

AUTISM SPECTRUM NEWS™

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SUMMER 2011

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 4 NO. 1

The Need for Science-Based Treatment and Services

Use Science and the Scientific Method When Considering Treatment

By Dr. Marvin J. Schissel and
Patricia R. Schissel, LMSW
Executive Director
Asperger Syndrome and High
Functioning Autism Association

Autism is a spectrum disorder that varies in degree from mild to severe, with a range of needs that call for a wide array of supports. AHA/Asperger Syndrome and High Functioning Autism Association's mission is to attain appropriate educational programs, effective social skills training, increased social and recreational opportunities, meaningful employment, and sufficient and satisfactory independent living accommodations for those with High Functioning Autism (HFA), Asperger Syndrome (AS) and related conditions. We work to increase awareness and knowledge of HFA/AS to the public and, especially, to the professionals who diagnose, treat, educate or provide services.

Parents of special needs children and adults on the spectrum are a vulnerable



population, too often ready to accept easy answers and magic cures, and too often taken in by dishonest professionals and salespeople of quackery. It is difficult to

accept the fact that the autism spectrum is not amenable to simple answers or magic pills, despite dubious claims to help individuals cope more easily with their world.

Such claims about autism and Asperger's are no different from infomercials promising 20 pounds off in 20 days or "natural cures that your doctor doesn't know about." Yet people still throw away their money on these scams.

The search for effective treatment is made more difficult because each individual on the autism spectrum is unique. There is no "one size fits all" treatment. Numerous interventions are being offered, including a wide variety of medicines, therapies, educational methodologies and nutritional approaches. While many of these methods reflect sound current practice, many of them do not. A parent, burning to take action, can easily be exploited by providers of costly, time-consuming, physically demanding and unsound practices. It is essential to study and learn what constitutes sound Science, and use this knowledge to make informed decisions.

The requirements of Science are poorly understood by most people. Treatment should produce measurable skill gains;

see Science on page 27

The Importance of Skepticism in Evaluating Claims, Selecting Treatments, and Enhancing Science-Based Treatment for Autism

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

The ivory-billed woodpecker (*Campephilus principalis*) was last known to exist in 1944. Unexpectedly, in 2004, it was purportedly seen near Brinkley, Arkansas. This claim resulted in a scientific expedition that produced an inconclusive video that was used to confirm the bird's reemergence from extinction, an article in *Science* magazine extolling the excitement that the bird was indeed back, and a worldwide fascination towards a species supposedly extinct but now here again. Yet, despite over 5 years of searching at a cost of over \$10 million, there remains no physical proof that the woodpecker is in fact alive (Radford, 2009).

At a 2004 Florida conference about treatment for Autism Spectrum Disorders (ASD), a medical doctor spoke to a group of parents about electromagnetic fields and their impact on autism. The doctor asked one parent if she used cell phones, to which the parent replied in the affirmative. With a grand wave of the hand, the doctor pronounced, "throw them out!" advocating for the unproven belief that the electrical energy emanating from cellular phones was somehow either responsible for or negatively impacting the symptoms of this neurological disorder.

When confronted with claims that are presented as true, how can we make a reasonable evaluation to ascertain, as confidently as possible, whether such claims have merit? This fundamental question impacts virtually all areas of our society. Claims abound – of alien abductions, the existence of the Loch Ness monster and Bigfoot, and the eating of wild boar meat

to cure autism. How can we "separate the wheat from the chaff" in a way that both prevents the acceptance of wildly suspicious claims that have no support, and permits adoption, with some level of certainty and comfort, of claims that are likely to in fact be true?

The best way known to evaluate claims is to adopt the intellectual discipline of science and the scientific method of investigation. This methodology involves carefully defining terms, conducting controlled experiments when possible, practicing the law of parsimony, and adopting "philosophic doubt" or skepticism (e.g., Cooper, Heron, & Heward, 2007). Although all of the methods of science are important, practicing skepticism is crucial to protecting oneself from believing unsubstantiated claims. Though the American public views science's effect on society as positive (in a recent survey, 84% of respondents said that the effect of science

was mostly positive and that the scientists were ranked as the third-most contributing profession to society, after the military and teachers; American Association for the Advancement of Science, 2009), the continued adoption of unproven beliefs, claims, and bizarre treatments (particularly in the field of autism) remains strong, suggesting that although science is lauded, skepticism - and scientific thinking in general - is not widely practiced.

Skepticism is not a view that promotes the disbelief of every truth or claim (Normand, 2008). Skepticism is more refined. Merriam-Webster Online (2010) defines it as, "an attitude or doubt or a disposition to incredulity either in general or towards a particular object" (emphasis added). The word is from the Greek "skeptikos," meaning "inquirer" or "investigator" (DiCarlo, 2009). Pigliucci

see Skepticism on page 24

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Table of Contents

The Need for Science-Based Treatment and Services

- 1 Use Science & Scientific Method for Considering Treatment
- 1 The Importance of Skepticism
- 12 Using Typical Peers as Role Models to Improve Social Skills
- 12 YAI Central Park Challenge Raises Record \$1.6 Million
- 14 Helping Parents Find Science-Based Treatment and Information
- 16 A Child's Right to Positive Behavioral Interventions
- 18 Computerized Games Promote Social Perceptual Learning
- 19 Funding the Special Needs Trust
- 20 A Look Inside the Hidden Curriculum
- 22 The Need to Plan for Your Child's Future is a Sure Thing
- 22 Higher Medical Home Designation for Premier HealthCare
- 24 Social Coping and Autism Spectrum Disorders
- 25 Employment and People with Disabilities
- 26 Law Enforcement and Loved Ones with Disability
- 27 The Lighter Side of the Spectrum - A Mom's View
- 28 The Ritvo Autism Asperger Diagnostic Scale-Revised
- 29 Robin's Voice - A Resilient Mom's Commentary on Autism
- 30 Parent Voices Drove Autism Certification Standards
- 31 Lessons from Autism
- 33 Vocational Opportunities for Adults in Software Testing
- 35 A Review of Autism Research

From the Executive Director

- 6 From the Publisher: Our Readership Survey

The Autism Spectrum NewsDesk

- 10 Autism Blurs Brain Tissue's Distinctiveness
- 10 Children with ASD in South Korea Go Undiagnosed
- 11 World Gathers at YAI's 32nd Annual International Conference
- 11 Early Intervention Improves Social and Communication Skills

Autism Spectrum News 2011 - 2012 Theme and Deadline Calendar

Fall 2011 Issue:

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

Deadline: September 15, 2011

Winter 2012 Issue:

"Science Matters: The Latest Advances in Autism Research"

Deadline: December 15, 2011

Spring 2012 Issue:

"Transitioning into Adulthood: Navigating the Complex Changes Ahead"

Deadline: March 15, 2012

Summer 2012 Issue:

"Vital Supports and Services in the Community"

Deadline: June 15, 2012

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Mailing Address: 16 Cascade Drive, Effort, PA 18330

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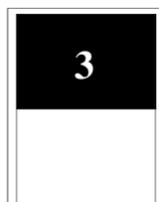
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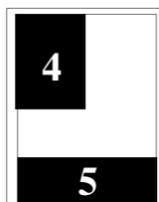
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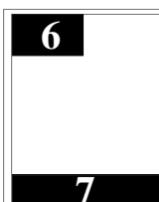
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The Autism Spectrum News - Mental Health News Readership Survey: Help Us Learn About Ourselves and Win a \$100 Amazon.com Gift Certificate

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

The first step in any effort to chart a course for the future is knowing where you are starting from. To accomplish this we are now actively involved in looking at ourselves like never before. We believe that the end result of our efforts will enhance our educational mission and enable us to better serve the readers of *Autism Spectrum News* and *Mental Health News*.

To help us in this endeavor, we are asking all of our readers to please take a few minutes to fill out and send in our 2011 Readership Survey found on the next page. To say thank your participation, we will have a drawing at the close of the survey process and award a \$100 Amazon.com gift certificate to the winner, who will be chosen at random. If you wish to enter into our \$100 Amazon.com Gift Certificate Drawing, please give us your contact information at the end of this short questionnaire. All information filled out in our survey will be kept in the strictest confidence.

Staying Relevant
 In an Ever-Changing Environment

We live in a world today that communicates by the click of a computer mouse or a



Ira H. Minot, LMSW

finger-swipe on a mobile device screen. Most hand-written letters have been replaced by E-mail, and Social Media formats such as Facebook, Twitter, Blogs and other new mediums have changed the way people gather and share their opinions. Print media is being replaced by electronic media. More and more people are reading their favorite newspaper, magazine, or book, on their iPhone, Droid, iPad, Zoom, or Kindle.

Following our Readership Survey we will take a look at developing a Social Media presence for *Autism Spectrum News* and *Mental Health News*. We've known for some time that we're only scratching the surface in terms of our readership audience for both of our publications. Having a Social Media presence may help us attract a whole new audience of readers who are looking for a trusted source of mental health and autism education. On a deeper level, we will be able to regularly read comments and reply to reader's questions who follow us on Facebook and Twitter.

The final way we can plug in to today's ever-changing media environment will be to offer *Autism Spectrum News* and *Mental Health News* on mobile devices such as the iPhone and iPad.

Why, How and When?

If we could flip a switch tomorrow and create a Social Media presence and have our publications available on electronic devices we would. The "Why" is simple - it would broaden our readership audience and our ability to communicate with you, our readers. The answer to "How" and "When" are a bit more complicated.

As a small nonprofit organization, we need to develop the financial resources needed to bring a Social Media consultant and an Electronic Media consultant on board to guide us through the intricacies

of these projects. Once established these media projects need to be monitored and maintained on a weekly basis.

We can't yet say when our plans for the future will come to fruition. We know that it will take additional financial resources that we do not yet have in our annual budget. If there are any angels out there that want to help us get there, we would love to hear from you.

The Autism Spectrum News
 Upcoming Calendar of Topics

We have an exciting lineup of topics for the fall, winter and spring issues of *Autism Spectrum News*. Our upcoming fall issue (deadline: September 15th) will focus on the topic: "Understanding and Addressing the Unique Needs of Individuals with Asperger's Syndrome and High Functioning Autism." Our winter 2012 issue will feature the latest advances in autism science with 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 write to me at dminot@mhnews.org.

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Autism Spectrum News	Excellent	Good	Fair	Poor
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Government Policies & Regulations	()	()	()	()
Interviews with Leaders in the Field	()	()	()	()
Consumer Issues	()	()	()	()

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About 3/4	MHN ()	ASN ()
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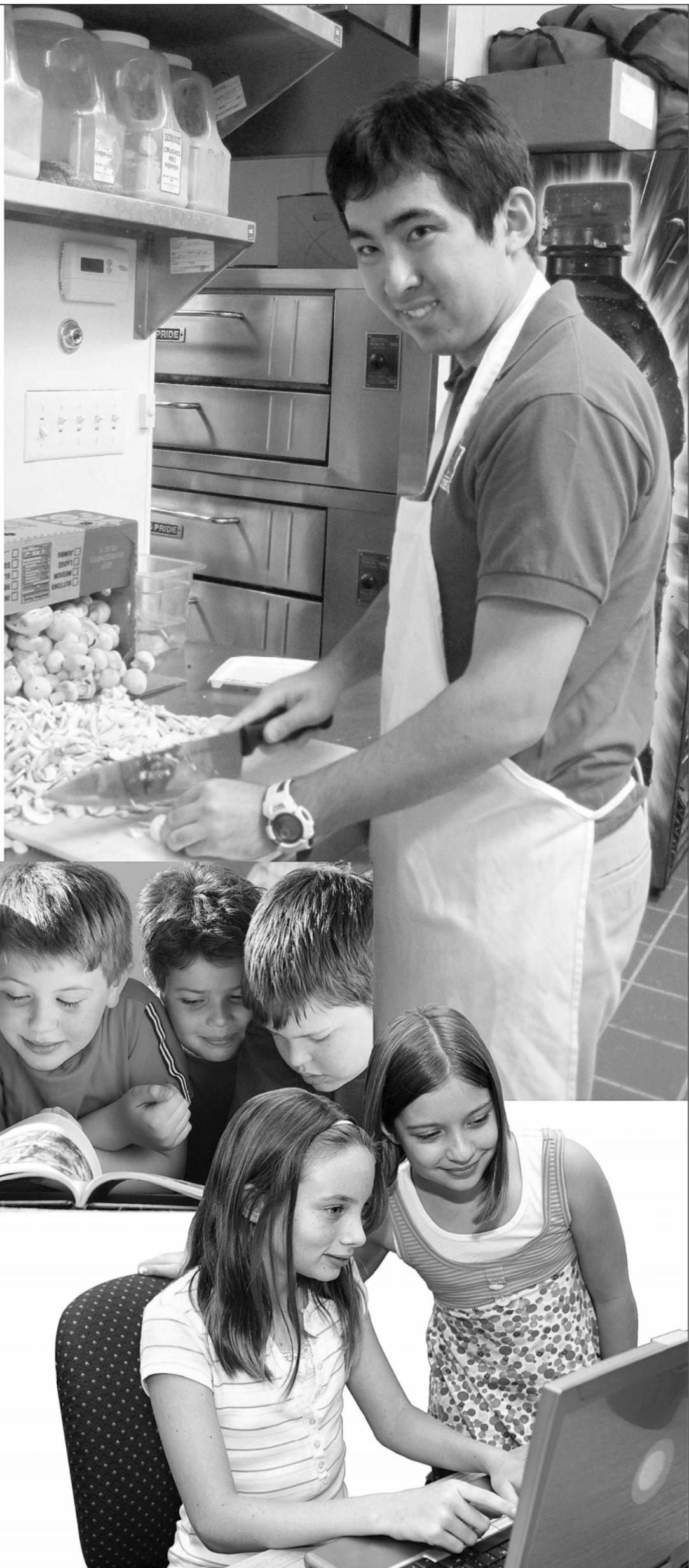
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AUTISM SPECTRUM NEWS DESK

Autism Blurs Brain Tissue's Distinctiveness - Erodes Molecular Identities in Cortex

By The National Institute of Mental Health (NIMH)

Autism blurs the molecular differences that normally distinguish different brain regions, a new study suggests. Among more than 500 genes that are normally expressed at significantly different levels in the front versus the lower middle part of the brain's outer mantle, or cortex, only 8 showed such differences in brains of people with autism, say researchers funded in part by the National Institutes of Health.

"Such blurring of normally differentiated brain tissue suggests strikingly less specialization across these brain areas in people with autism," explained Daniel Geschwind, M.D., Ph.D., of the University of California, Los Angeles, a grantee of the NIH's National Institute of Mental Health. "It likely reflects a defect in the pattern of early brain development."

He and his colleagues published their study online May 26, 2011 in the journal *Nature*. The research was based on post mortem comparisons of brains of people with the disorder and healthy controls.

In fetal development, different mixes of genes turn on in different parts of the brain to create distinct tissues that perform specialized functions. The new study



suggests that the pattern regulating this gene expression goes awry in the cortex in autism, impairing key brain functions.

"This study provides the first evidence of a common signature for the seemingly disparate molecular abnormalities seen in autism," said NIMH director Thomas R. Insel, M.D. "It also points to a pathway-based framework for understanding

causes of other brain disorders stemming from similar molecular roots, such as schizophrenia and ADHD."

In an earlier study, the researchers showed that genes that turn on and off together at the same time hold clues to the brain's molecular instructions. These modules of co-expressed genes can reveal genetic co-conspirators in human

illness, through what Geschwind and colleagues call "guilt by association." A gene is suspect if its expression waxes and wanes in sync with others in an illness-linked module.

Using this strategy, the researchers first looked for gene expression abnormalities in brain areas implicated in autism — genes expressed at levels different than in brains of healthy people. They found 444 such differently expressed genes in the cortexes of postmortem brains of people with autism.

Most of the same genes turned out to be abnormally expressed in the frontal cortex as in the temporal cortex (lower middle) of autistic brains. Of these, genes involved in synapses, the connections between neurons, tended to be under-expressed when compared with healthy brains. Genes involved in immune and inflammatory responses tended to be over-expressed. Significantly, the same pattern held in a separate sample of autistic and control brains examined as part of the study.

Autistic and healthy control brains were similarly organized — modules of co-expressed genes correlated with specific cell types and biological functions.

Yet normal differences in gene expression levels between the frontal and

see Brain on page 30

Many School-Aged Children with ASD in South Korea Go Undiagnosed

Total population study points to need for better epidemiological methods, screening, and services

By The National Institute of Mental Health (NIMH)

The prevalence of autism spectrum disorder (ASD) among children in South Korea appears to be much higher than the range of estimates previously reported in other countries, according to a study partly funded by NIMH. The researchers found that two-thirds of ASD cases occurred in children attending mainstream schools; these children had not been previously diagnosed and had never received treatment for the disorder. The study was published online ahead of print on May 9, 2011, in the *American Journal of Psychiatry*.

