himself, this tough, burly man connected well with all of our kids and worked hard to ease Jack's transition with each new phase of the project; "Jack, tomorrow we're going to start installing the floors. It's gonna be loud!"

The only problem was Maggie, Matt's beloved yellow lab. Most days Maggie traveled shotgun in Matt's red pick-up truck and while the other kids loved it, Jack was beside himself. He's been terrified of dogs since he was about two, and being within a mile of one can set him off. Every day I steeled myself for an outburst as he walked past the truck with a wary look on his face, as if Maggie might open the door handle herself and spring out. Every day I vowed to talk to Matt and insist he leave her home, that it was too much for Jack, that we were already asking a lot of him by gutting the one bathroom he used consistently (He peed in the woods a lot that summer).

But each day the walk past the red pickup truck got a little easier, and before I knew it he was asking to peek in the window and see the small yellow lab.

see Angels on page 37

Welcome to My World
A Mother's Annual Letter to New School Teachers

By Hayley Kamis, MA
Mom

After seven years of parenting a child enrolled in the local public school system, I've come to understand that, at least in our neck of the woods, each new grade begins with an automatic and inherent "do-over" mechanism in place. Regardless of how many copies of reports, summaries of treatment, useful examples, or offers to provide reference materials as well as funding to train our school's teachers (i.e., extend free continuing education credits) regarding the unique needs of children with Asperger's Syndrome, every year begins as if it were my child's first foray into the building with a shocking and unexpected diagnosis.

It's been suggested that informing my son's new teachers about his quirky learning style may be considered a violation of his privacy...despite the fact that, as his legal guardian, I have personally requested such administrative divulgence. Whereas offering students a clean slate with which to begin the year may appeal to some families, I find a solid heads-up to be a valid and useful educational tool for the individual tasked with teaching my child. Let's face it, folks: first impressions can have a very lasting impact. Without advance notice of the fundamental need for situation-specific understanding, patience and a collection of strategies with which to support, instruct and reinforce the academic and social efforts of a child with an autism spectrum disorder, lack of preparation for a student's "autismness" can have tremendously negative effects on a child's self-esteem and motivation to learn. Seven years of public school, people. SEVEN YEARS. Been there, done that.

Hayley Kamis, MA

The way I see it, an ethical realtor would advise his or her client that location, location, location is a key consideration when purchasing a home; the parent of a child with Asperger's Syndrome recognizes the necessity of context, context and more context for properly, appropriately and compassionately educating his or her child.

Thus, after all these (seven) years, I've found a useful solution that eliminates disillusion and promotes interdisciplinary camaraderie. Each year I begin my teacher notification with the following email template, updating it as appropriate to my son's age, pertinent behaviors and current goals. I find sending this email the day before "Back to School Night" opens a useful dialogue within the perfect window of opportunity for both the "clean slate" and "FYI" approaches, while simultaneously saving time, a bucket load of tears, a flurry of confusion and oodles of frustration secondary to unintentional ignorance. Been there, done that, too. So if you find yourself searching for a voice to communicate your quite valid and well-documented concerns, feel free to use mine as you wish. Then we'll have been there and done that together. Power to the Parents!

Dear Teachers,

First let me introduce myself. I'm the nutty mother from whom you will likely be receiving regular emails over the next year. I apologize in advance for making a pest of myself, but: 1) it's my job, and 2) I'll try to keep all future communication brief as well as humorous. This will be the only soapbox monologue I send you; I truly value your expertise and tight schedules, so I won't take up too much of your time. Straight and to the point - that's just how I roll.

I am writing on behalf of my 13-year old, 7th grade son. He is funny, enthusiastic, inquisitive, bright, and a stellar student. He is incredibly artistic. He is a living, breathing film and TV database. He has a memory that can rival any elephant, so be very careful what you say. And chances are you won't soon forget him...partially because he's a super kid, and probably because my child also has Asperger's Syndrome.

For any of you unfamiliar with this condition, a term sometimes used interchangeably with "High Functioning Autism," it is a variable diagnosis along the autism spectrum. Bill Gates, Dan Akroyd, Jim Henson and some say Albert Einstein and Sir Isaac Newton had it, and my son is quite happy to be in their company.

In a nutshell, my child comes across as "quirky." He has some pretty unusual and sophisticated interests about which he knows more facts and figures than Wikipedia. Some topics are entertaining

see Annual Letter on page 34

Helpful Hints From the Trenches: What to Expect in College

By Patrick Hourihane
College Student with Asperger's Syndrome

The first day of college can be a little scary just like any first day in a new school or a new grade. I would like to share with you some of my experiences and offer some helpful tips so you too can survive college and have a successful and positive experience.

What was very helpful for me in order to get used to the way that college works was that I took a summer college class at C.W. Post while I was still in high school. I got to experience what college life is really like; what to expect by doing so and what they expect from me.

College is pretty much what you did in high school, but now you are your own manager and have to advocate for yourself. In high school, I had teaching assistants that helped me out, coaching me, reminding me of things, and helping me navigate my way, but in college I am my own manager. So basically, I remember what they did to help me in high school and now I just do it myself. In your last years of high school try to practice doing what your assistants had done for you. The teaching staff in college will not remind you of daily homework or assignments. At the start of each class you get a syllabus, which is like instructions for the entire semester, and it is your job to follow that and plan ahead for future assignments that will be due later. My best advice is to read the textbooks so that you understand what is going on and to help keep up with the class.

Patrick Hourihane

High school English does not prepare you for college English! English class in college is completely different than English class in high school, and the style of writing can be quite difficult to get used to.

Make the Disability Support Services Office (DSSO) person your best friend! Set up ahead of time to meet with them as needed or like I do, once a week, so you can get help solving problems or concerns right away. Consider them to be your support team and lifeline to solving problems. The DSSO is also where you go to let them know you are a student with a disability so you can get accommodations like extended test taking time, copy of notes, etc.

Register for classes in-person with your academic advisor instead of registering online. This way you can pick the time of day that works best for you, like if you are a morning person or if you do better with the afternoon. Your academic advisor can give you an idea about the professors, their teaching style, personality, and if they are flexible and understanding of students with special needs. This is very helpful to know when picking your classes. For example, I had a problem last semester because I had several instructors that have different accents. On Fridays, I had back-to-back classes with professors that had accents. My computer professor had a Russian accent and my biology lab professor had a Middle Eastern accent and sometimes I found it difficult to understand them or transition from one to the other. Not to mention, on Tuesdays and Thursdays I had a professor with a French accent!

When dealing with class schedules, if you receive extended test taking time, make sure to plan a free block of time in your schedule in between classes to avoid conflicts with your other classes and that you have enough time to finish the tests.

Find a system to take your own notes that works best for you, even if you get a copy of notes. You can always rewrite them after class.

Self-advocate for yourself and become a self-manager. If you need help, ask for it. Find out who to go to for help and where, since college campuses are large and have a lot of separate buildings.

Take advantage of tutoring services and the writing center if you feel you need help. Sign up early so you can get a slot in the tutor's schedule that works best for you.

Let the professor get to know you and, if needed, make an appointment with them if you need help or need to talk to them in private. All professors have office hours so make sure you get their office hours schedule. Professors also like class participation, so don't hesitate to give them some input or ask a few questions now and then.

There is a lot of writing in college so do not let assignments back up by waiting until the last minute to do them. Make sure to use a flash drive and back up any work that you have done, and always carry it with you so if you need to change anything while on campus, you can get it

see From the Trenches on page 38

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Top Names in Autism to Participate in Rockland Autism Symposium

Staff Writer
Autism Spectrum News

For the sixth year in a row, several of the nation's foremost autism experts will come together in Rockland County as part of the Rockland Autism Symposium. Renowned autism advocate Dr. Temple Grandin will give the keynote address and several of the nation's top autism researchers, including Dr. Peter Gerhardt, of The McCarton School and Dr. Emanuel DiCicco-Bloom of UMDNJ, will share new findings about autism's causes and treatments. In 2010, Dr. Grandin was named as one of Time Magazine's most influential people.

This year's event will be held on Wednesday, October 26, 2011 at the Pearl River Hilton, Pearl River, New York.

Last October, over 800 people attended the symposium. This year the event was moved to a larger venue to accommodate additional attendees. Admission is free, courtesy of the MindWorks Trust, but preregistration is required. Scientists, physicians, psychologists, educators, parents, siblings, the media, and people with an autism spectrum disorder diagnosis are all invited to attend. The event is co-sponsored by the Rockland County Board of Legislators, the Autism Science Foundation, Camp Venture and the honorable John Murphy.

"We are pleased, once again, to present an exceptional program with presentations from leading professionals in the field of Autism Spectrum Disorders," said Legislator Murphy, "The U.S. Centers for Disease Control (CDC) reports that the prevalence of autism disorders is now estimated at 1 in 110 children, an increase over the previous estimate of 1 in 150. That is 673,000 American children that have an autism disorder. These numbers are mind-boggling and there is no definitive plan for their care once they reach adulthood."

For more information or to register for the symposium, please visit www.RocklandAutismSymposium.com.

Important Facts About Adult Autism Employment

By Scott W. Standifer, PhD
Disability Policy and Studies
University of Missouri

We don't know how many adults in the U.S. have autism. The CDC number most frequently quoted for Autism in the U.S. (1 in 110) is the prevalence rate for the autism diagnosis in 8-year-old children in 2006 (released in 2009). This rate is an average of data from 11 sites across the U.S., with rates ranging from 1 in 84 in Missouri to 1 in 240 in Florida. There is no established explanation for this variation. Researchers do not know how the CDC 2006 rate compares to previous generations who now compose the adult population.[1]

There is no information on how many people have Asperger's Syndrome compared to Classic Autism. The best estimate is that people with Asperger's/high functioning autism represent fewer than half of people with autism spectrum disorders and perhaps 25% or less. Most statistics do not separate the two groups.[2]

The most frequently quoted figure for the number of people with autism in the U.S. is an estimate from the Autism Society of America - between 1 and 1.5 million people. This figure is based on multiplying the total U.S. population by the CDC prevalence rate for 8-year-olds. That assumes there has been no increase in autism over the last 40+ years.[3]

Scott W. Standifer, PhD

The dramatic, widely-reported increase in autism over the last two decades is based on the increased prevalence of the diagnosis among school children since the early 1990s as documented through U.S. Department of Education data. Researchers disagree about whether this is an increase in the prevalence of the DIAGNOSIS (how many children have been identified with autism), the prevalence of the DISORDER (how many actually have it), or some combination of both.[4,5,6]

A 2011 study of adult autism in Britain concluded there has not been a significant increase or decrease in the prevalence of autism in that country during the last few decades (it was consistent across all generations). A 2009 study of children in California suggest there may have been an increase among children independent of the diagnostic changes.[7,8]

Whether the increase in diagnosis represents a significant increase in actual prevalence or not, autism is not new and there is a significant "hidden" adult population with autism in the U.S. In the past, people with autism have often received a different diagnosis, such as mental retardation, and either housed in institutions, or sent out on their own to live as "odd" individuals in the general community. Thus, adults with autism often lived hidden from the awareness of the general public. In addition, many functional, independent adults have begun to realize that what they have always considered oddness and differences in themselves are actually features of undiagnosed Asperger's Syndrome or high functioning autism.[9,10]

There is a rising Great Wave of young adults with autism graduating from high school.

The demographic bulge of children with the autism diagnosis is beginning to enter adulthood and apply for vocational rehabilitation services.[11] Even if the increase in prevalence is only diagnostic, the increased support for these children has led to a generation that is more visible and empowered than previous generations.

We don't know the unemployment rate of adults with autism in the U.S.

Without any data on how many adults have autism, there is no way to calculate an employment rate. There is some information about young adults (see below) but not older adults.

The employment rate for people with disabilities is very low and is even lower for young adults with autism.

In 2010, the proportion of people with disabilities aged 16 - 65 who were working was less than one half that of people without a disability aged 16 - 65 (29% vs. 64%) (Bureau of Labor Statistics).[12]

From 2001- 2009, the U.S. Department of Education's National Longitudinal Transition Study (NLTS2) surveyed 11,000 young adults with disabilities ages 15 – 21 to document their living situations. The information below is drawn from tables generated online using this data.[13]

- In 2009, the percent of young adults with autism who had a job was nearly half that of all young adults with disabilities (33% vs. 59%).

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Regulation from page 10

upset. Because of the inherent difficulties with language processing for many individuals with ASDs, visual imagery may also be used to help the child reach a state of emotional calm. Relaxation exercises are often included in cognitive behavioral treatments to manage emotions. This involves deep breathing and progressive muscle relaxation techniques. As with the positive self-statements, these techniques need to be practiced on a routine basis so that they are accessible to the child when he or she is emotionally aroused.

For some children, problems with emotional regulation are at a clinically significant level and professional intervention is warranted. This may involve behavioral interventions, medication management, or a combination of both. Parents are encouraged to seek professional treatment when the child's behavior is causing significant to distress to himself or others.

There are several ongoing research studies at the Center for Autism Research aimed at understanding the relationship between emotional regulation and the symptoms of ASDs. One study is assessing emotional arousal during social interactions using the physiological measure of heart rate variability. Some researchers (Porges, 2011) have proposed that there is a neural social engagement system and if it is not properly activated, the individual is operating from a "fight/flight" or "freeze" defensive response, and therefore does not send or receive appropriate social cues. The functioning of this system can be measured by assessing the action of the myelinated ventral vagus (the 10th cranial nerve) on the heart by the respiratory sinus arrhythmia (RSA). There is some evidence to suggest that many individuals with ASDs experience a heightened sense of alarm or potential threat when socially engaging with another person, and thus have lower RSA values. This level of arousal may interfere with successful social interactions. If these findings are supported through additional research, it may lead to additional intervention strategies to improve emotional regulation abilities in individuals with ASDs.