Background

Recent reports of increased prevalence of ASD have raised concerns among parents, researchers, and policymakers. However, it is still unclear whether these estimates reflect a true rise in ASD occurrence or improved rates of detection and diagnosis. And because different studies use different designs and methods, they may not be truly comparable. There are also limited



data on the prevalence of ASD in countries outside of North America and Europe.

To address these issues, Young Shin Kim, MD, PhD, of the Yale School of Medicine, and colleagues targeted all children ages 7-12 in a South Korean commu-

nity representative of the country's general population. The researchers asked parents and teachers about the children's social interactions, and whether they had communication problems or restricted and repetitive behaviors.

The researchers then evaluated 286 children suspected as having ASD based on the answers given. Of these children, 114 attended special education schools, had a history of mental health service use, or were listed in the local disability registry. For study purposes, the researchers considered these children to have a high probability of having ASD. The other 172 children attended regular schools, had never received special education or mental health services, and were not listed in the disability registry.

The study incorporated multiple measures to address potential cultural issues. For example, board-certified Korean child psychiatrists trained in both Korea and the United States conducted the diagnostic assessments using screening and diagnostic tools validated for Korean children. An anthropologist on the research team also organized focus groups with local parents and teachers to identify beliefs that may influence symptom reporting and to address stigma related to ASD.

Results of the Study

Based on diagnostic assessments, the

see Undiagnosed on page 38

AUTISM SPECTRUM NEWS DESK

The World Gathers at YAI's 32nd Annual International Conference

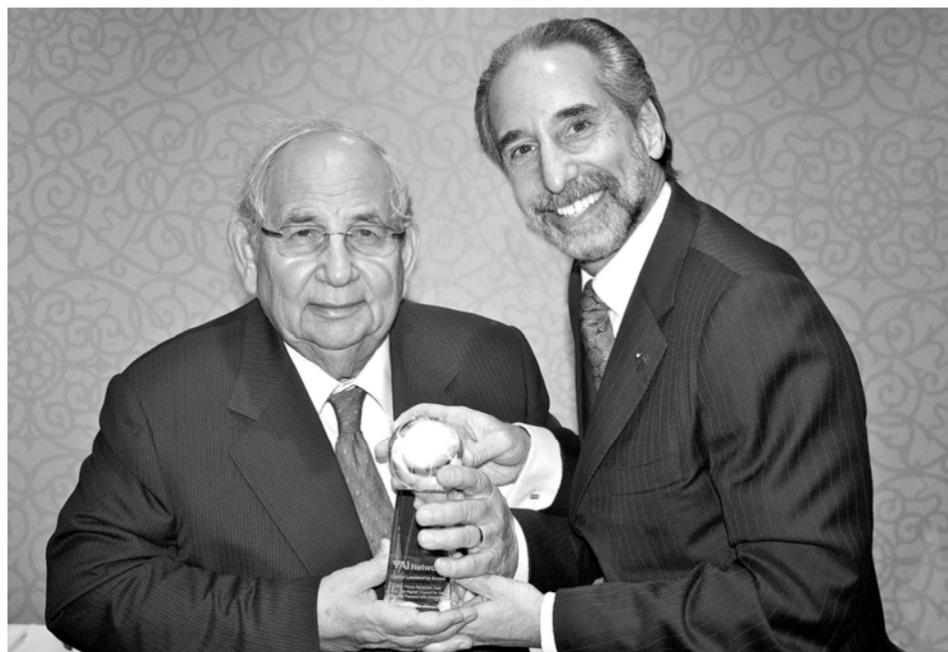
By The YAI Network

Approximately 3,000 attendees from across the U.S. and from 40 countries gathered at the YAI Network's 32nd Annual International Conference to learn about effective strategies and best practices in working with individuals of all ages with intellectual and developmental disabilities (IDD). The conference, "Bridges to Success in Developmental and Learning Disabilities," took place May 2-5 at the Hilton New York.

An inspiring, standing-room-only keynote address kicked off the event. His Royal Highness Prince Raad bin Zeid of Jordan accepted the YAI Network's first Global Leadership Award on behalf of the Higher Council on the Affairs of Persons with Disabilities, which spearheaded the opening of Jordan's first two group homes on April 20, 2011.

"We can build bridges and hotels, but building new ideas... that's something very special we are doing with thanks to our friends at YAI," Prince Raad said.

Incorporating common sense and humor into his keynote presentation, Dr. George S. Everly, Jr., provided insight on the importance of resiliency. His message resonated with attendees from across the globe.



His Royal Highness Prince Raad bin Zeid of Jordan, left, receives the YAI Network's first Global Leadership Award on behalf of the Higher Council on the Affairs of Persons with Disabilities, from Dr. Philip H. Levy, CEO and President of the YAI Network

"Your legacy will be etched not in stone, but in the lives of those you touch," he said.

Throughout the week, attendees enjoyed presentations by more than 250

experts in the disabilities field from across the U.S. and around the world. Presenters covered a range of topics, including advocacy and self-

determination, autism spectrum disorders, day and residential services, early intervention, education, legal and financial planning, sexuality and socialization, special education, strengthening families, workforce and technology issues.

"This is the best conference," said Than Johnson, President of CRSI, an organization in Ohio. "I've very much enjoyed years of association with YAI."

Attendees received in-depth information through two full-day conferences, one on health care for people with IDD sponsored by Premier HealthCare, and one by Dr. Carol Westby on literacy in play and learning with children with disabilities and delays.

"I'm getting to meet so many people who I've read about and whose research I've used -- to see them come to life and present has been so wonderful!," said Sadna Balton, a speech and language therapist at a large academic hospital in South Africa.

Gena Norquist of the Fairfax County Public Schools came to the conference for the first time because she is interested in taking her special education career overseas. "The presentations have

see World on page 23

Early Intervention Improves Social and Communication Skills

Research Pinpoints Early Signs of Autism and Develops Key Intervention Programs for Toddlers

By Rebecca Landa, PhD, Director
Center for Autism and Related Disorders
Kennedy Krieger Institute

Autism is the nation's fastest growing developmental disorder, with current incidence rates estimated at 1 in 110 children. This year, more children will be diagnosed with autism than AIDS, diabetes and cancer combined, yet profound gaps remain in our understanding of both the causes and cures of the disorder. Continued research and education about developmental disruptions in individuals with autism is crucial, as early detection and evidence-based intervention can lead to improved outcomes in individuals with autism.

One of the nation's leading programs for autism research is the Center for Autism and Related Disorders at the Kennedy Krieger Institute in Baltimore, MD. As director of this multi-faceted, multidisciplinary program for children with autism spectrum disorders (ASD) and their family members, I work together with my team to conduct research to understand how to promote development in toddlers who show social and communication delays.



Rebecca Landa, PhD

This research includes direct intervention with the children as well as approaches for parent training and parent education.

In 2007, our study published in the *Archives of General Psychiatry* found that approximately half of all children with

autism can be diagnosed around the first birthday. The most common very early signs of autism include poor eye contact, infrequent response to his or her name being called, infrequent attempts to initiate communication with others and the presence of repetitive behaviors. By identifying these early signs of autism, we open the door to early intervention, which can provide toddlers with tools and skills to increase social opportunities throughout their lifetime, positioning them to have the best possible outcomes. The "wait and see" method, which is still often recommended to concerned parents, could lead to missed opportunities for early intervention.

The importance of early intervention for all medical and behavioral diagnoses is well recognized. In the case of autism, early intervention not only helps to put children's development on a healthier track, it may also serve to prevent certain difficulties, such as aggressive behavior, additional delays and the development of unusual learning styles. Early learning experiences are important, particularly in the first three years of life, because the brain is most malleable early in life. As children learn, there are anatomic and

physiologic changes in the brain. The brain literally changes the way it develops, with healthy and more mature connections within and across brain areas.

In a 2010 study published in the *Journal of Child Psychology and Psychiatry*, my fellow Kennedy Krieger researchers and I found that early intervention can improve the core symptoms of ASD in very young children. This was the first randomized clinical trial measuring how a group-based early intervention model impacts social development in toddlers with ASD. Participants included two groups of 24 toddlers with ASD, ages 21 to 33 months, who received identical intervention for six months. However, one group received a greater number of orchestrated opportunities for social engagement. This specially designed socially-directed intervention provided organized opportunities to respond to and initiate joint attention (pointing out things of interest, showing and giving for social purposes), imitate others during social interaction and share positive affect (smiling paired with eye contact). The most significant improvements were found in how the

see Early Intervention on page 29

Using Typical Peers as Role Models to Help Improve Social Skills for Children with Autism Spectrum Disorders

By Jill Krata, PhD
YAI Network

Children diagnosed with autism spectrum disorders (ASD) typically display great difficulties in social communication and social interaction skills. These skills are core deficits which quite often impede their interactions with peers and adults. Children on the spectrum often fail to interpret social cues accurately, which can lead to unproductive and unsatisfying social experiences.

The development of appropriate social skills becomes even more important as more schools welcome children with special needs into inclusive classrooms. In such settings, children with ASD must adjust to the increased complexity of social demands such as meeting academic and instructional goals, and learning how to interact with typically developing counterparts. Unfortunately, without social skills training, students with special needs often face rejection and isolation.

Since the prevalence of ASD is increasing, evidence-based interventions in the study of social skills among children with autism are critically important. One intervention that has been successful in meeting evidence-based criteria and in improving social skills among children on the spectrum entails using typical peers as role models.



Jill Krata, PhD

Using Typical Peers as Role Models for Children on the Spectrum

Typical peer model interventions are effective because they provide visually cued instruction with modeling for children with autism, who usually demonstrate a preference for visual learning such as the use of visual support instructional

strategies. In this intervention, a typical peer model demonstrates a socially appropriate behavior, such as introducing himself or herself to a new friend, and the child on the spectrum is expected to imitate that behavior (McConnell, 2002). Adults may facilitate and monitor the intervention from close by, although they never intervene directly with the target child. These strategies help promote learning in a natural social context with peers and/or siblings by transferring learning from these models within a realistic environment.

Implication for Evidence-Based Intervention

Over the last several years, research has supported the use of typical peer models as a way to promote and enhance social skills and social interactions of children on the spectrum. It is important to acknowledge that evidence-based studies have identified typical peer model interventions as having a prolonged effect on the social interaction of children with ASD, as demonstrating increased spontaneous engagement with the people around them, and as being an emerging and effective practice.

Specifically, research supports typical peer model interventions as highly effective in promoting social interactions among children under 8 years of age diagnosed with an ASD. Further comparisons also suggest that these interventions were more

effective in enhancing social responses in younger boys when older male siblings served as the peer model, especially when the intervention occurred in their home.

Where Do We Go From Here?

Increased social interactions can ultimately set the stage for other developments such as language acquisition, inclusion in educational settings, and the development of more positive and long-lasting peer relationships. Using typical peer role models corroborates the belief in the continued importance of early intervention for children with autism.

Parents and professionals should continue to focus on the importance of family involvement in the intervention process, specifically when the goal is to increase social skills and social interactions for children with autism. Parental involvement has been a crucial component of the habilitation process and of evidence-based interventions such as using typical peer models, and should continue in the home and community settings. Siblings have shown to be a major part of the process and are effective in promoting learning of social interactions in natural settings.

Families should be aware that using typical peer models is a viable, proven and evidence-based method for promoting social interactions among children with ASD. By using typical peer models, children

see *Typical on page 39*

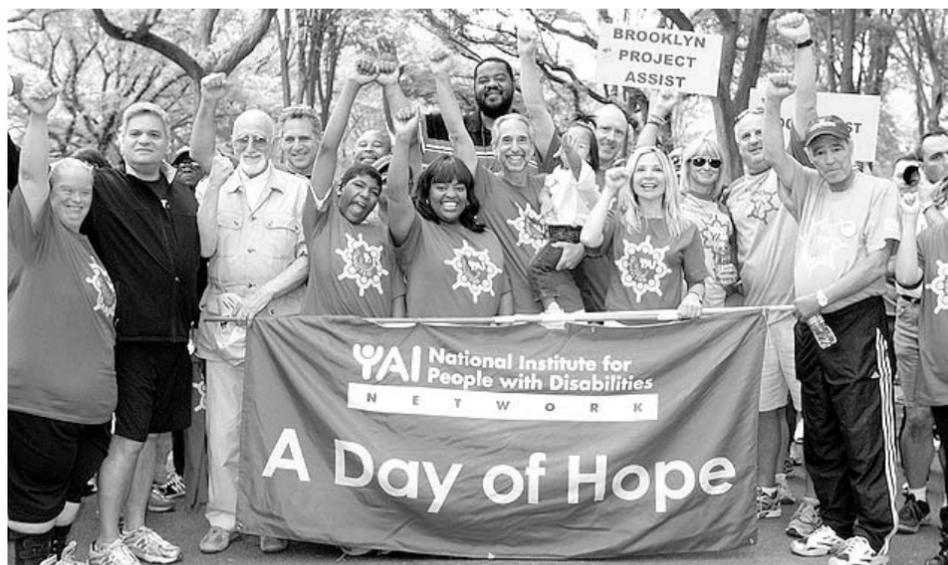
YAI and Broadview Networks Central Park Challenge Raises Record \$1.6 Million Proceeds Benefit People with Disabilities in YAI Network Programs

By The YAI Network

More than 12,000 family members, people with autism and other intellectual and developmental disabilities, friends, supporters, corporate partners and YAI Network staff gathered on Saturday, June 4, 2011, for YAI and Broadview Networks Central Park Challenge, which raised a record \$1.6 million. The event featured a competitive 5K run, a 3K fundraising walk, children's activities, food and entertainment.

An array of celebrities came out to show their support, including YAI Network Spokesperson Sherri Shepherd, co-host of ABC-TV's "The View" and NBC-TV's "30 Rock," Bill Ritter, Anchor of WABC-TV's Eyewitness News, Grizz Chapman of NBC-TV's "30 Rock," Dominic Chianese, of "The Sopranos," Maria Milito, DJ of Q104.3 FM, Dan Lauria of "The Wonder Years" and Kaitlin Monte, Miss Southern New York.

"Amid one of the most severe economic climates that our nation has encountered, we have raised more critical funds and awareness about the rights of people with disabilities, making this our most successful Central Park Challenge,"



Celebrities, people with developmental and learning disabilities and their families, and corporate partners joined YAI Network staff at YAI and Broadview Networks Central Park Challenge on June 4, 2011

said Dr. Philip H. Levy, CEO and President of the YAI Network. Proceeds from the event support thousands of people with disabilities and their families who receive services from the YAI Network.

"Unfortunately in this climate, when the government is cutting budgets, chil-

dren and adults still have special needs; that's not going away," said Shepherd, whose son benefits from YAI Network services. "Thanks to the YAI Network, my son is talking, walking and running. YAI has given him the services he needs."

The real star of the day was Xi'Xi

(pronounced She-She), the 3-year-old YAI Network preschooler whose shining eyes and ear-to-ear grin delighted the crowd. Joined by her parents, Cindy and Pat, Xi'Xi helped pump up the energy at the start of the 3K walk by waving to participants. She also enjoyed dancing on stage with Sherri Shepherd to the music of Dr. K's Motown Revue.

"Xi'Xi's progress has been amazing," Cindy said. "She's walking, she's talking - these are things she could not do before starting school. It's a miracle what YAI has done for her."

"Even though I have read about Xi'Xi's progress and her family's journey on YAI's website, seeing the bond between all three of them elevated the vibe on the stage," said Lauren Morris, who competed in the 5K run. "It wasn't just love that I was seeing between Xi'Xi and her parents, but it was pride. As a mother, that's a very powerful thing to witness."

Ritter delivered an inspiring message before thousands of individuals with and without disabilities set out on the 3K walk. "Remember, when we're walking today, we're trying to level the playing field," he said. "We want equal opportunities for people with disabilities."

see *Central Park on page 29*



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Serving People with Disabilities and their Families

Assisting Parents in the Struggle to Access Science-Based Information and Treatments for their Children with ASD

By Kristin Knapp-Ines, PhD, BCBA,
Melissa L. Rinaldi, PhD, and
Kristin V. Christodulu, PhD
University at Albany CARD

Families of children who receive a diagnosis of an autism spectrum disorder (ASD) are faced with profound challenges, and many feel a tremendous burden (Mulligan, Steel, Macculloch & Nicholas, 2010). The time of diagnosis may represent a pivotal point for both the child and the individuals closely connected to the identified child, and may have been preceded by months or even years of unanswered questions, long-standing concerns, and previous observations, including comparisons with siblings or other peers.

Once a child has been diagnosed, parents enter a phase which includes information seeking and the desire to access services, possibly accompanied by questions regarding the validity of the diagnosis and questions related to the uncertainty associated with the course of this developmental disability.

Given that the primary and secondary characteristics of autism present themselves in a pervasive manner across all aspects of a child's life, such as adaptive skills as well as across play, social and educational domains, this new diagnosis



Kristin Knapp-Ines, PhD, BCBA

may present significant emotional challenges for the family (Mulligan, Steel, Macculloch & Nicholas, 2010). It is, therefore, unfortunate that families frequently report dissatisfaction with the quality of information they receive following a diagnosis of autism (Howlin &

Moore, 1997). Parents also report that having to locate information on their own leads to increased feelings of worry and hopelessness, due in large part to the lack of credibility and negative tone of the information they find (Osborne, 2008). It is not surprising, then, that parents frequently are using other parents of children with ASDs as a means of both information and support (Mackintosh, Myers, & Goin-Kochel, 2006). In addition to accessing other parents, mother and fathers are more often turning to books and websites for facts than to physicians and other professionals. Since physicians and other professionals generally have the greatest access to science-based resources, it is concerning that parents do not seem to be utilizing these individuals more.

The amount of trust parents place in different sources of information is another area of concern. A recent study of a large national sample of parents of children with ASD (n = 1,552) examined the amount of credibility parents placed in different sources regarding the topic of vaccine-safety (Freed, Clark, Butchart, Singer, & Davis, 2011). Although parents trusted the information from their doctor most often (76%), parents placed "some trust" in the information provided by celebrities (24%) and by parents who believe their child was harmed by vaccines (65%). Since parents are gaining access to information from

multiple sources and putting their trust, at times, in individuals based on their visibility in the media and/or their emotional appeals, it is even more important for the scientific community to assist parents in accessing accurate information.

As many families experience the two-fold challenge of: 1) the profound personal and family life changes associated with an autism diagnosis, and 2) the existence of a large array of low quality information and many non-credible and non-validated treatment methods and strategies for which there is little in the way of scientific support and efficacy (Simpson & Myles, 1998), there are several factors which provoke an even larger dilemma for some families. Certain child and parent characteristics, as well as resource-related characteristics, pose additional barriers to accessing high quality autism-related information, including science-based treatments which have met rigorous peer review and have shown positive results over an extended period of time (Simpson, La Cava, & Graner, 2004). These child/parent characteristics and resource-related factors determining access to quality information and care are multi-fold. Children of minority race and ethnicity are less likely to receive services and, if they do receive services, it is at a

see Assisting on page 36

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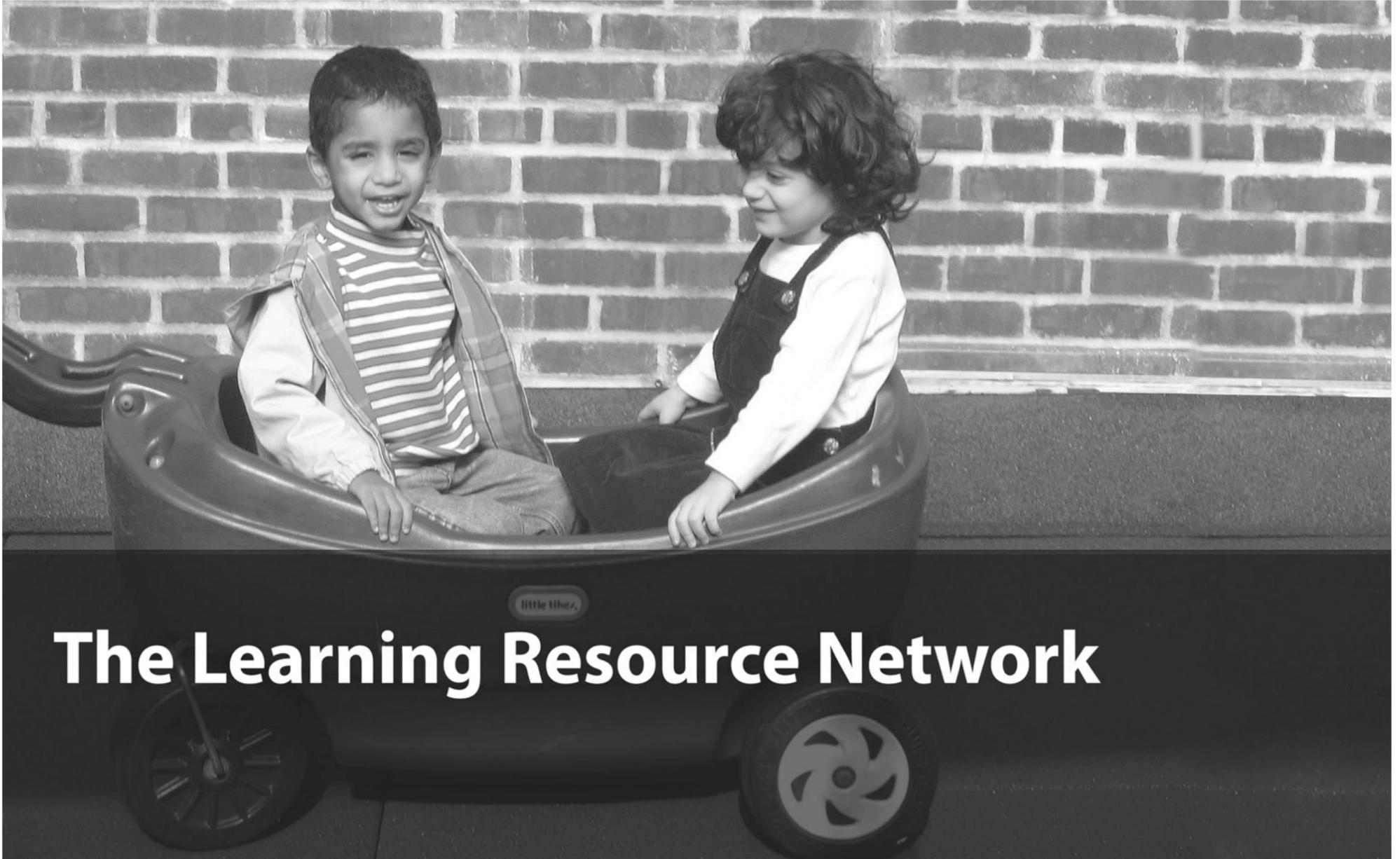
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A Child's Right to Positive Behavioral Interventions

By **Laura Henderson, MA, BCBA** and **Nicole Pellicciari, MS, BCBA**
Center for Neurological and Neurodevelopmental Health

Autism Spectrum Disorders (ASDs) are complex neurobiological disorders of early brain development. The deficits associated with ASDs may affect many aspects of individuals' lives including socialization, such as developing relationships, communication, and activities of daily living. Government statistics suggest the prevalence of the rate of autism is increasing 10-17 percent annually. Currently, an average of one in 150 children in the United States has an autism spectrum diagnosis. The national prevalence of Autism is 60-70 per 10,000. The ratio of males is 4:1. The ratio of females is 8:1. Sibling incidence is 15:1. Autism Spectrum Disorders estimated at approximately 5.6 per 1,000 children in the United States.

As the incidence of individuals with ASD increases, it is critical for caregivers and educators to understand the behavioral challenges that surround the diagnosis. An individual with autism may experience problems with verbal fluency, attention, differentiated responses, inability to initiate or cease action, as well as difficulties regulating and modifying behavior.

Cognitive and communicative abilities among individuals with ASDs may range



Laura Henderson, MA, BCBA and Nicole Pellicciari, MS, BCBA

significantly. In order to create optimal social and academic environments for individuals with an ASD diagnosis we must understand the needs of each child and implement treatment based on empirically based interventions.

Academic services and procedures required under the Individuals with Disabilities Education Act (IDEA) are designed to ensure that: (1) challenging behaviors are addressed through positive behavioral interventions, (2) children are not improperly

disciplined for conduct related to their disabilities, and (3) children with disabilities receive free and appropriate public education (FAPE) even if properly excluded from school for disciplinary reasons. Children with disabilities in preschool may never be suspended or expelled from school (N.J.A.C. 6A:14-2.8(a)(1)).

Whenever the behavior of a child with a disability interferes with the learning of a child or others, the child's Individualized Education Plan (IEP) team must consider for inclusion in the child's IEP "positive behavioral interventions and supports" and "other strategies" (which are often described in a "behavioral intervention plan") to address that behavior (20 U.S.C. § 1414(d)(3)(B)(i); 34 C.E.R. §). A child with a disability must be reevaluated whenever the child's functional performance, including behavior, warrants a reevaluation (20 U.S.C. § (a)(2)(A)(i); 34 C.E.R. §). Such evaluations should assist the IEP team in determining what services or accommodations are necessary to enable the child to be educated with his or her non-disabled peers (20 U.S.C. § 1414 (b)(2)(A)(ii); 34 C.E.R. §), and, where appropriate, must include a "functional behavioral assessment" (20 U.S.C. § 1414 (b)(2)(A); 34 C.E.R. §). In addition to positive strategies and interventions, the IEP should include any modifications to the Code of Student Conduct, which are necessary for the student (20 U.S.C. § 1414 (d) (1)(A)(ii)(IV) 34 C.E.R. §).

Functional behavior assessment (FBA) can be conducted to aide educators in understanding the child's academic and social needs. The purpose of a "functional behavioral assessment" is to identify the functions of an individual's challenging behavior in order to develop positive behavioral interventions and supports to address aberrant behavior. The topography of the behavior must be clearly defined. Once the targeted behaviors are defined, a hypothesis of the function of those behaviors must be developed.

"The FBA is generally conducted in a collaborative fashion, bringing together input from the child and a variety of individuals who work and interact with the child. It uses a child-centered approach based on the understanding that behavior serves a particular function for each child and that effective interventions must be tailored to address the function played by the behavior within the context in which the individual child lives and learns and in light of the child's unique strengths and needs. An FBA should be conducted by a professional who can demonstrate (e.g., through a specialized degree or credential) experience, knowledge and skill in positive behavior support, which include training in applied behavior analysis" (Education Law Center, 2008).

"Once the FBA is complete, the IEP

see Positive on page 38

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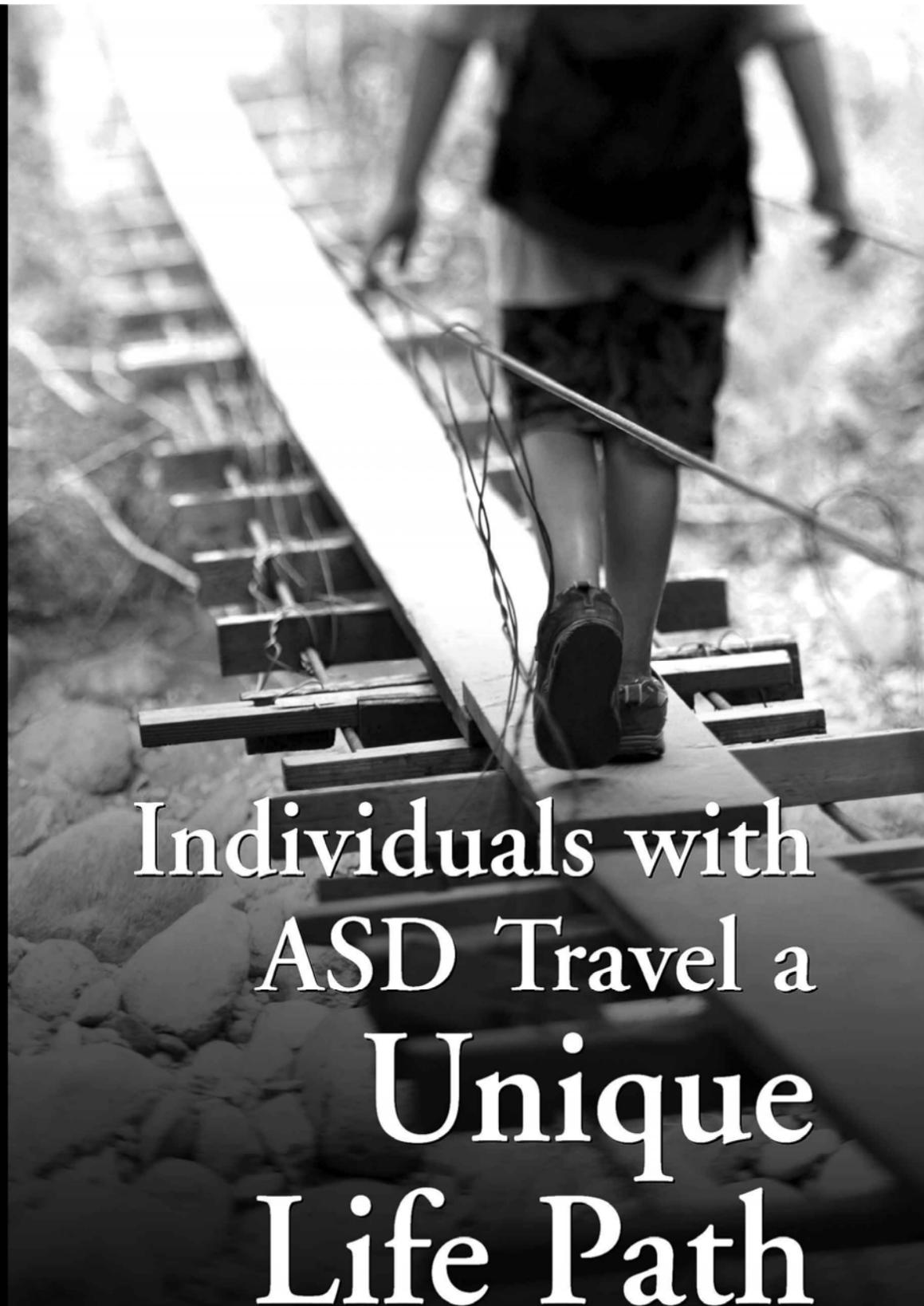
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Computerized Health Games to Promote Social Perceptual Learning in Autism

By Gregor Kohls, PhD and Robert T. Schultz, PhD
Center for Autism Research at
The Children's Hospital of Philadelphia

Many individuals with autism spectrum disorders (ASD) struggle to read nonverbal social cues, such as facial expressions, and often have difficulty recognizing a person's identity from their face. New computerized video games being developed by the Center for Autism Research (CAR) at The Children's Hospital of Philadelphia are being tested for their effectiveness for improving face perception skills in children with ASD.

Recognizing facial information and understanding it are essential skills for competent social functioning, like grasping what another person is thinking and feeling. Functional brain imaging studies have shown that regions of the brain specialized for reading faces are less active among individuals with ASD compared to typically developing peers, indicating that these skill deficits have a discrete basis in the brain. Using infrared eye tracking, research shows that individuals with ASD look less at faces, especially the eye region. New research is studying whether this is because social interactions are less pleasurable for individuals with ASD, such that focusing their gaze on faces is less "rewarding." The first functional im-



Gregor Kohls, PhD and Robert T. Schultz, PhD

aging studies of reward processes, in fact, do suggest that persons with ASD get less pleasure from observing social images. Using this framework, researchers are now beginning to design computer-based interventions to teach social perceptual skills and to enhance pleasure from social activities.

Computerized video health games are an especially promising intervention tool because they are naturally engaging and

allow the child to learn skills in the context of an activity that is intrinsically rewarding and self-motivating. These games demand increasingly fine perceptual discriminations, gradually teaching advanced skills. Anecdotal evidence and empirical data have shown that many children with ASD have circumscribed interests in technology such as computers, and prefer computer gaming over other activities. Furthermore, several re-

cent studies have reported that persons with an ASD can in certain regards derive more therapeutic benefits from computer-based approaches than direct teacher or therapist instruction. Hence, there is a natural fit for using computerized games as a therapy in ASD.

The Center for Autism Research (CAR) at The Children's Hospital of Philadelphia recently developed a set of therapeutic computer games called *FaceStation* to improve face perception skills among children with ASD, and to boost the reward value of faces. The *FaceStation* game suite builds on an earlier game platform called *Let's Face It!* (LFI), developed by CAR's Director, Robert Schultz, PhD, and James Tanaka, PhD (at the University of Victoria). In a study published last year, LFI was shown to significantly enhance perceptual skills for face recognition in children with ASD.