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state of hyper-arousal.

Studies on the neurobiology of AS and HFA have provided clues to why individuals with these conditions may be more prone to developing PTSD after being bullied. Neuroimaging studies have found differences in the structure and function of the amygdala and prefrontal cortex in the brains of individuals with AS and HFA, as compared to typically developing individuals. The amygdala is the area of the brain that is involved in the detection of threat and the formation of fear responses to a threat. These responses, also known as "fight or flight" responses, are mostly automatic/instinctive and are critically important for survival. The amygdala is activated when a threat is identified and rapidly activates different brain regions to prepare the mind and body for action. At the same time the prefrontal cortex assesses whether an action needs to be taken, and therefore has a modulating effect on the amygdala and the fight-flight response.

Individuals with AS and HFA have been shown to have an overly active amygdala that acts semi-autonomously due to under-developed connections with key regions of the prefrontal cortex. This may lead to exaggerated fear responses to events and, through the amygdala's effect on the memory circuits of the brain, the formation of intense fear-based memories of these events. The overly active amygdala also increases the stress hormone response to such events, leading to hypervigilance and hyperarousal. This neurobiological model helps explain why intense experiences such as bullying may cause post-traumatic stress symptoms in individuals with AS and HFA.

Building on neuroscience research findings, Markram and Markram (2010) have articulated the "Intense World Theory of Autism," which may have relevance to the experience of bullying in individuals with AS and HFA. The theory describes psychological and brain functioning in individuals on the autism spectrum that places them at heightened risk of developing exaggerated responses to environmental stressors. The model proposes that individuals with autism spectrum disorders experience sensory inputs in an exaggerated form, hyper-focus on certain aspects of the environment, form clear and intense memories of the events that unfold, and have heightened emotional and fear responses. This leads to changes in neural circuits that "cements" the negative experience of the initiating sensory event.

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Self-Reinforcing My Own Behavior Plan

By Travis E. Breeding
Author and Public Speaker

Applied Behavior Analysis (ABA) is scientific approach that involves using modern behavioral learning theories to modify overt behaviors. As an adult with Asperger's Syndrome, this is a theory that I find useful to practice in my own life. It is extremely challenging to self-reinforce my own behavior plan. I apply ABA to social situations so I can learn adaptive skills and function better in those areas.

I often run into people, some of whom are in the Autism community, who say ABA is not applicable to people with high functioning Autism or Asperger's Syndrome. I respectfully disagree with this opinion and have personal experience to back it up.

I tend to exhibit some classic Asperger's Syndrome traits such as coming on too strong with people and being overbearing. I do this by texting or communicating with an individual too often. This behavior is not readily accepted in our society; there are unwritten boundaries set in getting to know someone. This behavior can cause people to be uncomfortable around me; therefore it is a behavior that I have to change.

Let me share an example of how I created and enforce my own behavior plan:

Travis E. Breeding

My Problematic Behavior: Calling and texting people too often, in excess of 25 times per day, 150 times per week.

The Effect of the Behavior: Others shy away from this type of social interaction and tend to avoid being around me.

Behavior Plan Outline: When I want to text an individual I choose to blog instead. By blogging about my feelings I am able to connect with others on a social level. Sometimes I even access the desired social interaction via comments and discussion about the blog. Now I am getting social interaction without being overbearing.

Positive Reinforcement: I self-reinforce with chocolate milk. Every night before bed I enjoy having a glass of chocolate milk. If I meet my goal of not texting someone that day I reward myself with a glass of chocolate milk that night.

Without access to services as an adult I have had to be creative and come up with some of my own ideas for intervention. I'm not a therapist but I do have the knowledge of understanding how my mind thinks and works. This has allowed me to come up with strategies for changing my own behavior. I know neurotypicals (people who are not on the Autism Spectrum) who use the science of ABA on themselves every day.

When applying ABA principles I have to remember a quote from Dr. Peter Gerhardt, which states "Context is king." It is not possible to just sit in an office and work on one social skill for an hour or two and expect to be able to walk into any social situation and use the skill correctly.

It's extremely important to teach a social skill in as many different contexts as possible. In the past, I have been in a therapist's office, spending on hour or two talking about certain social skills. Then, as soon as I left the office my environment changed. There are too many factors that come into play, which make it necessary to practice a newly acquired skill in as many social environments as possible. While a therapist can't be with me at all times, I like the idea of training a friend or relative to go out with me and practice the skill in different settings such as a book store, library, museum, or club.

Typically when a child is receiving ABA services, the therapist is not only working with the child but they are training the parents, or caregivers of the child, to put ABA methods into practice. The child is not able to provide his own reinforcement at this stage in his life. The parents can then leave the therapy session knowing how to apply ABA therapy on their child in day to day life situations. The child is then able to practice the new skill every day, increasing the opportunity for it to become automatic.

Positive reinforcement is very important. As I previously stated, I make it a point to reinforce skills I use daily. However, being my own reinforcement is a challenge. I find relief when I write. For another person, positive reinforcement should be something that person finds pleasant. It is viewed as a reward for doing something positive.

I analyze things differently than most

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an OPWDD Commissioner who was prepared to improve this office in a very reform-minded fashion. He brought me in to make some of the changes that they thought were necessary in that regard and I feel very privileged to be here.

Q: How will you improve the availability and quality of programs and services to better meet the needs of the growing autism community?

A: I have seen the demographics and am aware of the growing and diverse needs of the autism community. I think it is great that the agency (then the NYS OMRDD) saw this was happening and took steps to address the ever-increasing needs of this expanding community of individuals. Back in 2008, the agency established the Autism Platform to identify the different areas where the state needed improvement, such as training people about autism, making sure we have the right support systems in place, and making sure there is scientific research being conducted at the Institute for Basic Research in Developmental Disabilities (IBR). Recommendations for improvement were recently updated in 2010 based on the findings of the Interagency Autism Coordinating Committee (IACC). The priority is to ensure that we are true to implementing what has been established through the Autism Platform.

In the near future, I will direct OPWDD to confirm that the Autism Platform is still relevant and continues to meet what we see as the challenges of the future.

Q: Will these improvements be statewide or more focused on specific regions in NYS?

A: I believe improvements need to be statewide. There certainly are pockets of innovation or places where there's a particular need, but the best thing we can do is learn from that innovation and make sure that, when we know something works, it gets disseminated and replicated. That is really the role of the state: to make sure the best practices get implemented.

We have had two major priorities since I have arrived, which are very relevant to autism in general. The first one is ensuring the safety of the individuals that we are serving. Much of this first priority comes as a result of some of the recent negative press. We have been implementing a number of different reforms in that area, including making sure we are hiring qualified people into the system - we didn't really have minimum qualifications previously - and then supporting them once they are a part of the system with the proper training.

An important aspect of employee training is making sure employees are knowledgeable about autism and the different needs of the population that we serve. If there is an incident, employees will be required to report it in a timely manner according to our new policy and procedures so that we can track that information in real time, analyze trends, and be proactive about preventing future things from happening.

We also have shored up our entire investigations process, making sure we have qualified, certified investigators. If something does happen, it will be properly investigated. Changing the culture of the agency to be one that is more sensitive to the needs of individuals is a priority so that people truly respect the individuals they are serving. We have many reforms that we are engaging in and that I think are very important. Ensuring the health and safety of the individuals we serve is essential.

The other exciting initiative we are implementing is an 1115 Demonstration Waiver, which we are calling the "People First Waiver." This waiver process looks at the current system we have and asks, "What do we want the system to look like in the future?"

Q: Can you give us an overview of the 1115 Demonstration Waiver?

A: The 1115 Waiver refers to section 1115 of the Social Security Act that is being waived. This is a "Research and Demonstration" Waiver, the most flexible of all of the different types of waivers you can ask for from the Federal Government.

We sent the Federal Government a concept paper showing what we would like OPWDD to look like in the future. The concepts are ones that provide more "person-centered" care, allowing for better care coordination, so that individuals are getting the services they want and need. Our current system is very complicated, with more than 5,000 different rates in the Medicaid system that providers have to deal with, resulting in more than 13 million transactions per year. The current fee for service system is very complex and doesn't result in the best outcomes because so much emphasis is placed on services as opposed to the client's needs.

As we look to reform the system, we have formed a Steering Committee for the People First Waiver, which will oversee and guide the development of the new waiver and shape the ultimate system reforms the waiver will achieve for New York State. The Committee is made up of individuals with developmental disabilities, family members, service providers, public officials, and noted experts in health care and long-term care.

The design teams for the People First Waiver will examine key policy aspects of the developmental disabilities service system and make recommendations to the People First Waiver Steering Committee regarding how New York State can best achieve the goals set out in the waiver concept paper. This concept paper can be viewed at www.opwdd.ny.gov/2011_waiver/images/concept_paper.pdf. The five Design Teams are focused on Access and Choice, Benefits and Services, Care Coordination, Fiscal Sustainability, and Quality Design.

The Access and Choice Design Team is focused on access and choice for individuals. This starts with the tools that you use to evaluate what people's needs are. Currently, the focus is on people's disabilities rather than their abilities and potential. The Benefits and Services Design Team will make sure we preserve the services and benefits that the population is going to need in the future. The Care Coordination Design Team will be addressing our desire for more integration, such as mental health care for individuals with

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Robin's Voice

A Resilient Mom's Commentary on Autism

What Do You Do When Relatives Don't Believe The Diagnosis and Question Your Parenting?

By Robin H. Morris
Freelance Writer

"Give him time."

"She's the last child born in the family; everyone does the talking for her."

"Your expectations are too high, every child has his/her own timetable."

"Don't put him under a microscope. Relax and he will be fine."

"When I had my kids, the world was more simple. Your generation over-programs."

"Look, she can read…she'll converse when she's ready."

"Let her just be."

Sound familiar? Living and observing the proverbial rollercoaster called autism is an exercise in defining human behavior. Not only do we question our own sanity, but we are obligated to navigate for family members and friends. We become unwilling guides, in a museum of dismay. We are expected to explain and respond to comments, as if giving permission for opinions when all we want to do is scream while begging: *Please, let me come up for air…I am trying to process this thing called autism. Don't muddy the already blurry puzzle…*

Robin H. Morris

It is the silence that is deafening. The raised eyebrows supported by an audible "tsk" are the precursors to well-meaning suggestions.

"My friend knows someone whose granddaughter did not speak until she was five. Call her."

"Maybe your doctor doesn't know everything."

"Remember, *there is more than one way to skin a cat*. Get another opinion."

"We've never had anything like this in our family."

"He will outgrow it, just wait and see."

Years ago, when autism was an uncommon diagnosis, a group of mothers met monthly at their child's private school which was dedicated to communication disorders. It was a time for sharing and purging thoughts of frustration. One mom was particularly upset with her mother-in-law. "Does she think I want my kid to be different? Her unsolicited advice kills me. She says I indulge him and that he is not different, just spoiled. Try waking up at three o'clock in the morning with Adam, while he literally climbs the walls!"

Another mom suddenly exploded with emotion. "You think that's bad. We finally agreed to go the route of implementing a behavioral plan to address Mary's tantrums. She was allowed to earn a piece of candy when she complied with a prompt. It seemed to be working, until my mother decided that our daughter should have M&M's whenever she wanted them. She told me that I am too hard on my own child! There went the plan."

A particularly stressful situation was explained by Jason's mother, who felt

see Question Parenting on page 39

Transitioning from page 16

college has to offer solely because of his or her disability. The student must self identify as a person with a disability in need of reasonable accommodations. It is up to the student to not only self identify with the college's office of disabled student services, but also provide documentation of the disability and need for reasonable accommodations.

The academic demands of college are not usually the downfall of students with autism spectrum disorders who seek higher education. After learning the system and routine, many students with ASDs adapt quiet well to the academics. It is the demands of the social environment where students on the spectrum struggle. The unwritten rules of the college classroom are quite different than in a high school setting and vary across instructors and even departments. Some instructors may be referred to by their first names. Others expect to be called "Dr." or "Professor." Often the nature of the lecture style classes is such that the professor is there to impart knowledge and will speak at length. They do not expect or even welcome interruptions during a lecture. Incessant questioning can alienate not only the professor, but classmates as well. Publically correcting a professor on a perceived factual error is another unwritten rule that a student must not do. Students on the spectrum must be explicitly taught these rules.

Perhaps, the most unpredictable and consequently most stressful social environment for students on the spectrum is living in the residence hall. Students with ASDs often have qualities of extreme naiveté and rigid adherence to rules. They can become victims of practical jokes and outright bullying. They can alienate their peers by strictly enforcing rules like "quiet hours" and running to the resident advisors at the slightest infraction. Impairments in executive functioning can lead to poor organization of their personal possessions, which can lead to roommate conflicts. Sensory integration dysfunction issues can be triggered by fluorescent lighting, typical dorm noise, and a roommate's use of perfumes or deodorants also can lead to conflicts.

The transition to college environments must be well planned and detail oriented. It is not simply sufficient for a student on the autism spectrum to be able to read, write, and do mathematics at a college level. Orienting a student with an ASD to the physical environment and the structure of college classes is only one part of the equation. The other parts of the equation are insuring that they are able to advocate for themselves in order to receive the services they are entitled to, providing skills to help them navigate the social environment, and instruction in a whole host of independent living skills. Planning for this eventual transition should begin in childhood in the family with the student learning basic independent living skills like cleaning his or her room, and the as the child ages these skills should become more advanced to include things like setting and waking up using his or her own alarm clock, and washing his or her own laundry. Formal transition planning can begin at age 14 through the Individualized Education Program (IEP) process. Parents as members of the IEP team should consider adding in other independent living skills as goals such money management skills and travel training. If appropriate, IEP team members should consider sending the student to summer college programs which are residential. Many colleges have a variety of programs where teens can live on a college campus and take enrichment courses. The focus for students with ASDs should not be on the academics, but on the independent living and social skill aspects. By sending a student on a spectrum to a college campus one or two summers prior to enrolling full time, parents and schools can ease the student's transition to college.

Some students, despite receiving special education services, will not be ready to enroll full-time in a degree bearing program or in a vocational training program after reaching age 18. These students with ASDs and other disabilities might be good candidates for Comprehensive Transition and Post Secondary Programs (CTP). These programs can act as a bridge between high school and the post-secondary environment. If the program is being used as a transition program, then it can be written into the IEP. The federal government re-affirmed this position when it responded to public commentary calling for explicit language concerning the funding of transition programs even those that are college based. The federal government's position was that the language was not necessary because IEP teams have always been able to write this into an IEP as they see fit in order to achieve FAPE for a student with a disability. The position was made clear when Congress passed the Individuals with Disabilities Education Improvement Act (IDEIA) in 2004 and solicited public commentary (See http://idea.ed.gov/explore/view/p /%2Croot%2Cregs%2C).

For those students on the autism spectrum who have graduated from high school and are no longer eligible for services and funding through IDEA, changes to the Higher Education Opportunities Act make it possible for students with intellectual disabilities (IDs) to receive federal financial aid. If a student with an intellectual disability is enrolled in a Comprehensive Transition and Post Secondary Program that is approved by the U.S. Department of Education, then they can complete the Free Application for Federal Student Aid (FAFSA). Currently, students with IDs, including autism, are eligible to apply only for Pell Grants and Student Work Study monies by completing the FAFSA. A complete list of approved CTPs can be found at www.thinkcollege.net.

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Motor Training from page 8

and toys flash on a computer screen. Infants in the passive and active groups were compared with each other, as well as to two control groups of untrained infants comprised of non-reaching 3-month-olds and independently-reaching 5-month-olds. Researchers found the following:

- The active group showed more interest in faces rather than objects. In contrast, the passive group showed no preference.
- Infants in the active group focused on faces first, suggesting strengthening of a spontaneous preference for faces.
- When compared to the untrained control groups, the social preferences of the 3-month-old infants who experienced active training were similar to those of the untrained 5-month-olds, indicating advanced development following training.
- Finally, individual differences in motor activity observed between all 3-month-old infants in the study were predictive of their spontaneous orienting to faces. Regardless of training experiences, the more reaching attempts infants made, the stronger was their tendency to look at faces. Thus, motor experiences seem to drive social development.

"The most surprising result of our study is that we see a connection between early motor experiences and the emergence of orienting towards faces," said Dr. Libertus. "Logically, one would predict exactly the opposite. But in the light of seeing actions as serving a social purpose, it does make sense."

A key question researchers hope to answer next is whether these early changes will translate into future gains for these children. "Our results indicate a new direction for research on social development in infants," said Dr. Libertus. Dr. Libertus and his colleagues will continue to observe these children to see if the social development benefits achieved during the current study are sustained one year later.

Support for this study was provided by grants from the National Institutes of Health.

About the Kennedy Krieger Institute

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

Recurrence from page 9

Fifty-four received a diagnosis of autistic disorder and 78 received a diagnosis of Pervasive Developmental Delay Not Otherwise Specified, considered a milder form of autism.

More males than females are affected with autism - 80 percent of all affected children are male. The risk to male children held true in the current study. Among the study participants, 26.2 percent of male infants versus 9 percent of female infants were diagnosed with an autism spectrum disorder.

The overall rate of autism spectrum outcomes for all study participants was 18.7 percent. However, there was a significant difference in the recurrence rate based on whether the child had one sibling or more than one sibling with autism. In families with one older child with autism, or simplex families, the rate of incidence was 20.1 percent. Only 37 of the study participants had more than one sibling with autism. But for those families, called multiplex families, the recurrence rate was 32.2 percent.

"It's important to recognize that these are estimates that are averaged across all of the families. So, for some families, the risk will be greater than 18.7 percent, and for other families it would be less than 18.7 percent. At the present time, unfortunately, we do not know how to estimate an individual family's actual risk," Ozonoff said.

Ozonoff said that the study's large size, prospective design, the young age of study participants at enrollment and the gold-standard direct-assessment methods used, as well as the geographic diversity of participants, reinforce the accuracy of its findings. The study design also minimized the effects of other factors such as "stoppage," the tendency of families with a child with autism to stop having children, which would lead to an underestimate of potential recurrence rates. The study accounted for stoppage by studying only families with later-born siblings.

She said that the study has significant family planning and genetic-counseling implications. "Parents often ask what their risk of having another child with ASD is and, until now, we were really not sure of the answer," Ozonoff said.

The study also highlights the critical importance of routine surveillance and rapid referral for treatment of infant siblings of children with autism. It is of paramount importance that primary care professionals monitor these children's development closely and refer them for early intervention when concerns arise, said Autism Speaks Chief Science Officer Geraldine Dawson.

"By pulling together data from many investigators who are studying infant siblings of children with autism, this study offers a more accurate estimate of the recurrence rate for autism in siblings," Dawson said. "Surprisingly, the rate is much higher than previous estimates. This points to the important need for closely monitoring and screening siblings so that they can be offered intervention as early as possible. Early intervention ensures the best possible outcomes."

In practice guidelines published by the American Academy of Pediatrics in 2007, being a younger sibling of a child with autism is considered a risk factor requiring special developmental evaluation and the current investigation supported that recommendation.

"This study shows that the younger siblings of children with autism spectrum disorders need to be tracked very carefully, and this may require more than the normal surveillance that a pediatrician might typically do," Ozonoff said. "This should include very explicitly and regularly checking in with parents on whether developmental milestones are being reached."

More information about Ozonoff's research can be found at the UC Davis MIND Institute's Infant Sibling Study website.

For more information about the early signs of autism, visit the Autism Speaks Learn the Early Signs website.

Other authors of the study are Gregory S. Young and Sally J. Rogers of the UC Davis MIND Institute; Alice Carter of the University of Massachusetts, Boston; Daniel Messinger of the University of Miami; Nurit Yirmiya of the University of Jerusalem; Lonnie Zwaigenbaum of the University of Alberta, Canada; Susan Bryson of Dalhousie University, Halifax, Nova Scotia; Leslie J. Carver and Karen Dobkins of UC San Diego; John Constantino of Washington University, St. Louis; Ted Hutman and Marian Sigman of UCLA; Jana M. Iverson of the University of Pittsburgh; Rebecca Landa of Kennedy Krieger Institute; and Wendy L. Stone of the University of Washington, Seattle.

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At the UC Davis MIND Institute, world-renowned scientists engage in research to find improved treatments as well as the causes and cures for autism, attention-deficit/hyperactivity disorder, fragile X syndrome, Tourette syndrome and other neurodevelopmental disorders. Advances in neuroscience, molecular biology, genetics, pharmacology and behavioral sciences are making inroads into a better understanding of brain function. The UC Davis MIND Institute draws from these and other disciplines to conduct collaborative, multidisciplinary research. For more information, visit mindinstitute.ucdavis.edu.

Sensory from page 23

calm. We all have sensory qualities that make us who we are. However, when these neurological qualities interrupt our participation in life in a negative way, it should be recognized and accommodated. There are many children with an array of diagnoses that are subject to sensory hyper - or hypo-sensitivities, motor difficulties, and social differences including Autism and Aspergers, ADHD, Sensory Processing Disabilities, Anxiety, and many other Developmental Disabilities. Why not make their clothing possess some of the very neuroscience qualities that could help enhance their social and emotional well being? As a mother of a child who suffered from sensory processing disorder and as a long time Sensory Pediatric Occupational Therapist and advocate, I know firsthand it is not easy for our children.

Parents, therapists, and educators often express to me the benefits of weighed garments, chew objects, compression garments, and a child's desire for soft materials. However, they frequently state that what is offered to them is too "therapeutic looking" and therefore stigmatizing. It's hard to use many of these garments throughout "normal" life.

When a garment is being constructed to address children who suffer sensory processing difficulties, specific consideration should be made to address ease of function, tactile sensitivity, relevant design, safety, consistency in design for spatial orientation, and proprioceptive input (the unconscious awareness of sensations coming from receptor's in one's joints, muscles, tendons and ligaments). This helps promote independence as well as organization, alertness, and simplicity where quickness of dressing is often expected throughout the child's day. When choosing a weighted vest or blanket for instance, it is significant to hear the child ask specifically for the "soft one," the "cool one," or the "nice one." It is as significant to give their parents beautiful, easy to use, and superior fabrics that are relevant and stylish. It is the right of the child and their parents to have non-stigmatizing products. Just as important is the idea of play, and accommodating products should express the darling nature and playfulness inherent in children.

Respect, pleasure, playfulness, comfort, and a feeling of security are aspects that can be inherent in children's clothing. As the design of the child's apparel and play products are considered, it is important that as many of their personal characteristics are taken into consideration, in addition to the ability for children to take some therapeutic qualities along with them anywhere all day long.

There are so many strategies that help a child with Sensory Processing Difficulties. Considering the aspects in their clothing is just another way a parent can simply use a non-invasive strategy aimed at helping their child and letting the child know that you understand and accept what they are feeling!

Susan Donohoe, OTR/L is a Pediatric Occupational Therapist with certification in Sensory Integration and an advocate for children with special needs. Susan graduated from the University of Pennsylvania and has been practicing O.T. for 30 years. Through many years of active practice and working closely with educators, therapists, manufacturers, and experts in Design founded Prince's Sensory Delights (www.princessensorydelights.com) in 2006 as a way to incorporate Neuroscience Principles into relevant designed apparel for children with special needs. With her passion and commitment, she developed the concept for a line of adorable coordinated sportswear and products that offer therapeutic value which are non-stigmatizing.

Autism Speaks Asperger Syndrome and High Functioning Autism Tool Kit

By Autism Speaks

In March 2010, Autism Speaks, North America's largest autism science and advocacy organization, launched the Autism Speaks Asperger Syndrome and High Functioning Autism Tool Kit (AS/HFA Tool Kit). The AS/HFA Tool Kit was created specifically to assist families in getting the critical information they need in the first 100 days after an Asperger Syndrome or high functioning autism diagnosis. The organization launched the AS/HFA Tool Kit in response to the rising demand for more information about Asperger Syndrome and high functioning autism. As of September 1, 2011, over 700 complimentary hard copies of the AS/HFA Tool Kit have been sent out to families of children with these diagnoses, and several thousand have been downloaded free of charge on the Autism Speaks website, AutismSpeaks.org. To view the Tool Kit directly, visit www.autismspeaks.org/family-services/tool-kits/asperger-syndrome-and-high-functioning-autism-tool-kit.

In creating the AS/HFA Tool Kit, the Autism Speaks Family Services team sought input from individuals with autism spectrum disorder, their family members, service providers and professionals. The feedback from individuals with Asperger Syndrome and High Functioning Autism played an especially critical role in ensuring the accuracy and effectiveness of the tool kit.

The kit opens with general information about Asperger Syndrome and High Functioning Autism, addressing the definitions, symptoms and causes, as well as the difference between the two:

"*The diagnosis of either High Functioning Autism or Asperger Syndrome can oftentimes feel frustrating to a parent and the child as it may seem that the terms are not clearly defined. It is essential to remember that both Asperger Syndrome and High Functioning Autism do present themselves largely the same way, and as a result may be treated in a similar way. The primary difference is that a diagnosis of High Functioning Autism requires that, early in development, the child had delayed language whereas in Asperger Syndrome, the child did not show a significant delay in language development. Compared with classic autism, children with Asperger Syndrome/HFA have IQs that fall in the normal or even superior range. To many, they may seem just like other children but not quite: children with Asperger Syndrome are socially awkward in a manner that's not easily understood*."

The "Interventions and Treatment Options" section provides families with information on how to best help their children. This information is essential because every individual with an autism spectrum disorder is different, so some may respond better to certain treatments than others. Options addressed include Social Skills Training and Speech Language Therapy, Parent Education and Training, Applied Behavior Analysis, Sensory Integration and Occupational Therapy, as well as Medications to treat some symptoms of the disorder. The "In the Classroom" section contains critical information about Individualized Education Programs and how to access special education services to ensure that your child receives the best possible education.

One section specific to the AS/HFA Tool Kit is "Transitioning to Adulthood." The transition period in the life of an individual with an autism spectrum disorder can be an extremely difficult time, so the information included about IDEA transition services entitlements, employment, and post-secondary education options is very beneficial to the many families entering this challenging phase.

The kit also contains a wide array of resources specific to each topic section, as well as general resources including books, websites, magazines and more. There is a clearly laid out week by week plan for the time period following the diagnosis, along with useful forms that help keep families organized and prepared.

The tool kit also addresses how the diagnosis may affect the rest of the family. It stresses the importance of remembering that though only one family member may have Asperger Syndrome or High Functioning Autism, each of the other family members is often confronted with different challenges and may need support as well. Parents, siblings, grandparents, and other family members are often overlooked when responding to the diagnosis, so the tips included in the AS/HFA Tool Kit are an extremely valuable tool for families.

Families of individuals diagnosed with high functioning autism and Asperger Syndrome in the past 6 months are eligible to receive a complimentary hard copy in the mail, along with a letter and a list of state and local resources specific to each family. For those who don't meet the criteria for a complimentary hard copy, the AS/HFA Tool Kit is available to download in PDF form free of charge at AutismSpeaks.org, and hard copies can be purchased in the Autism Speaks store.