Following this initial success with LFI, *FaceStation* takes this approach even further. It was designed by a team of psychologists, clinicians and computer programmers to fulfill two key components of successful health games: (a) to be therapeutically effective and (b) to be intrinsically engaging so to perpetuate game play and hence learning without any teacher or therapist oversight. Unlike conventional teaching and training methods, the *FaceStation* games aim to tap "reward" circuits

see *Games on page 31*

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Stephen A. Ehrens, CPA, CLTC

Parents or guardians of a dependent with special needs are likely to be familiar with the legal document commonly known as the special needs trust. With the help of an attorney who has expertise in this area, they've come to understand that the purpose of the special needs trust is to provide extra and supplemental care, maintenance support and education above and beyond that which is already provided by any local, state and federal programs.

The trust is an important tool for protecting a dependent's assets as well as his or her eligibility to receive government assistance. It enables friends and family to direct assets to the trust rather than directly to the person with special needs – thus preserving the individual's eligibility to receive benefits.

With a special needs trust in place, families are taking a giant step toward securing a future of financial security for their loved one with special needs.

A Trust is of No Value Without Funding

The challenge for many families is to determine the best way to fund the trust, because a special needs trust by itself has no value without financial assets.

An attorney can establish the trust, but you'll want to work with a specialized financial professional to help quantify the projected costs of care for the dependent and to determine the best means for funding the trust to provide for the lifetime of your loved one with special needs.

Funding a special needs trust can be an overwhelming undertaking for many families. Present-day costs for care may have them thinking there will be little left to put aside for future planning. However,

families have choices in deciding the best ways to fund a trust in light of their personal circumstances. For some families, funding the trust may require a reallocation of current assets, while others may need additional assets to secure the level of financial security they desire for their child or dependent.

There are many ways to fund a special needs trust, including the aforementioned family assistance of leaving money or property to the trust. For example, parents can leave a portion or all of their estate to the trust; inheritances from relatives or friends can be gifted to the trust; and investments such as CDs, IRAs and Keogh plans can also be directed to the trust.

For many families, life insurance may be the most feasible way to leave the dependent sufficient funding for the future. In fact, a paid-up life insurance policy in a trust may be one of the few methods to guarantee future funding.

While there are several types of life insurance, the most effective methods for providing a lifetime of coverage are the following:

- Whole life insurance lasts the entire lifetime of the policyowner and provides both death benefit protection and cash value accumulation. With these types of policies, part of the premium paid by the policyowner builds equity in the policy. We call this equity cash value which is acces-

sible to parents and family. Whole life insurance policies may also be eligible for dividends (Dividends are not guaranteed and are subject to change).

- Second-to-die life insurance, which is a permanent life insurance policy that provides much needed resources at a time when the funds will likely be most needed – at the death of the second parent. The cost of a second-to-die policy is typically lower than that of a single life policy. Proceeds can be directed to the special needs trust and used for supplemental long-term quality of care needs.

Friends, grandparents and other relatives may consider this funding solution as a way to allocate assets to their loved one. By designating the special needs trust as the beneficiary rather than the individual, proceeds can be left to help provide for the individual without penalizing him or her from receiving third-party benefits.

Funding From a Holistic Perspective

It's hard to expect parents and guardians to know the best ways to fund their dependent's special needs trust until they've weighed all their options with a financial professional experienced in special needs planning. An experienced

see *Trust on page 37*

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A Look Inside the Hidden Curriculum

By Brenda Smith Myles, PhD
The Ziggurat Group

The hidden curriculum is assumed knowledge - the expectations, rules or guidelines that are not directly taught because they are universally known (Garnet, 1984; Hemmings, 2000; Jackson, 1968; Kanpol, 1989; Myles, Trautman, & Schelvan, 2004). It also addresses the incongruities of how skills are executed differently across communicative partners and environments, making it an essential set of skills for individuals with autism spectrum disorders (ASD) who often do not detect the subtleties of situations and are often routine bound, literal, and rule enforcers.

The absence of instruction of the hidden curriculum, however, does not belie its importance. The hidden curriculum is significant and can impact social interactions, school performance, and safety. Despite its considerable value, little information on hidden curriculum has been published because it has been largely considered "common sense" and is often only recognized after a hidden curriculum error has occurred. For example, there is a hidden curriculum for nose picking. It is not "pick your nose." Rather it is "pick your nose in the bathroom and use a tissue." Violation of this hidden curriculum item can result in a child being isolated from peers.



Brenda Smith Myles, PhD

Impact of the Hidden Curriculum

While some hidden curriculum items may seem humorous, the impact of not knowing or following the hidden curriculum can be serious. A demonstration of not understanding the hidden curriculum can cause an individual to be bullied, ignored, made fun of, or to be misunder-

stood. Hidden curriculum challenges can be even more serious impacting health and well-being. Its impact can be felt in the school, home, community, in emergency situations, on the job, or in the judicial system.

School - Schools have their own multifaceted hidden curriculum. How to dress, what type of backpack to carry, how to greet peers, what games are acceptable to play, etc... Teachers have their own hidden curriculum. Even though a classroom rule telling students not to talk is posted, that rule is not always in effect. Johnny, a third grade student with ASD, did not understand this and refused to talk during cooperative group time because he did not want to break the no-talking rule. Johnny's teacher assumed that all students inherently knew that talking during when in cooperative groups was permissible.

Home - The hidden curriculum at home often is related to values and rules. At other times, the hidden curriculum is related to good etiquette and tradition. Parents and caretakers often explicitly teach some hidden curriculum items as they become aware that their children have deficits in these areas. However, these deficits sometimes become apparent during times of stress in the home and, as a result, children do not receive patient instruction, but instead are given a rule without explanation. Millie's family had a

chair designated as "dad's chair" in the living room. When a family guest sat in "dad's chair" Millie became extremely anxious and began to pace. Her behavior escalated as she loudly challenged the visitor, "Get out of that chair now! It is not yours." Millie did not understand the hidden curriculum rule that visitors were permitted to sit in "dad's chair."

Community - While home-related hidden curriculum items are often easily remediated by caretakers with little damage to self or others, errors made in the community may have negative ramifications. Peter Gerhardt talks about the hidden curriculum of urinals. For example, if there is only one man at a urinal, a newcomer should not go to the urinal next to that man. Rather, the newcomer should be at urinal that is at least two stalls away. Failure to understand this rule and similar others can result in others seeing the individual as gullible and naïve and could perhaps lead to that person being taken advantage of.

Emergency Situations - As much as possible, it is necessary to teach learners on the spectrum how to address urgent and unexpected events. These can range from downed power lines to tornados to coming into contact with poisonous substances. Spencer's mother was trying to

see Curriculum on page 32

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Thanks to the 2,700 families in the Simons Simplex Collection



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.

More than **2700** families, over **10,000** men, women and children, traveled to one of **13** collection sites across North America — taking time off work and kids out of school — to dedicate hours and days to interviews, assessments and giving blood.

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).

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

**SIMONS SIMPLEX
COMMUNITY**
@interactive autism network

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 170 requests for biospecimens by scientists; 120,000 samples have been shipped.*
- *more than 70 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.

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AUTISM RESEARCH INITIATIVE

While the Science is Still Uncertain, the Need to Plan for Your Child's Future is a Sure Thing!

By Bernard A. Krooks, Esq and Sheryl R. Frishman, Esq
Littman Krooks, LLP

When a parent is given a diagnosis for their child of Autism or Pervasive Developmental Disorder (PDD), they are bombarded with a variety of medical, therapeutic, educational, and holistic treatment methodologies that promise to “cure” Autism. This leaves parents in the position of believing that their child's developmental issues may be resolved and may not require a lifetime of care. Even though these treatments are available and may be extremely effective, they do not alleviate the necessity for parents to take the steps to plan for the future of their child. Often in our practice, parents of children with Autism and PDD are reluctant to plan, because they are still waiting to see what the outcome will be of the therapies and interventions. While understandable, waiting is a mistake. If a plan is not put in place, you are hurting your child, the person whom you are trying so desperately to help.

The thought of you predeceasing your child is frightening. It is so frightening that you may do everything you can to try not to think about it. Who wants to



Bernard A. Krooks, Esq

face their own mortality? Who wants to face it, especially when you are so busy bringing your child from therapy to therapy and hoping for a successful outcome? Nevertheless, there will most likely be a time when you will predecease your child and it is essential that you put a plan in place to ensure that



Sheryl R. Frishman, Esq

your child is taken care of properly. This is the case whether your child is “cured” or not. Here are five things you can do to give yourself greater peace of mind and to protect your family: Prepare a Letter of Intent; Execute a Will; Create a Supplemental Needs Trust; Sign Advance Directives; and Obtain Guardianship.

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 typical children, to have a Letter of Intent which will help the people that will be caring for the 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 for guidance 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

see Plan on page 33

Higher Medical Home Designation for Premier HealthCare is Good News for Patients with Autism

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

Like many people as they age, individuals with autism also experience more health issues as they grow older. However, according to information presented at the International Meeting for Autism Research in San Diego in the spring, the age at which the health of people with autism often begins to decline is just 45, much earlier than the general population.

Unfortunately, finding a doctor who understands the unique needs of adults on the autism spectrum can be difficult for patients of any age. It's likely that more families will be seeking those special health care providers, as one-in-six children in the U.S. are diagnosed with a developmental disability, the Centers for Disease Control reported in a recent study. And with budget-strapped states struggling to find new, cost-efficient ways to deliver Medicaid services to individuals with autism and other developmental disabilities, many in the field fear the problem may be further compounded.

For the past 14 years, Premier HealthCare, a member of the YAI Network, has been providing outstanding health care services to individuals with autism of all ages. Today, the medical practice, which features doctors, dentists and specialists trained to treat pa-



Marco R. Damiani, MA

tients with disabilities, is better positioned than ever to meet this growing need as a recently designated a Level 2 Patient-Centered Medical Home (PCMH) by the National Committee for Quality Assurance (NCQA).

Only Medical Home in New York City
for People with Special Needs

Premier HealthCare is the only or-

ganization specializing in the care of people with developmental disabilities in New York City to achieve this prestigious distinction. All of Premier HealthCare's five practices – in Manhattan, Queens, the Bronx and two in Brooklyn – received this prestigious distinction.

“The medical home model is all about redesigning care processes to make certain that patients and families are active members of the health care team – and that health care professionals maintain their focus on helping people achieve the best health care possible,” said Dr. Michael S. Barr, MBA, FACP, Sr. Vice President, Division of Medical Practice, Professionalism & Quality, American College of Physicians. “Premier HealthCare is clearly dedicated to this mission for people with developmental disabilities. Achievement of recognition by the NCQA is proof of Premier HealthCare's efforts.”

The PCMH is designed to enhance the patient-physician relationship, and to provide better coordinated care through communication among practitioners, patients, their families and other caregivers.

Taking the Time to Treat Patients
and Include Families, Caregivers

“When you're treating an individual with autism or other developmental dis-

ability, communication is critical,” said Dr. Peter Della Bella, Medical Director of Premier HealthCare. “We may have to speak to the patient's family or caregiver, or use untraditional methods to understand that the patient has a stomach ache.”

The team approach, which goes beyond a typical office visit, can include further education and helping patients take a more active role in their treatment through self-management tools. The impact of this partnership on patients is improved integration of care, greater efficiency and better outcomes.

“Premier HealthCare patients receive the highest quality care,” said Dr. Philip H. Levy, CEO and President of the YAI Network. “Our doctors, nurses and other clinicians understand that the focus is, and always will be, on the patient and his or her family.”

“The medical home designation will continue to enhance our patient care and keep Premier HealthCare at the forefront of health care reform,” said Stephen E. Freeman, Chief Operating Officer of the YAI Network.

Marco Damiani, M.A., is Senior Director of Clinical and Family Services (www.yai.org/services/familysupport) for the YAI Network. To learn more about health care services available through Premier HealthCare, call 1-866-2-YAI-LINK or visit yai.org/phc.

World from page 11

been very thought-provoking for me. I picked all the international sessions," she said, citing presentations by professionals from India, Russia, Spain and England.

Building on the YAI Network's successful partnership in Jordan, "Bridges to Success" also provided an appropriate setting for Inclusive Society Pakistan Chapter (ISPC) to sign an agreement with the YAI Network to provide technical, health care and rehabilitative assistance to the country, where 10-15 percent of the population has disabilities.

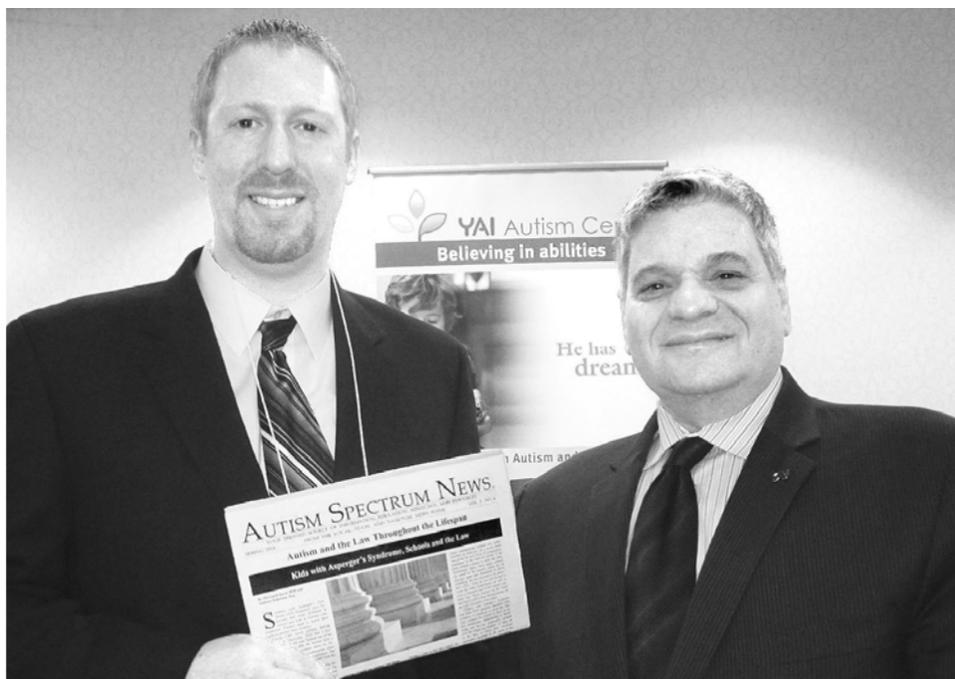
"The people of Pakistan haven't seen success stories," said Sadia Mumtaz, Founder and Executive Director of ISPC. "Just because you have a disability doesn't mean you can't do anything. Together with YAI, we will initiate that change."



The YAI Network's 33rd Annual International Conference will be held on April 30-May 3, 2012, at the Hilton New York. Visit yai.org/conference for more information about attending, presenting or exhibiting.



Sadia Mumtaz, founder and Executive Director of Inclusive Society Pakistan Chapter, signs an agreement with Dr. Philip H. Levy, CEO and President of the YAI Network, for YAI to provide technical health care and rehabilitative services to Pakistan, where 10-15 percent of the population has disabilities



David H. Minot, Associate Director of Mental Health News Education, Inc. with Stephen E. Freeman, Chief Operating Officer of the YAI Network

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Social Coping and Autism Spectrum Disorders: The Power Combination of Psychology and Speech Language Interventions

By Stacey Kanin, MS, CCC-SLP,
Samara Pulver Tetenbaum, PhD, and
Shana Nichols, PhD
ASPIRE Center

Throughout our years working with the ASD population, parents often inquire about whether their child should be receiving speech-language or psychological services. The answer is frequently "both." Research demonstrates that individuals with ASDs are at great risk for developing significant mental health concerns which often stem from the core social and communication impairments associated with their spectrum diagnosis (Gjevik, Eldevik, Fjæran-Granum, & Sponheim, 2011). Effective treatments must address the core social and communicative deficits while at the same time promoting coping and emotion skills development through the use of evidence-based techniques.

As professionals, we need to move away from "silo treatments" for the individual difficulties facing our bright verbal clients with ASD based on our area of expertise (e.g., speech language, mental health). Rather, we need to consider utilizing a multidisciplinary approach. We know that individuals with ASDs struggle with gestalt processing - that is taking individual pieces of a puzzle and recognizing how they all fit



Stacey Kanin, MS, CCC-SLP

together to create one picture or main idea. If a child sees a psychologist for emotional regulation and coping strategies and then separately sees a speech-language therapist to work on conversation skills, their core deficits make it difficult for them to understand how those two sessions fit together - that their difficulty initiating an interaction with a peer is causing an emotional response.



Samara Pulver Tetenbaum, PhD

What is the Role of the
Speech-Language Pathologist (SLP)?

Given the nature of ASDs, speech-language therapy is considered a primary intervention at all ages, and has been shown to be critical for promoting social communication, relationships and social cognition (National Research Council,



Shana Nichols, PhD

2001). Current research is demonstrating a need for a new type of communication-based treatment for individuals with more complex language abilities, such as those with diagnoses of Asperger Syndrome (AS) and High-Functioning Autism (HFA). This new method not only teaches

see Coping on page 36

NADD, an association for persons with developmental disabilities and mental health needs

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- NADD 28th Annual Conference & Exhibit Show ID/MH Nov. 2-4, 2011 Nashville, TN

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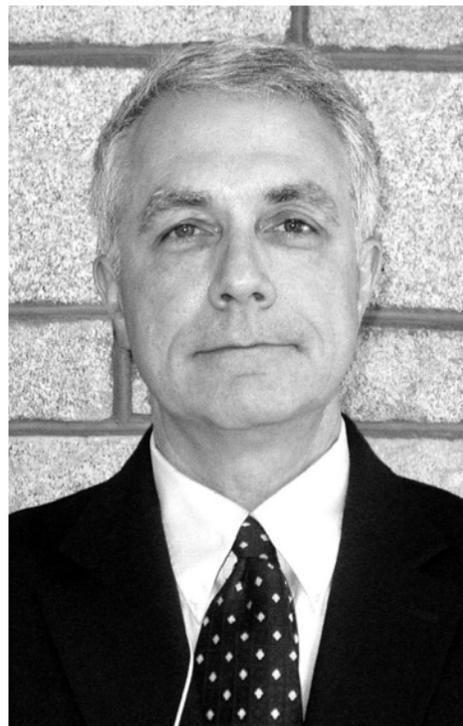
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Skepticism from page 1

(2009) defines skepticism closer to the original Greek meaning as the suspension of judgment (either to adopt or reject) until sufficient evidence is examined.

Kurtz (2010) stresses this perspective with his discussion of "skeptical inquiry," an approach that promotes the examiner to "...seek, when feasible, adequate evidence and reasonable grounds for any claim to truth in any context." (p. 21, as quoted in Normand, 2008). Claims of all kinds should be, before adoption or rejection, examined for the amount and quality of evidence that supports them. Thus, if there is a particular treatment for which there is valid scientific evidence for support, that treatment should be adopted and viewed as evidenced-based. However, when a claim is shown to have no evidence, or evidence that is weak and of poor quality (such as solely relying on the opinion of the claim maker), the rejection of such a claim or position should be the decision. Simply put, skepticism is the position of objectively evaluating, by looking for empirical evidence, the validity of any claim of fact, and basing adoption or rejection on the evidence (or lack thereof; Normand, 2008).



Thomas Zane, PhD, BCBA

This skeptical attitude, and the corresponding investigatory approach, reduces the possibility of adopting, as true, a claim

(or treatment) that may not be true. As is often said, extraordinary claims could be true, but a skeptical approach towards them would require extraordinary evidence and evaluation of that evidence. To reiterate, a skeptical thinker does not reject all claims; nor does s/he accept all claims as true. Rather, the position of a skeptical thinker is one of assessing the validity of the evidence before rendering a decision. The type of evidence is important, and there is an acknowledgement that there exists quite a bit of variation and debate regarding what evidence constitutes "valid" evidence (Zane & Hanson, 2008). But there is general agreement that the methods and criteria used by science is the most acceptable perspective to take.

Normand (2008) smartly acknowledged that the literature provides little specification on exactly how to behave skeptically. To increase the number of people who are "scientific skeptics" (a term coined by Normand; those who think and act skeptically), several suggestions are offered.

First, study and adopt the methods of science, scientific investigation, and skepticism, as described by numerous textbooks that exist on these subjects (e.g., Cooper, Heron, & Heward, 2007; Sagan,

1996). The scientific perspective and method of inquiry will inoculate against the reflexive acceptance of claims that are baseless.

Second, require that anyone making extraordinary claims provide extraordinary evidence to substantiate those claims. For example, when the practitioners of craniosacral therapy assert that they do not even need to touch the client's body in order to change the course of the cerebral spinal fluid (Zane, 2005), they should be required to present evidence that this is in fact true. When Gutstein, the developer of Relationship Development Intervention, asserts that, "The RDI Program is for every age group and for every range of severity, including those who are severely affected by autism" (Connection Center, 2005), he should be required to present the evidence that backs up this extraordinary claim.

Third, don't be gullible - do not accept claims without evaluation. Accepting all claims is not only intellectually dishonest, but potentially dangerous and fatal (Pigliucci, 2009). For example, promoting holistic remedies for curing AIDS will likely result in the unnecessary deaths of

see Skepticism on page 32

Employment and People with Disabilities: A Social Ill to Change, Not Manage

By **Nicholas A. Villani**
President/CEO
Career and Employment Options, Inc.



Nicholas A. Villani

During the last twenty-five years there has been a cataclysmic shift in the employment world of Americans. The fundamental shift and loss of the manufacturing base in America impacted not only the middle working class but also those individuals with disabilities who would have had a more secure start into the workforce in the manufacturing sector. The loss of entry level jobs that did not require college but might require mechanical, vocational, or skills in the trades were essentially wiped out. The Free Trade Agreements (which spanned several administrations both Republican and Democratic) essentially moved entire industries, their support industries and suppliers either overseas or over the border. Left behind were jobs that were retail based or jobs that were at the end of the manufacturing process. Students in Special Education, with high or low incidence conditions, were all affected by these events. Those students and adults who might have had access to the workforce through school, families, friends or major industries within their home communities find those opportunities now gone. Good paying jobs with security have left with little chance of returning. The education sys-

tem did not fully understand this change fully during the last twenty years as they continued to push traditional college enrollment as a means to job attainment despite the increasing unemployment for classified students. The *employment* rate for workers with disabilities of all kinds still hovers (in NY) around 35%, unlike non-disabled workers who remain at or around 84% (Cornell University 2007 Disability Status Report).

Concurrent to this cataclysmic event, in the field of developmental disabilities another event occurred that would impact the same people it was supposed to serve. Medicaid funded services, now waived from their regulatory restrictions, were promulgated as being the start of a new world for individuals with the most severe disabilities. Supported employment was advertised as the means to socially correct the inadequacies of congregate and segregated services for the most significantly impaired. A large share of employment funding went to the most significantly impaired to correct years of neglect. However the greatest, and not coincidentally most, amount of funding went toward habilitation services such as Service Coordination, Day Habilitation and Residential Habilitation. This shift moved the large human service agencies from a professed employment outcome as their goal for their constituents toward a more lucrative and high margin service. The profit margin of revenue to staffing (salaries were and remain very low, attracting mostly semi-skilled workers) was so large that there was an inevitable shift away from actual employment support to group habilitation services. This shift enabled most of the agencies to become mega-agencies with disproportionate amount of revenue toward habilitation and away from employment as an outcome. This growth did little to increase the number of individuals employed but certainly impacted their financial and organizational size. In addition, Vocational Reha-

bilitation (VR) funds are significantly lower than those of Developmental Disabilities despite the differential social impact on communities and the economy. This system too, was driven to provide the most amount of money to the most severely disabled while its funds and programs for individuals with less severe disabilities were limited with big gaps. Schools will send students to the State VR systems without a complete understanding of the services and probability of success. State VR and their supported employment arm provide a comprehensive service for the severely disabled but their job placement services have huge gaps for the less impaired. Essentially there remains a need for a service that provides individuals with mild disabilities some level of support as the Vocational Rehabilitation models at this time do not include intermittent long-term services.

Individuals with Learning Disabilities, Asperger Syndrome and High Functioning Autism, were being pushed out of, or never seeing decent paying jobs that might have been available if not for the major shift away from manufacturing and their support industries to a service economy. They were not suited to the mega-agencies as the programs and staffing skills don't often match their unique capabilities and level of cognition. However left without adequate services they often took the Medicaid route in order to have some safety net.

see Employment on page 39

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Lynda Geller, PhD

Founder of Spectrum Services and Psychologist, lynda.geller@aspergercenter.com

Mary Riggs Cohen, PhD - Psychologist, mc@autismsrc.org
Dale Delarocca, BA - College Coaching, dalelarocca@gmail.com
Enid Gort, PhD - College Coaching, info@ejgcoach.com
Mitchell Nagler, MA, LMHC - Mental Health Counselor, mnagler@gmail.com
Aliza Rabin, MD - Psychiatrist, aliza.rabin@gmail.com
Shuli Sandler, PsyD - Psychologist, shuliw@aol.com
Ilene Solomon, PhD - Neuropsychologist, isphd@aol.com
Beth Yurman, PsyD - Psychologist, byurman@aol.com

David A. Cooperman, MD - Psychiatrist, dcoopermanmd@gmail.com
Valerie Gaus, PhD - Psychologist, gaus@optonline.net
Rhea L. Hooper, MA, CCC-SLP - Speech and Language Pathologist, rlooper@gmail.com
Stephen Migden, PhD, ABPP - Independent Educational Consultant, drmigden@verizon.net
Michele Robins, PhD - Neuropsychologist, robinsm@email.chop.edu
Leslie Sickels, MSW - Social Worker, leslie.sickels@gmail.com
Renee Soufer, MA, EdM - Psychologist in training, rsoufer@gmail.com
Jaime Black, PsyD - Post-doc, jaimeblackpsyd@gmail.com

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

Walking the Safety Tightrope: The Intersection of Law Enforcement and Loved Ones with Disability

By Bruce Handler, MD
University of Illinois at
Urbana-Champaign

The incidence of persons with Autism Spectrum Disorder has increased 4,000 percent over recent decades throughout the world. The chances of law enforcement encountering a person with a disability is 7 times more likely to happen compared to the general population. For those empowered to serve and protect the safety of all citizens in the community, often times law enforcement comes in contact unprepared and untrained to recognize the totality of situations involving those with special needs. This potentially can conclude with an unnecessarily tragic outcome. Realizing the importance of 21st century policing, over 450 jurisdictions throughout the United States, Canada, Great Britain, Israel and Australia have adopted and instituted Crisis Intervention Team (CIT) training for their officers.

Growing out of a series of bad outcomes in Memphis, Tennessee in 1988, the final one culminating in the death of an individual in crisis from mental illness by police, CIT was conceived. Through the cooperation and collaboration of law enforcement and the National Alliance on Mental Illness (NAMI), a weeklong, 40



Bruce Handler, MD

hour training program was developed to educate law enforcement. Acting as first responders and often skeptical initially, veteran police officers learn the signs and symptoms of those with developmental, physical and intellectual disability based on their observed behavior and circumstances. They learn to “stop, look and

listen.” Ensuring safety as the primary goal for the officer, for the person in crisis and any other citizens present, law enforcement is given the tools to recognize that the person’s actions may be due to disability rather than criminal in nature. Additional skills in de-escalation techniques: active listening, empathy statements and adoption of a calm tone and non-threatening body language increase the likelihood of a safe resolution and outcome for all.

Specific to persons with Autism, officers learn the spectrum of disorders including those who are non-verbal but responsive to non-threatening body language. One incident involved a child who had wandered and was located by an officer at a park and nearby pond. Unable to establish verbal communication, the child moved away each time the officer stepped toward the child. Seeing a ball nearby, the officer picked it up and tossed it toward the boy. The boy eventually returned the ball in the officer’s direction. After some time, the officer established the trust of the child and was able to coax him into the patrol car and safely return him to his home. Officers also gain appreciation for recognizing certain mannerisms, hand flapping, rocking, lack of eye contact and hyper- or hyposensitivity to external stimuli. They know to turn off their sirens and radios and anticipate interest in shiny ob-

jects like badges, handcuffs and weapons and take steps to discourage reaching or touching them. They also learn to ask for written identification or look for identifying information sewn in clothing or on shoes and shoelaces. Police learn more about the American with Disabilities Act and how some behavior may not be considered criminal within the parameters of their special needs. Important is the fact that persons with Autism can be unwitting perpetrators of crime. They can be a victim or witness to crime as well and police learn additional investigative tools to respond to those occurrences as well.

Included in the training is the opportunity to meet persons with disabilities, mental illness and substance abuse along with family members and community providers to put a “face” on those not in crisis and learn more about their stories, the impact of living with special needs. Critical to completion of the police training is the opportunity to “role play” with professional actors using their newly acquired skills in a safe monitored environment and be evaluated and critiqued by other veteran trained CIT officers. Up to 75% of those taking the training volunteer with no extra pay involved and do so usually because they have a loved one or know of someone with special needs.

see Law Enforcement on page 39

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

By Carrie Cariello



Being Jack's Brother

Every year I write each of my children a letter on their birthday and keep it in a small journal. These letters describe the person they are at that particular age; their likes and dislikes, favorite activities, and overall temperament. The following is an excerpt from the letter I wrote my oldest son this year.

Dear Joey:

You've just celebrated your 8th birthday, and it's been another wonderful year. We've watched you blossom into an avid reader (the Harry Potter Series), a somewhat interested baseball player (less dandelion-picking than last year), and a Lego fanatic (you just finished Hagrid's Hut).

You continue to handle the role as eldest of our clan with grace and ease. Each of your siblings, especially five-year old Charlie, competes for your attention and it's sweet to see you direct and manage them during play time. It's especially endearing to watch you with two-year old Henry, whom you've affectionately nicknamed Twubs. Although you crave quiet space amongst the madness of four sib-



Joey Cariello with younger brother Jack

lings, you work hard to maintain composure when your patience is tested (like the time Henry bashed Hagrid's Hut into pieces with Rose's mini saucepan).

You and Jack have a very interesting relationship and I've really enjoyed watching it over the years. As you learned this

year, Jack does have autism and it can make him somewhat challenging as a brother. We waited to tell you about Jack's diagnoses, simply because we didn't think it was information you needed or were ready to process. But I think you always knew he was unlike most in many ways.

One time in the kitchen we were all enjoying a family-favorite meal - breakfast for dinner - and you and Charlie were fooling around like the crazy boys you are. Ten minutes into it I lost my patience and threatened to separate you from each other. You protested that I couldn't seat you apart because Charlie was "best brother." Gritting my teeth I asked about Jack. Wasn't he a best brother too? You calmly replied, "No Mom, Jack isn't normal." What followed wasn't pretty, basically the Mama Bear in me started bellowing things like, "Why isn't he normal? Why?" Ever the cool cucumber you nodded your head down the length of the table in his direction, as he nonchalantly blew his nose into his pancake, rolled the whole thing up, and popped it into his mouth. OK, maybe not so normal.

Then one day it was official. You came home from Lego club and asked, "Does Jack have autism?" You went on to ask questions I'd been hiding in my heart for years. Would he always be autistic? Would he ever get married? Is that why he hates dogs?

A few years ago we accepted a much-anticipated invitation to your friend Josh's birthday party. As the time for the party drew near, you became alarmed when you saw me packing Jack's bathing suit for the

see *Brother* on page 37

Science from page 1

accountability is essential. It is necessary to have a sound framework of understanding, based on evidence-based scientific principles, to evaluate suggested interventions. We advise that, before accepting or recommending treatments, you become familiar with the rules of scientific method. The following terms and definitions could be a useful start to incorporate scientific thinking into your daily life:

Scientific Method - Drawing conclusions based on collection of unbiased data.

Faith - Belief, despite the absence of evidence.

Science - Belief based on evidence. It is risky to base treatment alone on faith in a method or a practitioner. Better to seek scientific evidence, and to understand the sharply defined rules of what constitutes scientific evidence.

Anecdotes, Unsupported Assertions, Testimonials - An anecdote is a story of an event, without evidence: "My son's diet is improving his social skills." An unsupported assertion is a statement of effectiveness without evidence: "This diet will improve your son's social skills." A testimonial is an anecdote without evidence affirming the worth of a treatment: "We went to Dr. X: his diet is improving my son's social skills." Anecdotes, Testimonials, and Unsupported Assertions, for good reason, have no place in the chain of scientific reasoning, and conclusions based upon them are not science but faith.

Placebo - A substance of no demonstrated therapeutic value used for the con-

trol group in controlled experiments to test the efficacy of another treatment.

Placebo Effect - The patient, treated with placebos but believing he is receiving valid treatment, reports and sometimes demonstrates improvement. Every medical intervention has some degree of this effect but the actual effect must be determined by controlled studies.

Double-Blind Study - This minimizes experimental bias and is considered the gold standard of controlled experimentation. A larger group is divided randomly into two groups: a control group receiving placebo treatment, and an experimental group getting the treatment to be studied. Double-blind means that neither the experimenters nor the subjects know which group is getting the placebo and which the experimental treatment, so any preconceived notions burdening researchers or their subjects cannot be a factor.