The AS/HFA Tool Kit contains a wealth of information to assist families during the critical time following the diagnosis of Asperger Syndrome or high functioning autism. These early days are some of the most important in the lives of individuals affected by an autism spectrum disorder and their families. The Autism Speaks Asperger Syndrome and High Functioning Autism Tool Kit is a perfect way to get informed, organized and ready for the journey that lies ahead.

Facts from page 27

- On average, young adults with autism with a job earned 86% as much per hour as all young adults with disabilities with a job ($8.90/hour vs. $10.40/hour).
- Nearly half of employed young adults with autism earned less than $7.25 an hour, twice the rate for all employed young adults with disabilities (44% vs. 22%).
- Nearly half of employed young adults with autism worked less than 20 hours a week, four times the rate for all employed young adults with disabilities (42% vs. 11%).
- The proportion of employed young adults with autism who were working full time (35 hours or more per week) was one third that for all young adults with disabilities who had a job (26% vs. 71%).
- The proportion of employed young adults with autism who worked in a sheltered workshop environment (only working with other people with disabilities) was seven times that for all employed young adults with disabilities (34% vs. 5%).

There are 10,500 vocational rehabilitation (VR) counselors nationwide helping people with disabilities get jobs.[14]

In the past, vocational rehabilitation (VR) services for people with autism have had mixed success.

Between 2002 & 2006, people with autism who got VR services were more likely to become employed than VR clients with other disabilities, but those jobs were of lower quality: far lower hourly wages, far fewer hours per week.[15,16]

The number of people with autism asking for vocational rehabilitation services is rising rapidly.

From 2003 – 2008, the number increased nearly 300%.[17,18]

There is growing interest in improving vocational rehabilitation services to people with autism

The Autism Works National Conference is an annual conference on improving employment services for people with autism (www.facebook.com/pages/Autism-Works/136057253090452). There are 2 federally-funded research projects on autism and vocational rehabilitation: VCU's ASD Career Links (www.vcu-autism.org) and SEDL's Vocational Rehabilitation Service Models for Autism Spectrum Disorders (autism.sedl.org). In spring, 2010, the Journal of Vocational Rehabilitation published an autism-specific issue (vol. 32, pp. 89-100). In 2009, the author of this article published to the web *Adult Autism & Employment: A guide for rehabilitation professionals*, (www.dps.missouri.edu/Autism.html).

Several state vocational rehabilitation agencies have designated statewide autism service coordinators and are participating in trainings on the needs of adults with autism. A growing number of subcontractors of the state vocational rehabilitation agencies have begun programs tailored to adults with autism.

There are some remarkable new models emerging of employment for people with autism

These are projects in which people with autism are working in their communities, side by side with neurotypical coworkers, for competitive wages, with no permanent job coaching:

- Walgreens Disability Inclusion Program – employing people with autism and other disabilities in regional distribution centers across the country (www.walgreens.com/topic/sr/distribution_centers.jsp)
- TIAA-CREF: Fruits of Employment – employing people with autism and other disabilities in commercial orchards (http://tcasset.org/innovation-stories/fruits-employment-program)
- Roses for Autism – employing people with autism in commercial rose production (www.rosesforautism.com)
- Aspiritech – employing people with autism in testing phases of software development (www.aspiritech.org)

A more detailed version of this article is available as an online fact sheet at http://dps.missouri.edu/Autism/AutismFactSheet2011.pdf

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Social Skills from page 14

group and the individuals within the group. A successful group is more than just a group with age- and developmentally-matched peers. There are numerous social skills programs and curricula which focus on developing essential social language skills. The following list reflects only a few of these programs: "Teaching the Hidden Curriculum," Social Stories™, and Social Thinking™. Additionally, many traditional social skills programs teach scripts. Scripts are defined as, "providing scenarios for social interaction through language in action." Based on my professional experience all of the programs have successful components and are excellent when used selectively to meet the needs of the group. But none of these programs were developed to be utilized in a "cookie cutter" fashion. A strong social skills group is able to use one or more of these programs as a base and then adapt it to meets the needs of the group creating an integrated approach to social skills training and treatment.

In the research, one of the greatest concerns is the issue of carryover of learned skills into "real life" social situations. Peer modeling intervention has been found to be an effective approach because it provides a more natural social context. Furthermore, practical carryover assignments can assist in the generalization of the skills, in addition, to providing a positive way for families to: gain a greater understanding of the individual's social skill strengths and needs, understand their role in modeling appropriate social skills, increase taking an active role in the therapy process and assist with practicing learned skills within a natural setting.

A few years ago, I worked with a very intelligent 17-year-old with Asperger's Disorder and gave him an assignment called a "Friend File." This task required him to identify 3 friends and then list what he knew about each person, state what they might want to talk about and then write down a couple of questions or comments to make in order to initiate a conversation. Surprisingly, he was not able to recall anything about his "friends" even with prompts. It was at that moment I began to wonder what he knew about his own family so I gave him a similar exercise, but it pertained to his immediate family. He responded that his mother "enjoys" cooking dinner and cleaning his clothes. No wonder he was not able to initiate a conversation with his family since he had limited awareness of his parents' and siblings' interests. As a result most of his social interactions were limited to expressing his basic needs. Needless to say, given his limited perspective taking skills I realized that asking him to focus on friends was too complex. Since this experience, I now believe strongly that the family is the critical place to start developing and generalizing skills. But families need education and direction on how to maximize success.

By the nature of the disability, individuals with AS and HFA have difficulties in the area(s) of communication and socialization. While it is true everyone is unique in his/her abilities and deficits, successful social skills, within a variety of settings and across people is quite complex even for those of us who are "neurotypical." While, most of us may not feel that we need to be "taught" all the social rules, and believe we are successful within various social settings, we must each recognize that there are times we may make "mistakes" or ineffectively communicate our message. Once we all recognize our own strengths, weaknesses, and challenges, we will become more understanding and empathetic to those who really have to "learn" all the rules.

In conclusion, when seeking a social skills program, remember for true success it is critical that the individual is truly interested in developing social relationships; that the family is prepared to take an active role in reinforcing trained skills and being a model; and most importantly, that the professional(s) running the group does not just use a social skills curriculum, but also has experience and knowledge of the complexity of not only social skills and language, but also HFA and AS. This ensures the facilitator's ability to continually address individual differences amongst group members. Overall, all programs should provide a very positive, warm social environment where the participant is able to understand, learn and generalize the skills that are necessary for social success.

Unemployment from page 15

staffing strategy?

The social responsibility and diversity reasons are obvious, but compelling economic reasons exist as well. It is estimated that 1.5 million individuals in the U.S. have been diagnosed with an ASD. When the close family members of those diagnosed are included (parents, siblings, grandparents, aunts and uncles), the population of people affected by autism is approximately 10.5 million, or 3.4% of the U.S. population. This number is as large as recent estimates of the lesbian, gay, bisexual and transgender population in this country. Like other groups, individuals who are living with autism, as well as their family members, can be issue sensitive consumers. At 3.4% of the U.S. population, individuals touched by autism comprise a meaningful market share to companies. To illustrate, within a two block radius of ASTEP's offices in NYC are stores from three pharmacy chains - Duane Reade, Walgreens and CVS. All three stores carry the same products for generally the same prices. Yet Walgreens and CVS are known employers of individuals with developmental disabilities, autism among them. At ASTEP we always choose a Walgreens or CVS over Duane Reade.

Reducing the cost of turnover is another benefit to employers in hiring individuals with Asperger Syndrome. Many companies experience high turnover during the early years of employment of recent college graduates. Given the characteristics of individuals with Asperger Syndrome – loyalty, desire for stability, extreme focus – they are less likely to "job hop" during the early years of their career. A program instituted by Home Depot illustrates this. In 1997 Home Depot created a program to hire individuals with developmental disabilities, including autism, in their stores. They found that the retention rate for individuals with a developmental disability was 50%, versus 34% for other employees. Greater retention results in reduced costs. Lastly, the social interactions required of a work environment are often the biggest challenge for an individual with Asperger Syndrome. The education and training required for an employee with Asperger's and their manager and colleagues to work together effectively is centered on education about Asperger's and communications training. The Asperger's education component involves making managers aware of the particular challenges faced by the employee with Asperger's – their communication style, learning style, sensory issues. The communications training includes teaching managers, colleagues and individuals with Asperger's how to communicate information and expectations, including behavioral expectations and needs, in a clear fashion. Appropriate communications training benefits all individuals who are trained, with those benefits improving all of their interactions at work, not only those with the employee who has Asperger's.

So if the benefits of hiring individuals with an ASD are so compelling, why aren't more employers seeking out these individuals? For those of us steeped in the subject and those who have Asperger Syndrome, the benefits are obvious. Unfortunately, the benefits are not so obvious to the rest of the working world. Employers are not consciously seeking out employees with Asperger Syndrome, and are not properly accommodating those employees they have with Asperger's, due to lack of knowledge, access and training. Many people and organizations that advocate for or support individuals with Asperger's are very focused on serving their clients, but do not spend enough time on educating employers. In a survey of 411 companies sponsored by the National Organization on Disability (NOD) and the Kessler Foundation in October 2010, less than half of the companies reported using non-profit, community based, state or federal service providers to recruit individuals with disabilities. Of the companies using these service providers, only 34% rated the service providers as being effective to extremely effective. Of the employers not using service providers, almost half (48%) felt they did not need the services they offer. If the vocational rehabilitation system – both public and private – is to be effective in finding jobs for individuals with Asperger Syndrome, or any disability, these views need to change; and the obligation to change these views lies with the service providers themselves.

Just as thoughtful communication can improve the chances for an individual with Asperger's of obtaining and retaining a job, it can improve the chances of employers and employment specialists creating a successful partnership. Some simple strategies for advocates can result in a strong employer/employment specialist partnership.

- Always use the initial meeting with any employer to have them to explain their business and hiring needs. Do not focus on the placement of any particular job candidates, unless the employer asks, at this time.

- Ask questions, and lots of them. Learn the culture in the workplace – is it a very social environment or not; do they have other employees with disabilities; do employees stay a long time or turnover frequently; does the company provide any skills training. Not only does this provide valuable information in assessing which clients may be appropriate candidates for the employer, it demonstrates to the employer interest in their business and needs.

- Work with the employer to develop a clear job description before trying to place any clients. For individuals with Asperger Syndrome, understanding the parameters and requirements of the job are critical prior to entering into the interview process.

- Carefully match employment specialists with companies and clients to ensure a peer to peer relationship.

The view of employers expressed in the NOD/Kessler survey needs to be changed, and will take the efforts of many to do so. But those efforts are underway. In 2006 the NOD narrowed their focus to increasing employment opportunities for the 79 percent of working-age Americans with disabilities who are not employed. In 2010, the Asperger Syndrome Training and Employment Partnership (ASTEP) was founded to promote education for employers, thereby driving change in the employment landscape for adults with Asperger Syndrome. As an employer focused organization, ASTEP strives to: 1) educate and train employers on the benefits of hiring individuals with Asperger's and the accommodations they may need for a successful employment outcome, and 2) assist employers in working with vocational rehabilitation organizations and employment specialists to recruit and transition individual's with Asperger's into work. At ASTEP we spend our days talking to employers about the benefits of hiring individuals with Asperger's and teaching them about the accommodations required to reap those benefits. Surprisingly, employers are more aware of Asperger Syndrome than one might think; but most admit feeling woefully unprepared to manage the issues that arise with employees on the spectrum. This awareness creates an opportunity for us to help employers better understand Asperger Syndrome and develop strategies to employ individuals on the spectrum.

The Asperger Syndrome Training and Employment Partnership (ASTEP) is a non-profit organization whose mission is to create and support programs that promote long-term employment for adults with Asperger Syndrome. ASTEP provides education and training to the corporate world on the benefits, challenges and accommodations present in hiring individuals with Asperger Syndrome. ASTEP will also work with employers to identify and hire individuals with Asperger's. ASTEP engages organizations and professionals who work with individuals with Asperger's to identify job candidates, develop recommended accommodations, train employers about the individual employees and provide any necessary ongoing support. For more information on ASTEP please visit our website at www.asperger-employment.org.

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school district's special education program, or lack thereof, the school district is still required to address a student's unique learning needs through services and/or specific goals in his or her IEP and program.

Along with tailoring the IEP to a student's unique needs, it may also be necessary to conduct a Functional Behavioral Assessment ("FBA") that would possibly result in a Behavioral Intervention Plan ("BIP"). An FBA and BIP would allow a student with problem or difficult behaviors to remain in the mainstream setting and learn alongside their non-disabled peers. Their removal from the general education program to a more restrictive educational setting can only occur when the district has reasonably exhausted the tools available to them. For example, a student, due to impulsivity and lack of social skills, may call out of turn constantly and be disruptive in the classroom. Before removing that child from the classroom, an FBA and BIP would need to be put in place to attempt to remediate the disruptive behaviors. Nevertheless, there are times when a student, even with a BIP in place, just may not be able to be educated appropriately within their home district. If the committee responsible for deciding the student's plan decides that this is the case, then the student may be educated in another program outside of the home school district in a program that can more appropriately address his or her unique learning needs.