Through AHA Association's support programs, website (www.ahany.org) e-list and newsletter, we make every effort to provide objective, up-to-date, reliable, evidence-based information, and urge you to thoughtfully evaluate any proposed treatment.

Dr. Marvin J. Schissel is on the scientific advisory board of the National Council on Science and Health (ACSH), has written extensively on quackery for www.quackwatch.com and authored three books on a consumer's guide to dentistry. Patricia R. Schissel, LMSW is the Executive Director of Asperger Syndrome and High Functioning Autism Association (AHA), and on the Editorial Board of Autism Spectrum News.



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The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R)

A Scale to Assist the Diagnosis of Autistic Disorder in Adults 18 Years and Older

By Edward R. Ritvo, MD,
Riva Ariella Ritvo, PhD, and
Max Ritvo

The RAADS-R is an eighty item scale specifically designed to assist clinicians diagnosing Autistic Disorder (AD) in adults eighteen years and older. It contains a total of eighty questions. Sixty-four short questions identify symptomatic behaviors that are scored on a 4-point Likert scale that takes into account developmental factors (True now and when I was young =3, True only now = 2, True only when I was younger than 16 years old = 1, and Never true = 0). It also contains and sixteen non-symptomatic questions that are scored in reverse order (True now and when I was young =0, True only now=1, True only when I was younger than 16 years old =2, and Never true =3). These sixteen questions are identified on the scale by an asterisk next to their question number.

The RAADS-R was validated in an international study conducted at nine medical centers on three continents (North America, Europe, and Australia). Subjects included 201 Autistic Disorder adults and 578 comparison cases (276 who never had a DSM-IV TR diagnosis, and 302 who had a DSM-IV TR diagnosis other than Autistic Disorder). Results re-



Edward R. Ritvo, MD

vealed: Sensitivity = 97% (percent of false negative or missed diagnoses), Specificity =100% (percent of false positive diagnoses), Concurrent Validity = 96% when compared with another diagnostic instruments (ADOS Module 4, SRS), and Test Retest Reliability $r = .987$.

Detailed statistical analyses are contained in the articles cited below.

To administer the RAADS-R, a diagnostician reads each question to the subject and marks the answer sheet. This insures that the questions are understood, the answers are properly coded, and the score can be quickly determined. Most importantly, however, it gives the diagnostician a chance to identify and discuss specific symptoms during administration. The average time to complete and score the RAADS-R is thirty minutes.

A total RAADS-R score of 64 or higher is consistent with the diagnosis of AD, and supports a clinician's diagnosis. However, if there is difference between the clinician's diagnosis and the RAADS-R diagnostic assignment, the clinician's diagnosis should take precedent. This is because symptoms may be revealed only during an interview. Also, the RAADS-R standardization study reported that many AD subjects, particularly those in their late teens and early twenties, failed to acknowledge the presence of symptoms that their families said were present and which were readily observed by the diagnostician.

The RAADS-R is not copyrighted and the authors have no financial interests in this scale or its use by clinicians.

The RAADS-R is available online from Springer Link free of charge for appropriate clinical use at www.springerlink.com/

content/fhj14075h450547q/. It is available in print via this journal: Riva Ariella Ritvo, Edward R. Ritvo, Donald Guthrie, Max J. Ritvo, Demetra H. Hufnagel, William McMahon, Bruce Tonge, David Mataix-Cols, Amita Jassi and Tony Attwood, *et al* (2011). The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R). A Scale to Assist the Diagnosis of Autism Spectrum Disorder in Adults: An International Validation Study. *Journal of Autism Developmental Disorders* (in press).

A Swedish version is available at this journal: Lisa M. J. Andersen, Katharina Näswall, Irina Manouilenko, Lena Nylander and Johan Edgar, *et al.* (2011). The Swedish Version of the Ritvo Autism and Asperger Diagnostic Scale: Revised (RAADS-R). A Validation Study of a Rating Scale for Adults, *Journal of Autism Developmental Disorders*. In press (Published Springer Link, Online First™, 17 February 2011).

Edward R. Ritvo, MD is Professor Emeritus at the UCLA School of Medicine. Edward R. Ritvo MD is an internationally recognized medical expert, researcher and pioneer in the field of autism and Asperger's Disorder and co-author of the official diagnostic criteria in the DSM (Diagnostic and Statistical Manual of Mental Disorders). Much of what is known about these

see Scale on page 37

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Robin's Voice

A Resilient Mom's Commentary on Autism

Advice for Parents as they Navigate the Science and Services for their Children with Autism

By Robin Morris
Freelance Writer

There is a famous movie misquote: "Fasten your seat belts, it's going to be a bumpy ride." It is a chilling reminder that parents face, following the diagnosis of autism. It is a bombshell for most families, and this roller coaster has no navigation system. It is up to you as parents to move forward with practical purpose.

Given that I subscribe to the "I'm From Missouri" ethic, my proclivity for investigation remains tenacious and intact. When Willard Duncan Vandiver, the congressional representative from Missouri made this statement in 1889, he may not have realized the impact of his words. Whatever barriers or challenges that have blockaded my path, certainly have met with a "Show Me!" Parents of autistic children are so very vulnerable that we are often willing to plunge into any intervention. My one caution and caveat is that



Robin H. Morris

there is money in autism these days. Beware of snake oil, or quack remedies.

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

Fifteen years ago, when my Dad was succumbing to colon cancer, a well-meaning friend suggested we try shark cartilage. Given that our options were depleted and that we considered it a benign intervention, my father tried the pale cream-colored powder, stirred in a glass of orange juice. He quipped, "I'll just imagine these little sharks, like pacmen, destroying my cancer cells." He died a week later, from the cancer that monopolized his life for 7 years. No regrets about the shark cartilage, though, we smiled at his joke, and that was it.

So here we are, we parents of autistic children. My initial venture into the world of rogue intervention was when I packed

up our 4 year old boy with autism, and traveled to Montreal for auditory training. I had read *The Sound of a Miracle* by Anabel Stehle and we decided that once again, a benign procedure was a win-win situation. Our son wore earphones tied to his hat (because he tried to remove them) for 2 solid weeks. We returned to the US, without regret, but there were no whistles or bells that rang to say it worked. Ironically, another more pressing issue intervened. Our son developed a type of parasite condition that was so severe, it rendered him 24 pounds at age 5. The skeptics might now cry, "leaky gut syndrome, prevalent in autism." Nevertheless, he was hospitalized and a myriad of anti-fungal antibiotics were administered. He was denied all food by mouth, in order to determine cause. Miracle of miracles, whether it was the behavioral modification (no food) or auditory therapy or just fate, he uttered his first clear sentence: "I want spaghetti!" The parasite left the way

see Advice on page 39

Early Intervention from page 11

children connected and socialized with others, a defining stumbling block for children with autism.

We placed a heavy focus on the ability of toddlers to pay attention to other people's actions and communication behaviors and prepare them to respond and initiate with others in socially appropriate ways. This is critically important because it opens the door to ongoing learning opportunities for toddlers with ASD. When toddlers are attuned to people, people are more motivated to stay engaged with them. Additionally, children learn through imitating others. The ability to connect with peers through imitation can open the door to acceptance and being chosen as a playmate in the classroom or on the playground, for example.

We found that children in both groups showed improvements. However, the most significant finding was that the children who received the specialized socially-directed intervention developed greater socially engaged imitation, which increased from 17 percent of imitated acts being

paired with eye contact prior to the intervention to 42 percent at the end of the intervention. This skill was generalized, or carried over into "real life" outside the classroom, and maintained through the six-month follow-up. Similar improvements were observed in the group for initiation of joint attention and shared positive affect. Specifically, how frequently toddlers initiated joint attention more than tripled from pre- to post-treatment, and the shared positive affect more than doubled. Overall, the children receiving the socially-directed intervention made 10 months of non-verbal cognitive gains in only six months time. The second most significant finding was that toddlers in both groups made improvements in expressive language (spoken language), with the greatest gains occurring during the time that the intervention was taking place. These results indicate that the improvement was due to the intervention.

From this study, several very important findings have emerged. We have found that the degree of social impairments involving imitation, face-to-face emotion sharing and initiation of social communication are diminished through these spe-

cially-designed interventions. In addition, gains in language and cognitive skills also occurred for children enrolled in these intervention programs. Gains are strongest when an intervention is comprehensive, addresses multiple aspects of development, and when there is a concerted effort to improve social learning. Gains are also improved when parents consistently attend parent-training sessions. For best results, therapists must use a comprehensive curriculum and create learning opportunities that are meaningful and motivating for children. They must build on children's strengths, interests and existing knowledge. It is important to find creative ways to engage children with different types of toys and to help young children learn how to use toys together in meaningful ways (putting blocks in a dump truck, putting a spoon into a cup and "stirring"). Play and interaction routines should be established to help children predict what will happen and respond in appropriate ways. As children learn these routines, new twists in the action should be introduced in order to help children learn to apply their new skills in different ways. A continuum of adult-

imposed structure should be used in early intervention, such that children have opportunities for guided play and discovery within natural contexts as well as explicit instruction targeting isolated skills.

Through our research, the Early Achievements intervention model has been empirically-validated. This cost-effective model offers a combination of center-based and parent-mediated intervention. The model is novel in that it is anchored in the developmental sciences, yet integrates principles of applied behavior analysis. The unique combination of group and individual intervention in the center-based component offers children the opportunity to learn with and from peers, as well as to receive intensive, highly individualized intervention. We are hopeful that the socially-directed early intervention model can achieve similar social skills gains in older children.

For more information about the Center for Autism and Related Disorders at the Kennedy Krieger Institute in Baltimore, MD, please visit www.kennedykrieger.org or call (443) 923-9200.

Central Park from page 12

While Broadview has been the premier sponsor of YAI and Broadview Networks Central Park Challenge since 2008, the partnership between the two organizations extends beyond Broadview's corporate support. At Broadview Networks Farmingdale, N.Y., warehouse, individuals with disabilities work side-by-side with Broadview's

crew. Employees of The Corporate Source, a member of the YAI Network, are part of a team that configure, package and ship thousands of Internet protocol phones every month to customers all over the country.

"Our commitment to YAI goes far deeper than dollars," said Mike Robinson, Chief Executive Officer of Broadview Networks. "Putting our name behind a cause means enlisting the involvement of all the

people and organizations that make our company successful. In addition, through our partnership with the YAI Network and its agencies, we are committed to helping people with disabilities thrive in the community. The workers from The Corporate have truly become members of the Broadview family and their hard work and dedication are making a difference to our work processes. It is through programs such as

this that we at Broadview hope to make a positive impact on individuals and changes lives, one job at a time."

For more information about getting involved in next year's YAI and Broadview Networks Central Park Challenge on Saturday, June 2, 2012, call 1-877-YAI-WALK or email cpc@yai.org. For highlights of this year's Central Park Challenge, visit yai.org/cpc.

Parent Voices Drove Autism Certification Standards

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

“It was a VERY troubling message” says Paul Andrew, remembering what he heard from a group of autism parents, advocates, and providers about the state of social services for people with autism in 2005. And it moved him to action.

As Managing Director of Community Services for the accrediting agency CARF International, part of Andrew’s job is to monitor the medical and disability communities for emerging service issues which are in need of new accreditation standards. For any given service area, CARF standards provide a tool by which families can identify dependable service providers - and avoid ones who may be well-intentioned but insufficiently prepared.

But Andrew’s experience with the autism community was unique. “What surprised me most,” he says, “was the overwhelming emotions of the parents. They were tired. They were discouraged. Most of them had had divorces or family issues based on trying to work with this child. They lacked support. They were lonely. They were frustrated with the community.” The parents, he remembers, often broke into tears as they spoke.

But there was a problem - the parents and advocates wanted CARF to single out



Scott W. Standifer, PhD

autism for special consideration in its standards. That is not how CARF usually works.

Headquartered in Tucson, Arizona, CARF, International, (originally the Commission on Accreditation of Rehabilitation Facilities) is an independent, non-profit accreditor of health and human services. CARF certifies the quality of service providers in areas such as medical

rehabilitation, pain rehabilitation, vocational services, and pediatric specialty programs, among others. CARF accredits providers in 17 countries in North and South America, Europe, Asia, and Africa. The services endorsed by CARF touch more than 8.3 million people each year in more than 20,000 locations.

However, when CARF accredits an organization for employment and community services, it is usually NOT for services to one specific disability group. “In our manual, we just talk about services,” says Andrew. This means the accreditation standards focus on service categories that meet needs for a range of disabilities - categories like medication monitoring, assistive technology, employment transition, respite care, or community integration. “We have very few sections that say, ‘Oh, yes, this is for persons with spinal cord injury, or persons with a head injury,’” Andrew comments. Officially, Autism was a type of developmental disorder, not something that needed unique standards - it should be subsumed by the general categories.

Dr. Joel Smith, Executive Director for Autism Services Association in Wellesley, Massachusetts, argued that autism was different.

Smith is one of CARF’s field surveyors - the on-the-ground people who take the CARF standards manual and make on-site visits to assess a provider’s services. In and around Boston, if you apply for CARF ac-

creditation in employment and community services, the chances are Smith will be the one who shows up at your door. Smith and Andrew have worked together for years.

In 2000, Smith was appointed to the Board of Directors for the Autism Society of America. Soon after, Smith got an idea - CARF and the Autism Society could team up on national accreditation standards for autism. “If we could get standards for autism,” Smith says, “then parents would be able to go to agencies that were accredited in autism and get quality services. It could also be an impetus for private providers to attain accreditation so that they would be able to serve people with autism.”

It was Smith who first told Paul Andrew that autism deserved investigation for emerging service issues. Initially Andrew was a little skeptical of Smith’s request: “We thought, ‘Well, why can’t you just fold this into something else? Why wouldn’t it just sort of fit in as this or that program? But the argument from Joel was ‘We need to identify this as a special, growing concern, and we need to bring this to people’s attention.’”

Smith was persistent, raising the issues several times over the next few years. Then Andrew began to hear similar requests from CARF surveyors in Canada. Finally, he agreed to investigate and asked Smith to assemble the focus group in Boston.

see Standards on page 34

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Brain from page 10

temporal cortex were missing in the modules of autistic brains. This suggests that the normal molecular distinctions - the tissue differences - between these regions are nearly erased in autism, likely affecting how the brain works. Strikingly, among 174 genes expressed at different levels between the two regions in two healthy control brains, none were expressed at different levels in brains of people with autism.

An analysis of gene networks revealed two key modules of co-expressed genes highly correlated with autism.

One module was made up of genes in a brain pathway involved in neuron and synapse development, which were under-expressed in autism. Many of these genes were also implicated in autism in previous, genome-wide studies. So, several different lines of evidence now converge, pointing to genes in this M12 module as genetic causes of autism.

A second module of co-expressed genes, involved in development of other types of brain cells, was over-expressed in autism. These were determined not to be genetic causes of the illness, but likely gene expression changes related to secondary inflammatory, immune, or possible environmental factors involved in autism.

This newfound ability to see genes in the context of their positions in these modules, or pathways, provides hints about how they might work to produce illness, according to Geschwind and colleagues. For example, from its prominent

position in the M12 module, the researchers traced a potential role in creating defective synapses to a gene previously implicated in autism.

Follow-up studies should explore whether the observed abnormalities in the patterning of gene expression might also extend to other parts of the brain in autism, say the researchers.

Reference

Transcriptomic analysis of autistic brain reveals convergent molecular pathology. Voineagu I, Wang X, Johnston P, Lowe JK, Tian Y, Horvath S, Mill J, Cantor RM, Blencowe BJ, Geschwind DH. *Nature*. 2011 May 25. [Epub ahead of print] PMID:21614001

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).

About the National Institutes of Health (NIH): 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 the NIH website (www.nih.gov).

Lessons from Autism

By Kim Wilson Owens, LCSW
Parent

About 16 years ago an unwelcome guest came to live in our home. Our beautiful daughter Khery was diagnosed with autism. It (autism) has been her constant companion. Unwanted and merely tolerated by all of us in our family and our home. In the beginning, I had high hopes that this unwelcome visitor would leave our family and let us get on with our lives. But it has not gone away.

As I look back over the years of joy and sorrow since Khery was diagnosed, I have come to a number of realizations. These ideas are based upon my own experiences and those of our immediately family members (I present them in no special order of importance):

- The grief that has been experienced as a result of this diagnosis has been ongoing. It is intermittent and is felt anew each time a milestone is not reached. This feeling of grief is not of the same intensity or duration each time but it is recognizable as grief nonetheless. Several years ago Khery, had she been a neurotypically developing young woman, would have been graduating from high school and applying to college. That was not to be. Even though I have known intellectually for quite



Kim Owens with her daughter Khery

some time that college was not in her future, I did not experience grief related to this loss until her 18 birthday. At that time I felt the pain of this loss very directly. It seemed as we attended graduations and had the opportunity to visit colleges that I experienced a deep sadness directly related to the fact that Khery would never be a college student.