The IDEA covers all "classified students" through the year in which the child turns 21 or graduates from high school, *whichever comes earlier*. The IDEA requires that by no later than the year a student turns 16, a transition plan be put in place.[2] The transition process and plan allows the student to easily transition to life post high school. The transition process is extremely important for all students, but in the case of students with Asperger's there are some specific issues that should be considered. For example, even though the student can be admitted to colleges due to his or her academic ability, does he or she have the requisite social and life skills to be able to survive the college environment? There are no IEPs in college, so the student must acquire as many of the requisite skills to be able to navigate the college environment before graduating high school. This is done through the transition process. The transition time is also very important for the student who may not be attending college. For example, many students with Asperger's, due to their high intelligence quotient ("IQ"), may not meet the criteria necessary for guardianship or public benefits (more fully discussed below). If this is the case, an alternate plan must be put into place and prepared for in order for the student to be able to achieve their post high school goals and receive the services, programs, and supports they may require after graduation. Unfortunately much too often in our practice, we see parents whose children did not have proper transition plans in high school, leaving the child and family with little or no support post high school. Often, this can be avoided simply by having an IEP that implements appropriate, person centered, transition services while the student is in high school.

Sheryl R. Frishman, Esq

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Adult Services

Access to Public Benefits

Once a child with Asperger's attains the age of 18, he or she may be eligible to receive public benefits. Public benefits are important because being eligible for them could open up an array of services. It may be difficult to access these important benefits due to the unique nature of Asperger's that typically include a high IQ. It is important to understand that there are appeal rights if your child is initially denied for public benefits, which is often the case when dealing with demonstrating the Asperger's disability. During the appeals process, a more thorough investigation is completed by the agency where parents can supply evidence to demonstrate a more complete picture of who their child is. The following is a brief overview of some of the more widely accessed benefits:

SSI: Supplemental Security Income ("SSI") is a monthly payment made to individuals with low income and limited resources who are 65 or older, or blind, or disabled. The amount of the SSI payment varies from state to state because some states add to the SSI payment. The applicant must meet the following requirements to be considered disabled and therefore eligible for SSI: (a) if working, he or she cannot earn more than $1,000/month (this amount can change every year); otherwise the Social Security Administration will find that the applicant is not disabled; (b) he or she must have a physical or mental disability, or a combination of disabilities, that results in "marked and severe functional limitations;" and (c) his or her disability must have lasted, or be expected to last, at least 12 months.

SSDI: An individual with Asperger's may also be eligible to receive non-means tested benefits through the Social Security Disability Insurance ("SSDI") program. SSDI pays benefits to adults who have a disability that began before the age of 22. The Social Security Administration considers the SSDI benefit a child's benefit because it is paid on a parent's Social Security earnings record. For a disabled adult child to become entitled to SSDI, one of his or her parents must (a) be receiving Social Security retirement or disability benefits; or (b) have died and have worked the requisite amount of quarters necessary to receive social security benefits. SSDI benefits continue as long as the individual remains disabled. There is no work requirement to receive these benefits. Unlike the SSI program, benefits received under the SSDI program are not means tested, meaning that assets are not considered in determining eligibility. There are work and income limitations, which can be restrictive when considering a person with Asperger's may be able to contribute to the workforce.

Medicare: Medicare is a federal health insurance program for people age 65 or older and for people who have been receiving Social Security disability benefits for at least two years. Typically, two years after one becomes eligible for SSDI benefits, they will also become eligible for Medicare benefits.

Medicaid: Medicaid is a health care program for people with low incomes and limited resources. It is a combined federal and state program and there are many state specific rules for eligibility. In most states, those who get SSI payments qualify for Medicaid. In fact, in many states, Medicaid comes automatically with SSI eligibility. In other states, you must sign up for it. Also, some disabled individuals can get Medicaid coverage even if they do not qualify for SSI.

SSI and Medicaid can be important benefits if one is unable to work and receives, or wishes to receive services through a state funded program or agency, including residential placement, day programs and other services. It is possible for a person with Asperger's to receive a combination of SSDI, SSI, Medicare, and Medicaid benefits. Generally, as long as one receives $1 of SSI benefit, he or she will be eligible for Medicaid. If one is dually eligible for Medicare and Medicaid benefits, Medicare is the primary payor of medical expenses and Medicaid is the payor of last resort, meaning Medicaid will only cover expenses that Medicare does not cover.

Guardianship and Advance Directives

When any child attains the age of 18, they legally become emancipated from their parents regardless of whether they have a disability or not. At this time, parents no longer have decision-making authority over their children, including financial transactions and health care decisions. This is extremely distressing to most parents of young adults with Asperger's. While their child is highly intelligent they may have extremely weak functional and/or life skills. Most parents feel that this leaves their child in a vulnerable position. Parents of children with Asperger's must consider what happens when their child turns 18. Do they seek a guardianship from the court, or consider legal documents to assist their child in decision-making?

A *guardianship* is a legal proceeding where a court determines a child to be "incapacitated" and unable to manage his or her affairs. The person appointed as guardian is usually the child's parent or sibling. Many state guardianship statutes are restrictive and cannot be tailored to the unique needs of a child with Asperger's. Typically, a child with Asperger's has worked very hard in their schooling and life skills to be able to succeed in adulthood and the last thing that a parent wants to do is take away complete decision making authority from their child. Further, a child with Asperger's may present himself very well and the disability is not apparent. If a parent is considering a guardianship for their child it is important that the child's doctors and/or psychologists be consulted. Also, the special needs attorney should meet with the child to determine, from a legal perspective, whether the child would qualify for a guardianship, or, in the alternative, other planning should be made.

The alternative to a guardianship is for the child to execute Advance Directives, which include a Power of Attorney and Health Care Proxy.

A *Power of Attorney* is a statutory document, usually with state-specific requirements, that allows an individual to designate one or more individuals (usually the child's parents and/or siblings) to assist them with financial decisions. This document has powers granted to the agent, which can be tailored to the person's individual needs. For example, the Power of Attorney can specify the agent's ability to deal with education matters.

A *Health Care Proxy* permits a person to appoint an individual, again typically a parent or sibling, to assist in health care decision-making. This document should be sufficient to authorize the agent to make all health care decisions. It is important for the Health Care Proxy include HIPAA authorization, which allows the agent to access medical records.

It is critical that the child and parents meet with a special needs attorney when preparing these documents and not use standard forms found online, as these documents must be tailored to specific circumstances. Additionally, if the capacity to execute these documents is ever questioned, it helps when an attorney, specializing in special needs planning, oversees the execution of these documents. Further, it is important to understand that your child can revoke a Power of Attorney and Health Care Proxy;

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To him, this wasn't a "not nice" comment. He thought it is just a fact that bologna is "yucky," so this wasn't a question of "niceness," and he had been told not to use the word "ugly," not "yucky."

Inflexibility is also a typical problem. These children have what I call "railroad track thinking." Most of us think like we drive: if a road is blocked, we detour around it. These children's thought process often can't detour; it's straight ahead or nothing. A parent told a child that he would get to go to McDonald's after his tutoring session. While he was in session, his sister got hurt, possibly breaking her arm. The mother picked him up and told him they had to rush to the emergency room. McDonald's was off. He was furious, screaming, "You lied!" He had no appreciation of the fact that his sister was injured, only that he had been promised McDonald's and McDonald's wasn't happening. His mother saw his behavior as a selfish lack of compassion for his sister, and he was punished.

These children are often punished or given detentions in school, and have no idea why, so they feel teachers and parents are unfair. An 8th grade boy was following friends who would misbehave. He might join in, or not, but to him, the behavior wasn't violating the listed rules. He had no idea why he was given detention and came to the conclusion that his teacher "was out for him" and hated him. In class, a high school student was supposed to work on a group project. To him, there was only one "right" way to do it; his teammates disagreed. He walked out of the room and refused to do the task, resulting in a grade of zero. Younger students often become guardians of the rules, and report classmates for minor infractions. It is a surprise to them that this often isn't appreciated by the teacher, and certainly isn't appreciated by the classmates.

It is evident by now that the inability of these children to appreciate theory of mind, the idea that someone might have a different point of view (and one that is legitimate) often gets in the way. The lack of social skills and social understanding makes it hard for them to anticipate the outcome of their behavior, and often if others object to their ideas, the children with AS think the teachers or peers are just "wrong." These children often express their ideas without appreciating "fine points" such as the authority of a teacher or parent. A high school student felt it was necessary to criticize his teacher in front of the class, since the teacher's lesson plan and behavior were "wrong." When we talked, he said his teacher was stupid and biased, and he was tempted to tell him that as well. A 7th grade girl announced to her assembled extended family that religion was stupid and she didn't believe in God during a religious celebration. Unsurprisingly, her grandparents felt she needed discipline and her parents were lax.

When working with these children, it's often very challenging to change their point of view; one has to settle initially for redirecting the response to something more socially appropriate and less offensive. I had a teenaged patient with AS who unfortunately was also quite depressed. At one point, the treating psychiatrist hospitalized him on an adolescent unit that I was assured "understood" AS. After two days, I received a call from the psychologist on the unit complaining about my patient, who was sitting in group therapy with his laptop open, despite the limits set by the psychologist. I told the therapist that in my opinion, my patient was doing pretty well, since in the past he would have announced that the group was stupid and he didn't care about it. Quietly working on a laptop was a much more acceptable choice and the product of hard work.

"What am I supposed to do," the therapist asked, "tell him he's doing well?" He obviously didn't get "concrete." "No," I told him. "You should tell him you understand that he probably isn't interested in the group and that you appreciate his social judgment in not saying so. Then either take him out of group, or let him have his laptop."

The point of this example, and this article, is how important it is for these children to feel understood, and how the adult must communicate respectful understanding of child's point of view before trying to correct his behavior. The adult in these situations must ask why this behavior might be happening, and essentially to perform a functional behavioral analysis, figuring out the child's thinking that had triggered the response. One we "get it," we can communicate understanding, building a more trusting relationship that gradually allows us to work towards more flexible and socially appropriate behavior.

Dr. Eckerd is a licensed psychologist working for over 25 years with children, teens and adults with Asperger's Syndrome, Nonverbal Learning Disabilities and PDD NOS. She provides therapy, neuropsychological evaluations, social skills coaching, and consultations for parents, schools, advocates and attorneys. She is a licensed psychologist on the National Register of Health Service Providers in Psychology, a resource clinician on OASIS/MAAP (Aspergers.com) as well as NLDline.com, a professional board member of CT Association for Children with Learning Disabilities and Smart Kids with LD, a member of the Council of Parent Attorneys and Advocates (COPAA). Her blog, "People Skills" is found on PsychologyToday.com.

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to the average person; some are quite unusual. Not always realizing that his communication partners may not share his interest in, say, the history of the Dutch East Indian Trading Company, my child might not always know when to change the topic or understand that conversation is actually an interactive sport. As such, he may automatically and unconsciously dominate the discussion with the potential to explode (in words, of course), mainly because it is literally too painful for him cognitively, emotionally and physically to filter or withhold what he feels compelled to share with the world.

Like every other 7th grader you teach, my son is learning to navigate the teenage social landscape of his generation, to modulate his unpredictable hormones, and to develop a sense of himself as he is and wants to be. But unlike many of his peers, he joins the game with a handicap that is neither tangible nor visible. So whereas he is frequently thought to be "charming" and "interesting" by adults, he is often considered "weird" or "annoying" by his peers, and he truly doesn't understand why. This semi-meta-awareness can be helpful in learning to communicate appropriately and effectively, but it is also a frequent source of frustration and confusion.

On the other hand, my son is as interested in social interaction as he is challenged by it: the subtle non-verbal cues and inherent unwritten rules of communication that are second nature to you or I can be completely unnoticed or misunderstood. You might observe that my son frequently gets "stuck in a loop," so to speak...kind of like a record skipping, for those of you young enough to remember LPs and 45's. Whether the momentum is driven by emotions (confusion, offense, anxiety, fear, excitement, enthusiasm, anger, happiness) or topic of discussion (Elvis, pirates, the James Bond franchise, or a 35-year history of Saturday Night Live), he easily gets caught in a perpetual thought cycle and may need assistance pulling out of it.

On a physical level, my child's eye contact is either sketchy or at times opposingly intense. He can chatter on loudly and rapidly, and frequently will close-talk better than any Seinfeld character. He can easily morph from Nervous Nelly to Chicken Little, literally expecting the sky to fall at any moment. During especially difficult times, my son will attempt to self-soothe these anxieties by drawing in his notebook, playing with his writing instrument, or via ticks such as picking his lip or scratching behind his ears...we've been working on these for several years now in terms of hygiene and social appropriateness, but it hasn't been easy. The up-side is that these un-poker-faced behaviors are a clear indicator of his stress and distraction level, and can be useful in identifying and helping him manage his responses to said stressors, as well as re-direct him back to the lesson at hand.

Added to my son's social challenges are concurrent diagnoses of ADHD as well as a metabolic condition. He takes medication for both, but it's a slippery slope managing appropriate dosing, especially during puberty. Issues of mood, appetite and sleep-wake cycle, just to name a few, can be affected by any or all issues, so I hope you will notify me if you see any changes in or concerning behaviors from my child while he is in your company.

My son, as an individual, is much more than a few medical diagnoses. At bare minimum, he is hilarious, creative, and has a perception of the world that's all his own. As his mother I love him for so effortlessly just being who he is. But it's not easy for him to be him when he's not privy to the rules of the game, or when he feels he's not in control of his own behaviors...not that it keeps him from bravely trying over and over again.

Scared yet? You shouldn't be. He's a great kid. He'll probably finish all his homework on time, follow all the rules (did I mention he's the honorary sheriff of the rule police?), actively engage in classroom discussion, be prepared for pop quizzes and earn honorable grades in your respective subjects. Our child actually WANTS to learn and will be the SpongeBob Squarepants of his class, soaking up as much as you can dish out. But don't be surprised when he marches to the beat of his own drum corps, as well as gets lost in marching band formation in the process.

In conclusion, I have a few reasonable (I think) requests:

1. Please be concrete and specific with your instructions to my son, otherwise he may not understand exactly what is expected of him or an assignment. That being said, be prepared for him to interpret everything you say literally, well, literally.

2. It's tough, but please try to keep in mind my child's context when he says something that may on the surface seem disrespectful, argumentative, blunt or curt, rather than jump to the conclusion that it's personal; it might make for the perfect learning/teaching opportunity regarding the subtleties of social interaction. He could really benefit from sensitive guidance and instruction when he uses "bloopers," as we affectionately say.

3. If you see any behaviors that seem out of the ordinary, any significant mood changes, or something that just catches your eye and seems off - even if you can't put your finger on it - I would greatly appreciate if you would shoot me an email and let me know. As I noted earlier, the physiological balance of his respective medical issues require vigilance, and since I am neither able nor desire to follow him throughout his entire academic career, I'm relying on you to fill me in when he needs help in his everyday environment.

4. Despite my own accounting of his idiosyncrasies and challenges, let's not forget that my son is not defined by anyone's checklist of observable behaviors. My greatest hope is that you think I'm a crazy, overprotective mother...nothing would make me happier. You might even be questioning if his diagnosis is accurate, that you would "never have known" that he has Asperger's had you not received this letter. If so, this is music to my ears for two reasons: First, it provides reassurance that my son is developing well and finding a comfortable place in the world. Second, it offers *you* an opportunity to better understand that autism spectrum disorders are just that - slight deviations along a continuum, with no two points, or in this case people, being the same. His is only one of the many faces of ASD, and if it's his face that can perpetuate open-mindedness, understanding, sensitivity and acceptance, he's doing a great job just by being your student.

Thank you very much for taking the time to read this. I'm happy to loan you any materials (books, articles, films) about ASDs in the teenage years, in the classroom, or just in general if you'd like to learn more. I also welcome any questions, comments, inquiries, or communication of any sort. But no chain emails. I'll delete those. Again, that's just how I roll.

Wishing you a great year, and much appreciation for your support.

Very truly yours,
My son's mom

Westbrook from page 18

Approximately 50% of this population at or during adolescence develops co-morbid anxiety, clinically significant depression and/or mood disorder, resulting in further management complexity. For some students, 24-hour therapeutic education is needed because their diagnostic picture has been unclear, despite the best efforts of mental health and education professionals. In many cases, numerous unsuccessful medication trials and/or ineffective medication cocktails have been employed. Typically, these individuals do not communicate well, hence do not access or seek support. They may also have the intelligence to compensate, and at times, mask their weaknesses. As a result, these youngsters can remain below the radar, receiving ineffective supports and evading the special education system until they can no longer cope in school and/or at home. Only then, with comprehensive assessment by specialists, are their diagnoses clarified and confirmed. As a result, their significant deficits and extreme disparities in functioning are revealed late in their education.

Although they have the POTENTIAL to be independent and functional adults, for students like these to meet their complex social, emotional, adaptive, communication, behavioral and academic goals, they require supervised, intensive practice and repetition virtually every waking hour; hence the necessity for a residential therapeutic school milieu. This includes skill acquisition in the adaptive domains such as wake-up, hygiene, participation in home/ residence chores and self-regulation. Also, keys to future success include the development of pro-social behaviors and coping strategies, as well as competency in effective and fulfilling communication and interaction with peers and the community both on the job as well as in other social settings. Like everyone, having a solid understanding and acceptance of themselves, including their own strengths and weaknesses is critical, both in knowing when and how to appropriately seek assistance in addition to managing issues like self-disclosure. Most importantly, developing as many of these skills as possible will support a positive self-image and maximize their potential for relationship development, successful and fulfilling employment, success, and ultimately happiness.

Westbrook, an all-residential program, is highly structured and utilizes a team approach with fidelity of programming across all domains: residential, academic, clinical, social, family support, vocational training, and community. In order to accelerate skill acquisition, a continuum model was established with individual goals embedded across all environments, with a particular focus on social skills development. A value -based token economy system was created and is consistently implemented by all staff throughout the entire day and evening to motivate the students. It incorporates core values in an effort to promote pro-social development and appropriate replacement behaviors while encouraging students to strive to meet their goals. Afterschool and residential hours especially focus on social communication skills, self-regulation, self-care, adaptive living skills and community integration. Westbrook's location in the middle of "Main Street USA" allows the students to be "pushed-in" to practice community experiences frequently; in fact the students consistently spend a portion of each day in local activities, such as playing a game of basketball at the park, swimming in the town pool, participating in their internships, etc.

The academic curriculum, aligned with the New York State standards, is a highly individualized learning model, to accommodate uneven academic profiles and learning needs. Students are Regents/local diploma bound and whenever possible, the academic program is designed around the interests and learning style of individual students and built upon their individual strengths. Comprehensive assistive technology is used in the classrooms such as interactive white boards, Mobile Science Lab, MAC computer lab, laptops, etc. Another important program component being taught is the importance of living a healthy lifestyle. This is done through a variety of daily exercise activities and a focus on healthy eating and lifestyle for the promotion of life-long health maintenance. The students participate in meal planning and preparation in addition to each day making their own lunches for the next day.

The overarching clinical approach utilizes a cognitive behavior therapy model with positive behavior intervention supports integrated throughout the program. This is enriched with the overlay of social pragmatics training across all domains in addition to individual and group settings, implemented through various approaches like a school store, media arts, cooking and karaoke clubs, among many others. In addition to individual, group and family therapy, the family program is well attended with family programming, support and/or training every Sunday.

"Transition begins the first day a student begins at Westbrook" is one of the mantras posted on the walls and implemented within and outside the walls of the program. Students have a short 18 – 21 years to be educated and prepared to live for decades, so teaching as many skills as possible, necessary to make those years fulfilling and happy ones, is our most important endeavor. Within a week of admission, an interest inventory and meeting with the full time transition coordinator (TC) is accomplished. The TC works with the student and family to support the student in creating and, as part of the team, fulfilling their dreams for their life. As soon as possible, and generally within a month of admission, all students are placed in supervised volunteer work or an apprenticeship, whenever possible linked to that student's personal goals and interests.

It has been said, "It takes a village to raise a child." On multiple levels, this supportive philosophy has been and continues to be evident in the development, opening and operation of the Westbrook Preparatory School. SCO Family of Services chose to open Westbrook within its mission to "…work with New York's most vulnerable…." Westbury, the village within which Westbrook resides, has fully embraced our school, students and staff. The newly established Community Connections Committee is helping to stock our library, is opening their places of business for internships and brainstorming ways to beautify our property. One member recently suggested a joint gathering to include the students' parents in order that "…the parents can get to know more people who are stakeholders in their children's futures…." The village of Westbury has become a "model village" and is becoming an unexpected yet welcomed partner with us in fulfilling the dreams of our students. The autism community at large has also embraced the opening of Westbrook, as they recognize the great need for programming such as ours. Our newly convened prestigious Professional Advisory Board includes the most internationally renowned in the world of Asperger syndrome and high functioning autism. We are establishing university partnerships to afford learning opportunities for graduate students entering the field and to support the development of a "best practices model program" for students with Asperger syndrome/high functioning autism and related conditions to enable replication in other communities. We also anticipate the development and implementation of outcome measures and a performance measurement program to determine best practices in this population. With the village that has been created around Westbrook, we feel confident in our ability to make these dreams a reality.

Westbrook continues to screen new student referrals through our rolling admissions process. For more information about Westbrook Preparatory School or to inquire about student enrollment, contact May-Lynn Andresen at 516-338-5280 or MLAndresen@sco.org.

May-Lynn Andresen RN is a co-founder of Westbrook Preparatory School and serves as Westbrook's Project Director.

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worldwide need for increased understanding of the disorder when, in 2007, the General Assembly declared April 2nd as World Autism Awareness Day. Despite the UN's and other organizations' information campaigns, societies still tend to believe that all individuals with Autism should suffer from either lack of language or mental retardation, or both, in co-morbidity.

So, what is it in the Autism label that is so damaging to a high functioning youngster? The drawback lays in the stereotypes that still are, and will most likely remain, embedded in the notion of Autism. This regrettably limits the potential of those who are diagnosed with PDD-NOS as toddlers and infants but who, thanks to an effective early intervention, show immense progress with emerging social and cognitive capabilities, receiving excellent prognoses from educators, developmental doctors and psychologists, with high possibilities of a full insertion in society later in their lives.

However, sticking an Autism tag on the forehead of a child that is, most certainly, expected to get married, go to college, get a job and give back to society, will invariably bring about social isolation, anxiety and depression at some point in their lives. Anecdotal stories from parents mention suicide attempts by their HFA and Asperger's teenagers who need to deal not only with the common age-related struggles, but with the consequences of having been exposed to society as Autistic in order to receive related services and curriculum accommodations. Many teenagers feel the frustration of being reduced to something that, no matter what they do, they will never be able to get rid of. Besides passionately increasing awareness about Autism at large, is there any other way to lessen the negative impact and weight of the disorder's name on the high-functioning community?

At this rate, the solution is giving it a new term, one with less severe connotations.

Autism is seen, as many other disabilities and conditions, as either black or white, while it begs to be seen as a colorful rainbow. The big disparity within the two ends of the Spectrum poses the dilemma on whether awareness efforts should continue to take place under a "catch all" Autism umbrella, or if there shouldn't be an urgent revision of labels and diagnostic methods towards a clearer categorization and differentiation.

While the Autism diagnosis empowers a stratum of the Autism population (those with full blown Autism), it equally hinders the fight of those with a mild condition, who at the other end of the Spectrum, must simply spell out their condition as "Autism" since there is no other available term.

As we witness an evident need to review the broad use of the Autism sticky tags on kids, there is an even more immediate, and long predicted, emergency: The need for the Board of Education to appropriately address the educational needs of this growing population.

Fortunately, there is already an exceptional and cost-effective response to this dilemma.

The ASD Nest program in New York City (http://schools.nyc.gov/Academics/SpecialEducation/EducatorResources/About_ASD.htm), developed and implemented by New York University in 2003, is a unique Integrated Co-Teaching program developed for higher functioning children with ASDs. It is carried out in neighborhood public schools to help children with ASDs become exposed to typically-developing peers while learning how to appropriately function academically, behaviorally, and socially.

The program is similar to the Collaborative Team Teaching (CTT) model, however the classes are smaller and include 10 to 20 general education students, 4 Special Education students (ASD as the only disability) and three teachers (General Ed, Special Ed and Cluster teacher) all trained in Autism. Working with therapists and specialized teachers, combined with the constant exposure to mainstream peers, children on the high functioning side of the Autism Spectrum improve their social and communicative skills and develop effective self-regulation strategies.

The current infrastructure only accommodates children until their fifth grade, though, given its success, there are already initiatives in place towards expanding the ASD Nest public schools and replicating the model in middle and, hopefully, high schools.

It is essential for parents, therapists and educators to continue to work closely to ensure that this emerging population receives the necessary treatments and education, with views towards their full integration in society, free of stigmatizing labels.

Jacqueline Aidenbaum, MA, is one of the main forces behind the General Assembly designation of April 2nd as World Autism Awareness Day. She works at the United Nations.

Video Modeling from page 22

scenarios that lead to social awareness and integration:

Level 1, build vocabulary - Treat the video footage like a picture book, describing what the children are doing. "The children are standing in a line."

Level 2, use vocabulary to introduce choices - As the videos become stories, begin to offer choices that encourage your student to engage in the scenario. Choices build options for those struggling with the knowledge or language to elicit their own response. "When we stand in line, what should we do? (Pause for response.) Should we stand still or push each other? Should we wait our turn or run to the front of the line?"

Level 3, use vocabulary to expose feelings - This level assumes a solid use of basic vocabulary and provides a building block toward the critical social skill of predicting outcomes. At this level, focus on feelings through the video subject's words or body language. Focus on telling the story through emotions. "What would you do if you saw your teacher crossing her arms and clearing her throat? (Pause for response.) 'Pay attention' is correct. Do you think your teacher is frustrated or angry? You're right. When someone crosses their arms it means they are upset."

Level 4, feelings and body language lead to inferences - It is important to discuss contextual cues in the video subjects' body language, behavior and emotions. While this seems similar to Level 3, it is critical to teach and reinforce because so many ASD learners struggle with nonverbal communication cues and making inference. Take the discussion further: "What is the girl in the video doing with her body to show that she is sad?"

Level 5, expand upon choices - This level introduces the social nuances that allow one to compare and contrast similar scenarios to determine the most acceptable pragmatic language and behavior in any given situation. Because social awareness is so subjective, this allows the person with whom you're working to make a detailed analysis of the better versus the best outcome. "That boy was yelling in the store because they did not have his favorite ice cream. What is your favorite ice cream? Do you like other kinds of ice cream? What are some other things you could do if the store did not have your favorite flavor?"

Beyond the Basics: Making Your Own Videos

I sometimes liken Social Skill Builder software to the solid basics of a good wardrobe: we have the jeans, the shoes, the socks, the sweaters. We've already covered standing in line without cutting, talking or pushing, eating quietly and politely in the cafeteria, taking turns on the playground, bully awareness and hundreds of daily, basic scenarios. The software contains graduated levels of learning as skills are mastered, so use our products to cover the behavioral basics and as a model of the different ways to address targeted behaviors. Then, add to the "wardrobe" with your own custom videos on specific behaviors, otherwise known as "do it yourself" (DIY) video modeling. You don't need to reinvent the wheel, just build on what is readily available to get the best possible outcome for your student.

DIY Video Modeling is Economical and Feasible

The technology available now is perfect for DIY video modeling, because it is economical, readily available, and easy to use. It is no longer necessary to rent or purchase complicated AV equipment, because most of us already have mobile phones with cameras or digital cameras, and small video cameras can be very economical, plus the technology is convenient and easy to manage.