- Parents of children with developmental disabilities make excellent friends and have a wealth of information. They have been by far our best resource.

- Many well-meaning persons who make suggestions have no idea what they are talking about. Some of these people are very insistent. Perhaps Khery appears to them as a “spoiled” or poorly disciplined child. Learn to agree to disagree. Nod, say thank you and move away. This can be tricky if it is a family member.
- Do not expect everyone to understand your atypical child and his/her special needs. Do not be put off by this. Continue to advocate for your child regardless of the feelings of others

- Trust your instincts. They are often right even if you have less book knowledge and clinical experience than the _____ (doctor, teacher, lawyer, and therapist). Fill in the blank.
- Learn to multi-task at least some things. It may be the only way those tasks get done.
- Do not assume that no one understands or cares. Many people want to understand and wish to be helpful.
- You must learn your child’s particular language. (This includes nonverbal grunts, yelps and maybe screams and everything in between.) You are the chief interpreter to the outside world. It is important that other family members are also versed in this special language. Our 23 year old son is often better at this interpretation than my husband and I, although we are pretty good. We are fortunate to have several teachers who are pretty good as well. If you have a caregiver working with your loved one he or she too needs to understand this language.
- One day at a time. I borrowed this idea from the 12 step folks. Often the day has to be broken into smaller units like one morning at a time.

see *Lessons on page 37*

Games from page 18

in the brain by challenging players to perform a wide range of tasks that promote social perceptual skill development.

There are several elements that are central to good game design: clear level goals, adequate positive and negative feedback and reinforcement, proper game controls, interface design, sound effects, supporting music elements, story lines and graphical themes. In designing the game suite, the *FaceStation* team took into account the complex environment of a sophisticated video game, and took precautions to ensure that the games did not cross over the line from educational and enjoyable to over-stimulating. Other player-related factors taken into consideration were age, motor skills, cognitive abilities, and prior gaming experiences. Game structure (not overly complex, but not too simple) and game content (thematically appealing and therapeutically meaningful) were constructed to foster learning in the target population. These elements, which are responsible for grabbing the attention and maintaining the interest of a game player, are often overlooked by educational game developers who primarily follow the repetitive approach of practice-makes-perfect at the expense of fun.

The *FaceStation* platform consists of seven different, stand-alone computer games. The suite has been developed over a period of several years and was extensively pre-tested in a group of children with ASD using behavioral observations, questionnaires and eye-tracking technology. The main design goals for

each game were as follows: (1) to ensure a large amount of repeated face identity and face expression matching, (2) to use autism-specific motivational hooks and clear reward contingencies for correct perceptual matching, (3) to have graduated game levels with increasing complexity, (4) to emphasize positive social behaviors rather than violent themes, and (5) to ensure self-directed game play rather than intensive case management. Additionally, a *FaceStation* internet homepage was created to host the games, the gamers’ profiles, and leader boards for each game and for the game suite overall, so that game players are able to compare their own gaming progress and achievements to that of other players. The homepage also enables *FaceStation* researchers to automatically collect online gaming data and skill improvement for each player over the course of the intervention.

Research on the effectiveness of using health games to improve social skills is still in its infancy. CAR is currently using *FaceStation* in a randomized clinical trial with children and adolescents with ASD that is funded by a grant from the Robert Wood Johnson Foundation. By using a controlled design with randomization to either active treatment or a waitlist group (which provides basic experimental control), CAR can rigorously evaluate potential changes in social perceptual skills attributable to the gaming “therapy”.

CAR researchers are assessing a broad array of outcomes, including enhanced face recognition and memory tests. CAR is also using functional magnetic reso-

nance imaging (fMRI) to measure changes in neural activity and organization that should accompany skill-based learning. This project aims to obtain fundamental insights into reward processes that motivate and promote social learning. In doing so, CAR will begin to be able to measure the malleability of the brain during game-based learning and skill development. Given recent findings on the genetics and neurobiology of ASD, which spotlight basic mechanisms at the level of cell to cell communication in the brain and the “plasticity” of neuronal connections as important to the cause of ASD, a focus on skill-based learning research with neuroimaging should greatly enrich researchers’ understanding of how, why and when rehabilitation games are most effective. As new medicinal therapies are developed in the future, it seems clear that they will be effective only when paired with rigorous teaching regimes. A modern view of the neurobiology of ASD suggests that ASD results from biological “blockades” which impeded typical skill acquisition during development. There is hope that new medicines (e.g., oxytocin) can assist by reducing these biological blockades, thereby allowing for enhanced skill acquisition, but only in the context of appropriately structured learning experiences. Self-motivating game-based approaches to enhance social skills could have a very important role to play in this new science of autism intervention. *FaceStation* can serve an important heuristic function, as a model of how to achieve these gains, and when successful, this approach can be adapted to other domains of learning (e.g., communication and language).

CAR is currently enrolling children ages 8-18 into the intervention study to measure the efficacy of *FaceStation*. Children participating in this research will be asked to play a series of computerized games at home over a 12-week period. Participants will receive noninvasive brain imaging before and after the gaming intervention to measure changes in the brain due to enhanced social perceptual skills. Additionally, participating children will receive diagnostic, social, behavioral, intelligence (IQ) and other developmental testing. Parents will be asked to answer questionnaires over the phone, in person, and on paper. Individuals who take part will receive a comprehensive evaluation and report. There is no cost to participate. Families will be paid for their time and reimbursed for their travel costs.

Many other studies are also underway at CAR with the aim to better understand the causal mechanisms of autism spectrum disorders, and to determine which treatments are most effective for which children (based, for instance, on their genetic, neural, and behavioral profiles).

For more information about the *FaceStation* project and other research programs at CAR, contact 1-866-570-6524 or autism@email.chop.edu.

Gregor Kohls, PhD is a Research Post-Doctoral Fellow at the Center for Autism Research at The Children’s Hospital of Philadelphia. Robert T. Schultz, PhD is the Director of the Center for Autism Research. Please read more about them at www.centerforautismresearch.com.

Curriculum from page 20

prepare her son for weather alerts before he went to college. Because their state often had hurricanes, she wanted to make certain that Spencer knew what to do in case this disaster occurred. "What would you do if there was a hurricane near you? You know that many buildings have glass doors in them. Hurricanes can cause devastating damage, such as blowing out windows and patio doors," she asked. Nonplussed, Spencer replied, "Why, I'd put on my shoes." His mother was dumbfounded. Spencer, who had an intelligent quotient in the above average range and had Asperger Syndrome, had seen countless hurricanes in his life and she assumed that Spencer knew what to do. Why would Spencer put on shoes? Because he wanted to ensure that he did not step on broken glass when barefoot.

Workplace - Mastering the hidden curriculum in the workplace can present a major obstacle. Many assumptions are made regarding understanding the hidden curriculum in a place of employment because adults are assumed to be knowledgeable about workplace rules

Skepticism from page 24

persons with the disease. Gullibly accepting the false claim that vaccines cause autism may lead to parents not vaccinating their children, and such an action puts children at risk for serious diseases. Furthermore, accepting claims without critical evaluation will result in significant costs in money, time, and emotion (Zane, Davis, & Rosswurm, 2009). Gullibility is the opposite of skepticism, so demanding evidence of truth will naturally protect one from being gullibly accepting every claim.

Fourth, behave according to this rule: "In science, keeping an open mind is a virtue - just not so open that your brains fall out" (James Oberg; Sagan, 1996). In other words, be intellectually willing to accept any claim, but always seek for evidence and proof of truth before acceptance is granted.

Finally, find contexts that promote skepticism. For example, attending meetings of other skeptics and listening to podcasts such as *The Skeptics Guide to the Universe* will prompt and reinforce skeptical behavior (Loxton, 2009). Consider following some of the suggestions in *What Do I Do Next*, a call for action on the part of all skeptics (Loxton, 2009).

Although many organizations officially promote the use of science-based treatment and services for individuals with autism (e.g., Association for Science in Autism Treatment; American Academy of Pediatrics), antiscience, pseudoscience, and bizarre claims continue to gain influence in the arena of autism treatment and this is partly due to the lack of understanding of the nature of science (Lamal, 2009). Skepticism is a key concept in understanding how to assess the level of believability of something. Pigliucci (2009) goes so far as to believe that there is an ethical requirement to be skeptical and question the veracity of claims. He asserts that everyone must seek the truth and this requires a "baloney detection toolkit" (Sagan, 1996). This set of analytic and decision-making procedures and

and, if they are not immediately competent on these issues, it is expected that they will be mastered in a short period of time. For example, it is wise to be nice to your coworkers, especially your boss, whether you like them or not. And the term "lunch hour" may not refer to a clock hour.

Legal System - The hidden curriculum surrounding law enforcement and professionals and the legal system is quite complex and a misunderstanding of this system can have severe ramifications for individuals with autism spectrum disorders (ASD). Recently, an evening news show featured a young man who had been arrested. The young man, who was obviously distressed, was sitting in a room with three-way mirrors with a detective. The detective was questioning the young man - rapidly firing questions at him. At one point, the officer told the man that if he would confess, he could go home. At that point, the young man confessed to the crime, which it turned out he did not commit, so that he could go home as promised. Of course, that scenario did not occur and the young man was incarcerated (Myles et al., 2004).

rules allow us to, as best as we are able, ascertain what might be true and what does not have evidence of believability. The adoption of healthy skepticism will result in a more informed public, more informed decision making about claims and treatments for autism, and have the overall effect of the promotion of truth and validity to protect us from extraordinary claims that have little reason to be believed. Persons with autism will be the beneficiaries.

Dr. Thomas Zane is a Professor of Education and Director of the Applied Behavior Analysis Online Program at the Van Loan Graduate School of Endicott College. Dr. Zane earned his Bachelor's and Master's degree in psychology at Western Michigan University and his doctorate in Applied Behavior Analysis at West Virginia University. He has served as a Post-Doctorate Research Associate at the University of Massachusetts, Professor at Mount Holyoke College, and Johns Hopkins University Department of Psychiatry. He is a licensed psychologist in New York and Massachusetts. Dr. Zane has published in various journals and books, presented at regional, national, and international conferences, and been an invited lecturer in Ireland and the Republic of China. His research interests include teacher training, staff development, and evidenced-based practice in autism. As part of his duties at Endicott College, he offers a BCBA certificate program through distance learning.

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Teaching the Hidden Curriculum

Social skills are not skills generally acquired naturally by individuals with ASD. It is important that parents and professionals working with these individuals teach them the skills necessary to navigate the hidden curriculum. A safety net, the Power Card strategy (Gagnon, 2001), the Incredible 5-Point Scale (Burton & Curtis, 2003), and the one-a-day method are four instructional strategies that have been used to teach hidden curriculum skills to individuals with ASD. The following paragraphs outline these strategies.

Safety Net - One of the most basic instructional interventions for teaching the hidden curriculum to individuals with ASD is to assist them in designating a person with whom they have rapport or safety net who will provide accurate information, answer their questions, and model appropriate behaviors related to the hidden curriculum. The safety net could be different for each individual. It could be a family member, teacher or other school professional, caregiver, friend, or peer in the work force. Regardless of who becomes a safety net, that person should have the following characteristics:

- They have an understanding of the individual - their characteristics, their perspectives, their needs
- They are able to listen to the individual without judging or interrupting and then know when to offer advice
- They are able to use problem solving techniques
- They understand things that might trigger tantrums or rage for that particular individual.
- They are able to set boundaries when necessary.

The Power Card Strategy - The Power Card Strategy, developed by Gagnon (2001), uses a non-threatening, motivating hero from a child's special interest to provide a visual sequence that models appropriate steps for completing a social skill such as those found in the hidden curriculum. The Power Card strategy is composed in two phases. In the first phase, the parent or professional identifies a hidden curriculum skill that is challenging for a

see Curriculum on page 34

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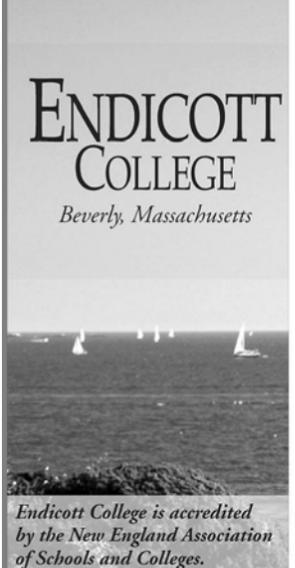
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tzane@endicott.edu or 978-998-7714

Harnessing the Power of Autism to Provide Vocational Opportunities to Adults with ASD in Software Testing: The Aspiritech Story

By Brenda Weitzberg, BA and
Moshe Weitzberg, PhD
Aspiritech

Our son's graduation in 2003 from a four-year university was a day of great joy and pride for the entire family, but it also left us with the sinking feeling of: "What's next?"

Our son had many areas of strength - he had taught himself to read at age three and had an extensive vocabulary - but also complex challenges, especially in the social and executive functioning arenas. These impacted his ability to be organized and planful, manage his time and priorities, and self-monitor. As a result, we were serving as his executive secretary, helping him to stay focused and organized!

Raising him had been a challenge. From age three to eight, we received multiple diagnoses including insufficient parental limits and Sensory Integration Disorder. At age eight he was diagnosed with PDD-NOS and only at age 14 (in 1993) did we first hear the term, "Asperger's Syndrome." There was absolutely no technology and very few resources at that time that could help him or us.

The end of formal schooling meant a drastic drop in services along with changes to daily routine and social oppor-



tunities. Much of his time was spent in front of the computer or TV. He also seemed to have a growing self-awareness of being different. As a child, we rarely knew how he felt, even when he had been bullied or when depressed or anxious. As an adult, the very same issues were exacerbated by his growing social isolation.

Finding a job for our son became a challenge. It also became evident that the rehabilitation system was not familiar with high functioning autism. Most of the jobs they found him were in retail, bag-

ging groceries and collecting carts; jobs not well suited to his social and motor skills. Understandably, fast-paced, high-volume retail stores valued employees that could easily move from task to task and multi-tasking was certainly not our son's forte! The high rate of manager turnover meant that, even if the first few supervisors were understanding and had been prepared by the job coach, their successors were not.

The current system provides job coaching for 90 days without long-term

follow up. Though our son typically required less time to learn a new job, he would have benefited from some ongoing support when misunderstandings or challenges in the workplace arose. For example, he excelled at cashiering only to be fired after two and a half years (by a new manager) because he lost track of time during mandatory breaks. Had the vocational counselor still been involved, this problem could have easily been resolved using a timer, watch or other cue.

Despite being "higher functioning," our son fell through the cracks as his impaired social, organizational and motor skills made him unfit for manual labor and his social demeanor made it impossible to get an opportunity at jobs that were more suitable to his intellectual abilities. We finally realized that we are setting our son up for a lifetime of continuous vocational failures and disappointments. Something had to be done!

In 2008, we founded Aspiritech, a non-profit with a mission to provide a path for high functioning adults on the autism spectrum to realize their potential through gainful employment.

We're thrilled with the results we've achieved so far and with how much our employees have accomplished. We've seen firsthand how the right environment

see Opportunities on page 38

Plan from page 23

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.

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 special needs child is no longer eligible for services from their local school district, the primary 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.) 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 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 benefits levels.

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 special needs child 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. A good place to start looking for such an attorney is the Special Needs Alliance, www.specialneedsalliance.org. There are different types of Supplemental Needs Trusts to consider and review with your attorney.

Advance Directives

Advance Directives allow a person to appoint someone to assist with financial and health care decisions if they are unable to themselves. The most common advance directives are Powers of

Attorney (financial decisions), Health Care Proxies, and Living Wills (medical decisions). Advance directives may also be an effective tool for the special needs child who does not meet the criteria for a guardianship (more fully discussed below).

Guardianship

Parents of a special needs child, or any child for that matter, are considered the natural guardians until the child reaches the age of 18. After 18 the child is emancipated regardless of their functioning level. Obtaining guardianship enables parents and relatives to ensure that they or others that they designate may act as advocates with legal authority and maximize all necessary and available supports and resources for the special needs child who requires some level assistance in managing their personal and/or financial affairs. In order to obtain guardianship, a court proceeding needs to be commenced. There are different types of guardianships, for example a guardianship that is plenary (covers everything), or one that is specifically tailored for the specific needs of the child (i.e., the child can take care of themselves in certain ways but needs assistance with certain aspects of their life). The guardianship that is right for your child can be determined with your special needs planning attorney.