Video Modeling Guidelines

The primary rule of video modeling is to present real people in real scenarios, rather than cartoons or drawn images. It is critical to focus on facial and body expressions to convey both verbal and nonverbal cues and to use same-age peers whenever possible.

When you begin planning your DIY video modeling project, first evaluate your student – what are their challenges and needs? Each video should focus on one concrete skill. Keep the video very short – no more than 30 seconds. Don't overload the student with too much action or too many choices that will cause them to lose focus. It is important to eliminate even small distractions, such as a t-shirt with words or pictures, or background noises or activity that can cause the student to fixate on something other than the task at hand.

Communication between parents, therapists and teachers is essential to key in to specific behaviors to target together. Refer to the video during daily situations that arise, and ask the student about the video they watched when they are in the situation themselves. Get the student into the habit of using the videos that they store so well in their memory as a guide to make better social guesses and make the video learning experience an integrated part of their daily life.

Keep things positive! Show the correct way to do something first, and then encourage the student to predict the positive outcome of a correct behavior with the goal of gradually introducing the consequences of negative behavior. Always keep in mind the objective of meeting the students' pragmatic needs and goals.

Think about how maximize every part of your videos to extract the full learning value, as well as the time and money that have been invested. For example, pull a still photo from a video and discuss it with the student. Point out posture, facial expression, eye contact, personal space, etc. You can use a still photo or a small clip from a video to stop the action and break down a skill into smaller steps in order to ensure learning. That's what a lot of therapists do with Social Skill Builder products; breaking down the lessons into more basic chunks and ultimately building the skills up to the full level.

For portable cuing of social situations, I often take a screen shot of a video or picture to take into a student's own environment. For example, if a student is having trouble waiting in line, I will play the video with him and then print off the screen shots and take them with us to practice when he is standing in line at school. This will help carry over the concepts and consequences learned in the program to his own waiting behavior, and it makes use of a video that you already have.

It is very important with any DIY video project that you obtain proper permission to take photos and videos of children. Many schools have signed photo waivers on file, and parents should be included in the decision and give authorization to take photos and videos of their children and the future uses of these projects.

Free Social Videos Online

In addition to available pragmatic language software and DIY video modeling, a wealth of free tools for teaching social skills can be found by a simple internet search on social language videos. Online video website such as YouTube.com, Howcast.com, and Videojug.com are fantastic sources of social videos. Subscribe, upload and join groups! Learning English videos that target on idioms and mime videos that focus on facial expressions are also valuable learning tools found on YouTube. Remember, you are looking for short videos using real pictures and succinct narration to show the skill you are focusing on.

Try these sorts of free video social stories in conjunction with Social Skill Builder's teaching software for even more versatility and application. For example, if you are working with a student on what to do when they go to the movies, use your DIY video or an online video as a basic overview, then dig deeper with the detailed analysis of our My Community CD's movie theater series of videos. As the student gains understanding and mastery of the skills through the software, use the still pictures from the YouTube video to have them create their own "social story" of going to the movies. This activity allows the student to carry skills over into another context, taking them closer to the goal of incorporating the skills into their natural environment.

Social Skill Builder has several instructive YouTube videos on DIY video modeling. Visit www.youtube.com/socialskillbuilder, and click on uploads to see the available videos. Some clips give tips specifically applicable to Social Skill Builder software, and some give more generic video modeling tips.

Would you like to learn more about using video modeling to teach social skills? We speak around the country to various state and national organizations. E-mail info@socialskillbuilder.com or call 866-278-1452 for more information. Visit www.socialskillbuilder.com for product information and demos of our software. Click on Products, then Choosing the Right Tool to see which programs target the specific skills you are looking for.

Laurie Jacobs, M.A. CCC-SLP, is co-founder of Social Skill Builder, a company launched in 1999 to provide computer-based tools for teaching social skills to children affected by Autism Spectrum Disorder (ASD). Laurie, along with her sister and co-founder Jennifer Jacobs, M.S. CCC-SLP, develops software products based on the unique needs of the ASD community.

Self-Reinforcing from page 28

people do. I live in my own world and see things in the unique way that I see them. My mind is blocked to other viewpoints and opinions. Sometimes I become very frustrated when my thoughts become negative. At times, life is hard for me. In these moments of negativity, I have to reshape my thoughts into something positive to avoid becoming very depressed.

I think ABA therapy provides an amazing gift to people with high functioning Autism or Asperger's Syndrome. We have the ability to communicate and work with our therapists. We can share with them how we analyze a situation and they, in turn, are able to share their opinions on how they would see it. The ability to bring the two schools of thought together is priceless and something that everyone on the spectrum should be able to access.

One of the greater frustrations for some adults on the spectrum is that access to ABA services is typically not available. The process of accessing treatment services is more difficult for someone who was not diagnosed until adulthood. When a child is diagnosed, some insurance companies allow a period of time for the child to receive services from a certified ABA therapist. However, as we age out of the education system at age 22, all services are pulled.

I used to be very upset and sad over this. But recently I've begun to accept the reality of the situation and embrace it. Yes, I have some extra hurdles in life but I am still a human being worthy of love and acceptance. I have learned that loving myself is all that really matters. If I don't love and respect who I am, then nothing else in life will ever fall into place. Enforcing my behavior plan has actually become easier since I came to terms with this. This also allows me to educate others about my challenges and help them interact with me in a positive way.

Travis Breeding is an author and speaker on Autism Spectrum Disorders. Born in March of 1985, Travis grew up knowing he was different and always struggled to make friends and fit in.

At age 22 Travis was diagnosed with Asperger's Syndrome, finally providing him with answers to all of those unanswered questions. After years of pain and frustration Travis has now begun the healing process and wants to share his story with others in hopes of helping people to better understand and relate to Autism.

Travis is the author of two books. I want to be like you: Life with Asperger's Syndrome and I am a child: Just Like You. Travis is currently working on his third book and presenting as often as possible. To read more about Travis, visit his website www.travisbreedingautism.com. To contact Travis Breeding, you can email him at travis@travisbreedingautism.com.

Plan Ahead from page 19

steps to shelter in place may be the best scenario for your loved one, but there will be times, as we have just seen with Hurricane Irene, that large scale mandatory evacuations are put in place. Do not wait until the time of the emergency situation to make plans with those family members or friends. Call your family or friends ahead of time so you will have accommodations with them should you need them. You may want to remind them every so often of the arrangement, just to be sure no one is caught off guard.

"Go-Bags" – Go-Bags are sturdy compacts bags which contain emergency supplies and are kept in a safe accessible place so they are ready at a moment's notice.

Your Go-Bag is an essential part of your disaster preparedness and should be taken seriously. A backpack or another easy to carry container in case you must evacuate quickly is best to use for this purpose. You may not be at home when an emergency strikes so keep some additional supplies in your car and at work. Think about what you would need for your immediate safety. One go bag should be created for each family member and don't forget about a bag for your pets. Make sure each bag has an I.D. tag. Some common items to consider when you are making up your bags include: a Flashlight; Radio – battery operated w/ NOAH station; Batteries (replace as needed so you have a fresh supply and ensure you have the correct size for the items that use them); Shoes such as work boots and a change of clothes (sweat shirt, clean underwear) a warm hat and gloves; Some extra money in small denominations (cash machines will be empty or not working); Whistle; Dust mask; Pocket knife; Can opener; Local map; Some water and non-perishable food; Permanent marker, paper and tape; Photos of family members and pets for re-identification purposes; List of emergency contact phone numbers and addresses (in watertight bag); List of allergies to any drug (especially antibiotics) or food; First aid kit; At least a 7 day supply of all prescription drugs; Copy of health insurance and identification cards; Extra prescription eye glasses, hearing aid or other vital personal items; Toothbrush and toothpaste; and an extra set of keys to your house and car.

There are many resources on the internet to find lists of items to include in the go bags. Parents and caregivers of individuals with autism, high functioning autism or Asperger's might consider additions to their go-bag. Some examples include, an information card about how to best interact with your loved one, contact numbers for physicians, therapists, personal care assistants and special comfort items. Comfort items may include portable electronic devices. Don't forget the replacement batteries. If your loved one has a special toy or blanket for comfort that they use daily try remember to bring that with you in an evacuation situation. A copy of a social story you have created for the evacuation situation should also be included.

Parents and caregivers should make sure they have an extra copy or two of their child's IEP and or behavioral plan in a water tight bag; in a long-term evacuation and recovery situation, this will be difficult to replicate. As these plans change over time, remember to replace the copies in your go bags.

Being involved with emergency planning is important for all. If you have a loved one with autism, high functioning autism or Asperger's, it is essential to preplan for safe outcomes in the event there is an emergency.

If your loved one lives independently it is especially important to help them prepare and go over the evacuation plans you both have put in place.

This all may sound alarmist in nature but it is not. If you are faced with a true emergency where evacuation is essential and immediately necessary, you will not have time to cobble these things together. Plan for the worst and hope for the best. In an emergency, the more time you have to calmly evacuate or secure your property and your family, the better for everyone. As the situation on the ground changes, and may change rapidly, your loved one will look to you to set the tone. Your calm execution with a pre-determined thoughtful plan will go a long way to temper their unavoidable anxiety and make everyone's situation better.

Post-emergency cleanup can take time and try on everyone's patience. There may be long periods without basic services such as water and power. Roads may be impassable for some time and access to the workplace and school may be hampered. Think and planning ahead for all possible scenarios will be tremendously helpful during the crisis and in the weeks or even months thereafter.

Autism is often difficult to manage. In an emergency or disaster situation, being prepared, as much as possible, ahead of time will make that situation easier to manage for everyone.

Madeleine Goldfarb is the Founder and Executive Director of The Noah's Ark Institute. Her work has been inspired by the many families and individuals on the spectrum it is her privilege to serve. Madeleine lives in Livingston, New Jersey with her husband, batik artist, Ahmi Goldfarb and their two sons. You can reach Madeleine through the Noah's Ark Institute. www.noahsarkinstitute.org

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Bullying from page 27

As a clinician, I find this model helpful in understanding how painful traumatic memories in individuals with AS and HFA form, and how bullying may lead to post-traumatic symptoms.

What Can We Do About Bullying?

Educators, clinicians, and caregivers should take seriously the issue of bullying among individuals with AS and HFA, especially since these individuals are frequently the victims of bullying and may be at risk of developing intense traumatic memories as a result. In the event that bullying has occurred, caregivers and professionals must ensure the bullying stops and, in addition, be alert to signs of post-traumatic stress so that a therapeutic intervention can be initiated.

Clinical studies with typically developing individuals have found that cognitive behavioral therapy is effective in the treatment of PTSD, and includes psychoeducation, gradual exposure, and the teaching of relaxation strategies. However, these therapeutic approaches (which are frequently manualized) need to be modified to meet the needs of individuals with AS and HFA who have PTSD.

Markram and Markram (2010) propose a therapeutic approach for individuals with autism spectrum disorders that would include progressive systematic desensitization to stimuli that have evoked heightened fear responses and intense memories. Their proposed treatment model is described as an extinction-based rehabilitation, with a cognitive behavioral component. Its success depends on the creation of a sense of safety, both with the clinician and in the environment more generally.

It is clearly important to recognize and treat any distressing and potentially disabling symptoms caused by bullying. However, this is insufficient. Strong policies must be established in schools, workplaces, and communities, to prevent the victimization and bullying of individuals with AS and HFA. Recent legislation in states like New Jersey aim to reduce bullying by implementing state-wide bullying prevention programs (Schroeder et al., 2011). However, much work needs to be done to ensure that policies are implemented and enforced so that all individuals, including those with AS and HFA, are safe from bullying.

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Angels from page 25

Matt, a man who is given more to observation than interaction, quietly watched Jack's progress and started taking baby steps to introduce boy and dog. Nearly every day for all of August, Matt would slowly ease Maggie out of the truck and call to Jack, asking if he wouldn't like to feel how soft her fur was or throw her the tennis ball.

Truly, I thought he was crazy. We could hardly get Jack to watch a dog do tricks on America's Funniest Home Videos, never mind tolerate one on his own driveway. But in time Matt's calm manner and persistence paid off, and Jack walked over to tentatively stroke Maggie's golden fur. It was an emotional moment for all of us, as this gentle man and his equally gentle companion were able to momentarily to permeate Jack's deeply-rooted dog phobia.

And then there was Texas Mike, the painter who worked on our front porch last fall (we bought a fixer-upper, OK?). Weighing in at 100 pounds after a soak in the dunk tank and with dreadlocks down to his bony hips, Texas Mike was an authentic Texan cowboy who spoke little more than monosyllables. On the first day he showed up at our house for the job with a battered radio in hand, and Jack delighted in his new best friend. He wanted to know every last detail of his radios, music selection, and why he drove a Subaru Legacy. How old was his mother? Did she die yet? Every time I looked outside Jack was trailing behind Texas Mike close enough to pull on a dreadlock, firing questions at him like a human machine gun. I never really heard Mike respond more than one-word sentences, and I figured his patience was wearing thin.

I tried to explain to Texas Mike that Jack had autism and that's why he fixates on unusual subjects like radios and birthdays. Till my own dying breath I'll never forget the way he gazed down at Jack, then slowly back to me before uttering four of the most beautiful words I've ever heard about my son in his exaggerated Texas drawl.

"Looks al-raht to me."

Why yes, Texas Mike, he looks alright to me too. Thank you for reminding me that he really *is* alright.

This spring Jack developed a crush on our teenage neighbor, Kristin. He demonstrated his love by constantly marching up to her and drilling her with questions about her car, her age, and how many radios she had (Quite the Prince Charming!). Every afternoon in April he perched on our front steps to watch for her bus, and as soon as the doors opened he would shout down to the street, "Kristin! It's Jack! I just downloaded Earth, Wind, and Fire from iTunes!"

Thankfully, Kristin isn't the typical teenage girl who is embarrassed when a 7-year old boy meets her at the bus braying the latest Maroon 5 song. She isn't the sort of teenager who hates to be made a spectacle of or is uncomfortable around people with social disabilities. She took Jack's admiration in stride and went out of her way to make him feel special.

Although extremely kind in general, Kristin really demonstrated her thoughtfulness on Jack's 7th birthday when she met him at the bus stop with a card she'd made for him. The combination of the homemade card, her getting up much earlier than usual to deliver it, and the immeasurable joy it brought him makes me tear up as I type.

Each of these three people touched me in three very different ways. Matt taught me that with the right amount of patience and perseverance, we can help Jack work through even his biggest phobias. Sometimes it just takes another set of eyes to see what I can't. Texas Mike reminded me to relax, take a deep Texan breath, and enjoy this little boy for exactly who he is. And Kristin showed me that Jack resides as firmly in other people's hearts as he does mine.

With people like this in our lives, it really is *al-raht*.

Do you have a story of your own to share or want to comment on this article? Email me at carrie@dovetaildental. Carrie Cariello lives in New Hampshire with her husband and five children.

From the Trenches from page 26

done quickly.

Make sure to check your emails because, not only do you get them from your instructors, but you also get important notices and news from the college administrators and any clubs that you may have signed up for.

I hope that my advice has helped you to be able to prepare better for college. Good luck knowledge-seekers and I wish you all success in college!

Patrick Hourihane is twenty years old and was diagnosed with Asperger's Syndrome and ADHD at age 8. He is currently attending his second year of college majoring in Forensic Science.Patrick made the Dean's List in his freshman year and is a member of Phi Eta Sigma, freshman honor society.

Patrick has presented at AHA's Spring and Fall Conferences. This article was published in the fall 2011 issue of AHA's On The Spectrum.

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a dual diagnosis. The Fiscal Sustainability Design Team will focus on how we can change the way we pay for services so that the desired outcomes can be achieved. And finally, we have the Quality Design Team. Currently, we have a very punitive checklist-type system where providers have to meet a list of minimum requirements – yet do not focus on what the outcomes are for the individuals. This is something we are interested in changing so that we can start paying for outcomes and provide incentives for providers to do things such as continuous quality improvement.

Q: Will the 2011 budget impact the provider's ability to provide safe, quality services?

A: The current tough fiscal environment we are in has forced us to become more innovative and creative, causing us to take a look at the current system and determine if it is really the right one.

I am often asked how OPWDD will meet the growing needs of individuals in the system who we have never served before, such as those with a dual diagnosis and who are medically complex. Our system is very "supply-sided" right now, where we have a lot of wonderful services and try to fit people to these services. Sometimes this is not necessarily what they need. For example, somebody may not need 24/7 residential care with daily day habilitation, but that is their only choice. We would rather see a system where individuals and their families can choose what they want. I think by fostering that approach we will be better able to see the demand and modify the numbers of services.

In these lean fiscal times, service providers are also being forced to get creative. OPWDD has been supportive in working with the providers to make sure that they can have economies of scale where they need it to deliver services. In this way we are serving as a conduit so the provider organizations can have those conversations on how they can work together, do things more efficiently, and collaborate.

Q: Can OPWDD develop a plan to provide more and safer community housing options for adults with autism spectrum disorders?

A: As part of our strategic plan, we are looking at housing and making sure people live in a home of their choice. We have some pilot demonstration projects in place to answer the question, "What are the proper supports that people need to be living in the community?" We will continue to research this. Technology provides us with some new options that we didn't have 10 years ago to provide additional forms of support for people in the community.

I can't overemphasize the importance of local communities working together on solutions to make sure people have integrated options.

Q: Can you share some of the vital new research coming out of the Institute for Basic Research?

A: They are doing a lot of exciting research, from diagnosis and screening to treatment and prevention. Something very exciting that the Institute for Basic Research is currently involved with is brain mapping, where they analyze very thin slices of brain tissue, which have been graciously donated by families, to see if they can identify autism spectrum disorders and the complexities associated with them.

They are also doing work on early behavioral assessments, working together with the State Education Department, and some promising research on folic acid and whether it has any link to autism. They are also examining the placenta to see if there are any clues there that might provide a link to autism spectrum disorders.

Q: What are your hopes and goals for the future of OPWDD?

A: I envision the New York State OPWDD becoming a system that supports exactly what people want and need, so that they have more choice in the services that they are receiving and that they have the option to access services in a more integrated community-based settings. This is a major goal of the 1115 waiver and a major focus of each one of the design teams we have.

Q: What message would you like send to the autism community of NYS?

A: I want the autism community to know that I am very committed to the challenges ahead, and I very much value the input of families and individuals in the community. When I first became Commissioner, I embarked on a statewide Listening Tour that was incredibly valuable in shaping what I think the priorities should be for OPWDD. I always want to have an open dialogue with the community. I heard many positive things from families about what a difference OPWDD services make in their lives and how glad they are that OPWDD exists to support them. Effective lines of communication are critical to OPWDD's reforms and long-term success. A priority of my administration is opening the lines of communication among people with developmental disabilities, family members, advocates, and employees.

Educational Rights from page 33

whereas, only the Court can only revoke a guardianship. This is an important consideration if your child is easily influenced by others.

Special Needs and Future Planning

As parents, there is nothing we hope for more than a crystal ball that would let us know what our child's functioning level will eventually be. While we hope that our child with Asperger's will be self-sufficient and/or not need to rely on public benefits for the services that they require, there is no guarantee that this will be the case. Unfortunately, there is no crystal ball. Thus, it is imperative that you plan for the worst, but continue to hope for the best. Not planning for the child's future could be devastating to the child that you are trying so desperately to help. There are tools available to ensure that your child will be taken care of. It is strongly recommended that you take advantage of the opportunity to plan while you are still able to do so.

Typically when a parent of a child with a disability comes to our office for future planning we suggest certain tools. These include a Letter of Intent, a Will, and a Supplemental Needs Trust.

A Letter of Intent: In order to get into the planning "mode" we ask parents to think for a moment what would happen if they were to die tomorrow? Who would be equipped to step into their shoes and take care of their special child? Who knows the child's likes and dislikes, their dreams and their fears? It is important for all parents of children with special needs, and even parents of typically developing children, to have a Letter of Intent which will help the people that will be caring for your child interpret your hopes and desires for that child. A Letter of Intent is not a document that is prepared by an attorney, nor is it a formal legal document. However, the people caring for your child will heavily rely on the letter after your demise. By compiling as much information about your child and his/her needs and your desires, you will be giving future care providers the knowledge and insight they will need to provide the best possible care for your child. Caretakers will not have to waste precious time learning how to manage and care for your child. This is not an easy letter to draft; it is very emotional and difficult. However, all parents must go through this very difficult step to ensure a well-planned future for their special needs child. Once you write the letter, sign and date it. Each year, you take it out and add to it (or revise it if it is on the computer) and sign and date the changes.

A Last Will and Testament: A Last Will and Testament is a legal document that provides instructions on how you want your assets distributed at your death. Why is it so important to direct how assets are to be distributed? When your child with special needs is no longer eligible for services from their local school district, most times the only way to receive the necessary therapeutic, residential, vocational, and educational services they require is through means-tested public benefits. These benefits, (for example, SSI, Medicaid, etc. more fully discussed above) not only require a determination of disability in order to be eligible, but an applicant must meet stringent income and resource levels. This means that if your child has more than, or inherits more than, the applicable income and resource levels they would not be eligible for public benefits. These benefits are typically the lifeline or services once your child's school program is done. A Last Will and Testament is an important tool since it would ensure that your child with special needs would not inherit your assets directly, which may put them over the applicable public benefit levels.

A Supplemental Needs Trust: While public benefits cover many services your child may require as an adult, they do not cover everything. Additionally, most parents are not pleased with the fact that they have to disinherit their child with special needs in order for their child to access public benefits. Fortunately, there is a very important tool that loved ones can use to allow a child to remain eligible for public benefits, but also have the "extras" that you would want them to have. This important tool is the Supplemental Needs Trust, also sometimes referred to as a Special Needs Trust. A Supplemental Needs Trust holds assets for the benefit of the special needs child without those assets being included in determining eligibility for public benefits. Generally speaking, monies in the trust can be used to pay for items that are not provided by the public benefit system. For example, money in the trust can buy a television, or pay for a companion, or pay for a vacation. An attorney who specializes in the area of special needs planning is necessary when preparing this type of trust. There are different types of Supplemental Needs Trusts to consider and to review with your attorney.

Due to the unique nature of high functioning Autism and Asperger's syndrome there are unique legal issues that affect this population. We hope this article has been helpful in giving you an overview of some of the common legal issues that we have seen in our practice.

Nothing in this article should be construed as legal advice. Please consult with an attorney before relying on the information contained herein.

References

1. There are some students with Asperger's whose disability does not rise to the level of being a student who can be classified under the IDEA. If this is the case, there may be services available under Section 504 of the Rehabilitation Act of 1973 ("Section 504"). Due to space constraints, this article does not address Section 504 services or plans.

2. While Federal Law requires that the transition plan be in place in the year in which the student turns 16, some states have a requirement that the plan be in place earlier.

Environment from page 8

Drawing upon state records, the researchers initially identified 1,156 twin pairs, with at least one member affected by an ASD, born to California mothers between 1987 and 2004. The children were all at least 4 years old, an age when autism can be reliably diagnosed. Ultimately, this group was winnowed to 192 twin pairs - 54 identical and 138 fraternal - for genetic analysis. Since autism disproportionately affects males, males outnumbered females by four to five times, with 80 of the pairs including both sexes.

Concordance for ASD was 77 percent among identical male pairs, and 31 percent among fraternal male pairs. In females, concordance for ASD was more closely spaced - 50 percent for identical and 36 percent for fraternal pairs. By contrast, previous studies had found concordance rates for fraternal twins that were much lower, ranging only in the single digits.

"Spectrum disorders traditionally thought to have less genetic loading turn out to stem from a similar mix of environmental and genetic heritability as narrowly defined autism," noted Thomas Lehner, Ph.D., chief of the NIMH Genomics Research Branch.

Yet, there can also be genetic influences that are not inherited from parents. New evidence (www.eurekalert.org/pub_releases/2011-06/yu-yrd060611.php) emerged last month that rare, spontaneous mutations (www.nimh.nih.gov/about/director/2010/in-search-of-the-missing-genetic-signals.shtml) occur at abnormally high rates in autism.

"Such non-inherited genetic changes were proposed as a major mechanism of autism susceptibility, based on the very low concordance among fraternal twins found in earlier studies and evidence of increased risk associated with older parental age," explained Risch. "In light of the high fraternal twin concordance observed in our study, such new mutations may play a more limited role, since they would primarily occur in only one member of a fraternal pair, which would not lead to concordance."

Also participating in the research were investigators at: Autism Genetic Resource Exchange; California Department of Public Health; Kaiser Permanente; University of California, Davis. The research was also funded by Autism Speaks.

The mission of the NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure. For more information, visit the NIMH website (www.nimh.nih.gov/index.shtml).

About the National Institutes of Health

NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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ridiculed by her own sister. "Why does she compare her typical son to Jason? She chided me when I shared my concern over his suffocating obsession with trains. She told me to calm down, that I was being overdramatic and that her boy liked trains too. She has watched as we have tried to escort Jason away from his toy train track. She heard his high pitched wail. She saw him tear at his clothes. Overdramatic? Hardly. I need validation from my own family."

The topic for one discussion revolved around the subject of blame. Parents of special needs children are often fraught with guilt. The "whys" and "hows" may remain unanswered and paralyzing for those who hang on to the "what ifs." The constant mantra in this support group was that the best action be a pro-active one. One mom said, "We can't whine about what we have, our obligation is to keep going. You throw enough *stuff* against the wall, something has got to stick."

Nevertheless, family members are verbal in offering their criticisms, albeit well meaning. Perhaps it is time to treat family as you would a stranger. Educate and make them aware.

- Itemize testing results in a simple and uncluttered manner
- Talk about his/her strengths and weaknesses
- Re-visit the same data after 6 weeks
- Show them a video glossary illustrated on the Autism Speaks website (www.autismspeaks.org/what-autism/video-glossary) which shows side by side examples of typical children and atypical children.
- Make a list of facts about your child.
  - Show data as to how many times your child shows eye contact, responds to questions, and tantrums
  - Create your own data trial and enlist the suggestions from your family member
- Show which therapy has worked/not worked

Perhaps it is necessary to spoon feed this information; an educated family member is a more willing partner. Autism is a family affair and the more people that you can recruit toward a common goal will ultimately be the best effort for your child.

Finally, share the science with your family members: The Autism Science Foundation website (www.autismsciencefoundation.org) will detail research opportunities into discovering what makes autism tick.

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Dr. Scott Standifer is a Clinical Instructor for the Disability Policy & Studies office (DPS) at the University of Missouri. He is the author of Adult Autism & Employment: A guide for vocational rehabilitation professionals, and of the online Handbook of Disabilities. He is an organizer of the annual Autism Works National Conference, held in St. Louis each March, and has presented on Current Trends in Autism Employment for The Thompson Center for Autism and Neurodevelopmental Disorders. He can be contacted at standifers@missouri.edu or through his website www.dps.missouri.edu/Autism.html.

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

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

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

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

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

For further information contact the facilitators:

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Dates for 2011: 10/23, 11/20, 12/18
Dates for 2012: 1/22, 2/26, 3/18, 4/22, 5/20, 6/10

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

AUTISM SPECTRUM NEWS

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