Follow-Up

Once the above mentioned five tools are put into place, it is important to se-

lect a combination of resources that will ensure adequate funds for your child's lifetime, such as insurance, savings, investments, family assistance, etc. Your special needs planning attorney can work with insurance and investment professionals to facilitate this. It will also be important to review the beneficiaries of all "non probate assets" i.e., employer sponsored retirement plans, IRAs, KEOGHSs, life insurance policies, etc. Additionally, it is important to hold a meeting with all interested parties, i.e., the Guardian(s), all Trustees and Successor Trustees and all siblings; and any other interested relatives, to review the estate planning documents, and to discuss the plan. Finally, it is important to review all documents periodically, especially if the child's condition changes or the parents' economic situation changes.

There is nothing we hope for more than science to come up with a cure for Autism. Unfortunately, this has not happened to date. Thus, it is imperative that you plan for the worst, but continue to hope for the best. Not planning 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 regardless of what science finds. It is strongly recommended that you take advantage of the opportunity to plan while you are still able to do so.

Nothing in this article should be construed as legal advice. Please consult with an attorney regarding your own particular situation.

Standards from page 30

That first group of around twenty-five participants included parents, service providers, funding providers, representatives from the Autism Society, and other professionals. It also included Dr. David Holmes, long-time autism advocate and founder of the Eden Institute in Princeton, New Jersey. While Smith was mainly focused on adult employment, Holmes brought a focus on planning across the life span.

For Andrew, the meeting started off like many other focus groups he has conducted before: "You bring them in. You ask them, what kind of achievements or outcomes do you want for your children? What are some challenges in your life as parents? What are some of the challenges that your adult children have in getting their job and living in the community? You kind of put that all up as your starting point and you begin to kind of bring it forward into what we should be doing in the standards to try and accomplish the kind of services that people need and want."

But it didn't go the way other focus groups had gone before.

Andrew remembers, "These emotionally laden things came flooding out of the parents, often times crying – they needed these services, they had to have these services, their lives had been trashed, the other kids were falling behind or having trouble. It's very hard not to take it personally, after all, given our mission statement and given the emotion that came flooding out of these parents."

After the focus group, Andrew contacted other CARF surveyors in Florida and New Mexico and held similar focus groups there. The results were the same – there were not enough supports, the children and adults often did not meet qualifying criteria, the existing services were not adapted to the needs of people with autism, and most agencies were not paying attention.

The strong messages from the focus groups convinced Andrew and his colleagues at CARF that autism DID need separate standards. "It's our contribution," says Andrew, "A way to grab people's attention and begin to build the proper kinds of funding, expertise, training, and



States with CARF-accredited adult autism service providers

referral sources so people know where they can find the services that will help them live their lives."

Within a year, Andrew's office circulated an initial draft for review. They got back more than four hundred comments and suggestions, including comments from Japan, China, and Europe, and the U.S. In August, 2007, the final standards were released to the CARF website.

They are quite detailed: the adult services standards are twelve pages long, the child standards are seven. Among other things, the two standards require providers to:

- Promote early detection
- Empower families and individuals to make decisions
- Create and support lifelong self-advocacy skills
- Provide mentoring services for families
- Develop lifelong supports and community resources for persons and families
- Increase social contacts and support communities

- Network with governmental, educational, employer, and other community resources
- Promote research-based therapies with peer-reviewed track records
- Train staff on the unique features and needs of people with autism
- Facilitate transitions from school to successful employment and community living supports
- Provide individualized, comprehensive life planning, based on the preferences and needs of the individual
- To be accredited, an organization must apply these standards in their services for at least six months

As of early 2011, CARF had accredited 9 child autism service providers in the US across 6 states (4 in Canada) and 14 adult autism service providers in the US across 10 states (4 in Canada). The CARF website (www.carf.org) provides a search tool to locate these organizations. (Note: some organizations providing autism ser-

vices are accredited under other CARF standards and are not yet listed accredited for autism-specific standards.)

Smith says that, although the collaboration between CARF and the Autism Society has not fully developed as he hoped, the standards are a major step forward: "It's not a great feeling to go to a provider and say, 'Can you serve my son?' and they reply, 'We really don't know anything, but we'll try.' That doesn't instill a lot of confidence in parents. Now, at a number of places I have gone to, they actually use the standards as a guide for their programming."

Andrew says he, too, is pleased with the standards. In particular, he is encouraging families and individuals to use the standards as a benchmark against which to measure their local service providers and start conversations with providers. It is important to remember that a service provider which lacks accreditation does not necessarily lack commitment or quality. It just means individuals and families may have to do some extra research on their own to ensure they get quality services. "If there's anything that I hope the standards will do," Andrew says, "It is to result in those families being able to mentor each other, develop supports with each other, and help the families impact their communities."

The autism standards are included in CARF's *Employment and Community Services Standards Checklist*, available for \$50 at www.carf.org.

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.

Curriculum from page 32

child or youth with ASD. They then develop a scenario in which the individual's hero (i.e., Spiderman) engages in the appropriate steps to complete that skill. After the scenario is introduced to the child or youth, he is given a power card, the size of a business card, with a visual and the steps for completing that difficult skill.

The Incredible 5-Point Scale - The Incredible Five Point Scale was created to assist parents and professionals in making behaviors more concrete for individuals with ASD by breaking them down into sequential, understandable parts (Buron & Curtis, 2003). This scale allows individuals to recognize stages in their responses to situations with the ultimate goal of learning to increase self-regulation, thus resulting in more appropriate responses to situations.

One-a-Day Method - This strategy involves introducing one hidden curriculum item each day to the individual with ASD. In the general education classroom, the teacher can begin the day by writing a hidden curriculum item on the whiteboard

and briefly discuss it with the entire class. All learners can benefit from the hidden curriculum; however, it is essential for individuals on the spectrum. At home, a caregiver can discuss one item at the breakfast table, during bedtime routine, or in the car running a regularly scheduled errand.

Summary

The hidden curriculum, an area often neglected in the instruction of children and youth with ASD, is essential to life success. A myriad of easy-to-use strategies, including using a safety net, Power Card strategy, the Incredible 5-Point Scale, and the one-a-day method can help make learning elusive hidden curriculum items motivating for individuals on the spectrum.

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Brenda Smith Myles, PhD is a consultant with the Ziggurat Group. Dr. Myles is the recipient of the 2004 Autism Society of America's Outstanding Professional Award and the 2006 Princeton Fellowship Award. She has written numerous articles and books on Asperger Syndrome and autism including Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns (with Southwick) and Asperger Syndrome and Adolescence: Practical Solutions for School Success (with Adreon). The latter is the winner of the Autism Society of America's Outstanding Literary Work. Brenda has made over 500 presentations all over the world, written more than 150 articles and books on autism and Asperger Syndrome, and served as the co-chair of the National ASD Teacher Standards Committee. She is also on the executive boards of several organizations, including the Organization for Autism Research and Maap Services Inc. In addition, she was recently acknowledged as the second most productive applied researcher in ASD in the world in a recent study conducted by the University of Texas. You may contact Dr. Myles by email at brenda_myles@mac.com.

A Review of Autism Research

Real-World Effectiveness of Early Teaching Interventions for Children with Autism

Reviewed by Kathleen Moran, MA
Caldwell College

Although many educational programs have been developed for children with autism, few studies have compared the effects of different programs. This study examined outcomes for children with autism in three community-based programs in the United Kingdom: a special nursery program, portage (home visits to conduct play sessions with the child and provide training to parents), and applied behavior analysis (ABA).

What Did the Researcher Do?

Fifty-three children with autism between the age of 2 and 4 years old

entered one of the three programs, depending on what was available in their area. Children receiving ABA treatment received about 30 hours a week under trained supervisors who were Board Certified Behavior Analysts (BCBA). Sessions were 2-3 hours in length and took place in the home using one-to-one teaching. In the special nursery program, children attended a class of six to eight children taught by specialist in special education. Most teaching was done in small groups and the average amount of treatment hours per week was 13. Portage was a low intensity program that involved teaching sessions with the child in the home for 40-60 minutes per day and parent training sessions weekly or every other week.

What Did the Researcher Find?

After eight months of service, students who received ABA had significantly larger gains in educational achievement than students in the other two groups and significantly outperformed the portage group (though not the special nursery group) on measures of intellectual functioning and adaptive behavior. Students in the portage group did not show gains on any measure and had the least favorable outcomes overall.

What are the Limitations and Strengths of the Study?
What do the Results Mean?

This study showed that ABA was par-

ticularly effective for teaching educational skills and that both ABA and special nursery classes had a greater impact on intellectual and adaptive functioning than portage. The biggest limitation is that groups were not randomly assigned. The study also did not focus on how well the interventions were delivered or what aspects of the programs were responsible for the children's improvement. Overall, however, the study provides important information about the comparative effects of different educational programs.

Reed, P., Osborne, L. A., & Corness, M. (2007). The real-world effectiveness of early teaching interventions for children with autism spectrum disorder. *Exceptional Children*, 73, 417-433.

Change in Autism Core Symptoms with Intervention

Both parents and therapists are forced to consider many different treatments for a child with autism, and finding the right one may be critical. This study compared two treatment approaches: Applied Behavior Analysis (ABA) and the Eclectic-Developmental (ED) approach. The ABA approach used in the investigation involved 35 hours per week of intervention that focused on one-to-one teaching in small steps, using repeated opportunities and systematic reinforcement, with the aim of addressing the main deficits in autism. ED was based primarily on developmental interventions such as the Developmental Individual-Difference Relationship (DIR) and focused on teaching imitation and social skills. It also included a

variety of other individual therapies (speech, occupational, etc.) and small group instruction. The amount of intervention varied across children in ED.

What Did the Researcher Do?

Thirty-nine preschool-age children with autism participated in the current study, including 19 in ED and 20 in ABA. Children were tested on measures of cognitive ability and autism severity when they entered the study and again after one year of treatment.

What Did the Researcher Find?

Although there were no significant differences between the groups prior to

intervention, there were major differences after treatment: the ABA group made greater gains in cognitive ability and reductions in autism severity than the ED group. This pattern was found both for children who were higher functioning at pretreatment (IQ above 80) and those who were lower functioning at pretreatment (IQ below 80).

What are the Limitations and Strengths of the Study?
What do the Results Mean?

Changes in cognitive ability and autism symptoms were more apparent with ABA treatment than ED. Although many previous studies have shown that early intensive ABA improves cognitive

skills, this was one of the first to show that this intervention also reduces autism severity. The study also confirms findings from previous studies indicating that ABA may produce more improvement than eclectic approaches. However, the study had a number of limitations. For example, cognitive ability was assessed for only some children in the study. Also, the amount of intervention in the ED group was not clearly specified but was probably less than in the ABA group.

Zachor, D. A., Ben-Itzhak, E., Rabino-vich, A. L., & Lahat, E. (2007). Change in autism core symptoms with intervention. *Research in Autism Spectrum Disorders*, 1, 304-317.

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

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

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

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

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

For further information contact the facilitators:

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

Dates for 2011: 9/25, 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

Coping from page 24

this population how to apply social communication skills within the social world, but also how to analyze and think about why social communication is necessary in their own lives.

A specific treatment program that promotes this goal is Social Thinking® (Winner 2000, 2002). SLPs working with this program will target skills such as perspective taking, nonverbal communication, and social interaction by exploring why these skills are important to the specific client. They provide ample opportunities for their clients to practice these skills in a variety of activities and environments.

Social Thinking starts by breaking down abstract concepts into smaller, more concrete pieces. For example, the concept of listening is taught through use of concrete vocabulary such as listen with our eyes™, listening with ears, and body is part of the group™. These are taught individually using multiple modalities such as discussions, visual stories, role-playing, and self-monitoring via video. While clients are building their social thinking vocabulary, they are taught to understand how these concepts are linked and why they are imperative for social success. Clients directly learn how their social behaviors impact the thoughts and feelings of others. They then learn why and how they can modify their behaviors (verbal and nonverbal) to allow others to think and feel positively about them. This program does not teach discrete social skills using behavioral methods like reinforcement. Instead it teaches clients the core skills required to explore the intentions and reactions of others across situations.

A recent research study targeted how the Social Thinking program could facilitate social communication and interaction skills in six 9-11 year old boys with AS and HFA (Crooke, Henrix, Rachman, 2007). Participants were taught the Social Thinking Vocabulary of expected and unexpected behaviors

(Winner, 2002). The boys participated in 60 minute group treatment sessions across 8 weeks. They were directly taught how their verbal and nonverbal actions have an impact on the thoughts and feelings of others. Other sessions targeted whole body listening; how to create social files to remember information about people, and filtering their comments. During four generalization sessions, the participants were rated on: expected behaviors (on-topic remarks, maintaining an interaction through single-word comments, initiating an interaction with a question or comment, and listening with eyes) and unexpected behaviors (negative or off-topic comments, perseverative topics, talking to self/mirror, and random body movements). Results demonstrated significant positive changes in the use of expected behaviors, even though these discrete skills were not directly targeted! Participants were also able to demonstrate the skills during real-life interactions.

Incorporating Cognitive Behavioral Therapy (CBT)

Not only do social skills deficits make it difficult for youth with ASDs to understand the thoughts and emotions of others, they also contribute to difficulties understanding and interpreting one's own thoughts and feelings. These deficits in turn can lead to difficulties with modulating emotions and behavior. Further, coping skills, or our ability to manage challenging life situations, are learned socially, most often in ways that are not explicitly taught. Therefore, many high functioning youth with ASDs struggle with experiencing negative thoughts and feelings without possessing the skills necessary to problem solve and cope with such situations, leading to significant mental health concerns.

Cognitive behavioral therapy (CBT) is a structured and goal oriented form of psychotherapy that has a large evidence base. CBT was initially developed for the treatment of depression but has been

successfully adapted for the treatment of a wide range of issues, including anxiety, social skills deficits, and anger management. Although originally developed for adults, CBT has been shown to be highly effective in the treatment of children and teens. CBT focuses on the thoughts, feelings, and behaviors that contribute to an individual's distress. CBT teaches children and teens to develop more effective coping skills through exploring the connection between thoughts, feelings, and behaviors. Within a CBT framework, a therapist can also target social skills deficits by directly teaching social norms and expectations as well as strategies for successful social interactions and relationship development. The targets of CBT as well as the structured nature of the approach, allow for effective adaptation for individuals with autism spectrum disorders. Several studies as well as anecdotal evidence support the use of cognitive behavioral therapy in autism spectrum disorders, though to date most of the research has focused on addressing anxiety (Reaven et al., 2009; Wood, Drahota, Sze, Har, Chiu & Langer, 2009; Sze & Wood, 2007; Gaus, 2007; Anderson & Morris, 2006).

The modification of CBT for use with an individual child with an ASD requires an initial assessment of the individual's particular strengths, weaknesses, interests, and preferred learning style. For example, many individuals with ASDs report that information presented visually is easier for them to process and retain. The CBT approach typically utilizes visually presented information and worksheets and these tools should be emphasized when working with children with ASDs. Additionally, a child's special interests may be used to increase motivation and facilitate the therapeutic process. When conducting CBT with youth with ASDs it is important to adapt the components to best fit an individual's needs based on a comprehensive understanding of the individual's cognitive and developmental level, areas of strength and weak-

ness, preferred learning style, interests and presenting difficulties. These factors help to determine where therapy needs to begin and how to best teach new skills, as well as set initial goals.

A randomized, controlled trial of individual CBT to target anxiety in children (ages 7-11) with ASDs provides an example of how treatments can be modified and the utility of CBT for children with ASDs. The researchers modified and augmented a standard CBT intervention for the treatment of anxiety disorders to both accommodate and intervene on adaptive and social skills deficits specific to the ASD population (Wood et al., 2009). The core CBT interventions included coping skills training and in-vivo exposure to feared stimuli. Modifications were made to the existing curriculum by using specific interests to teach therapeutic concepts and providing reinforcement throughout the intervention. Additional modules were added which provided specific social skills instruction and focused on building independence in self-help skills. The researchers compared children who received the modified CBT curriculum with wait list controls (N=36). After 16 weeks of treatment, 78.5% of children who had received the intervention showed significant improvement, whereas only 8.7% of children in the wait list group showed improvement.

The Power Combination

For individuals with ASDs, the power combination of CBT and Social Thinking® facilitates the development of both social skills and adaptive coping skills. Together, these strategies improve the ability to modulate emotional reactions, facilitate social communication and interaction, and reduce depressive and anxious symptomatology. By working collaboratively as well as modifying strategies to best suit individual needs and abilities, psychologists and speech language pathologists can together best meet the therapeutic needs of bright, verbal individuals with ASDs.

Assisting from page 14

later age. Also, children of minority race and ethnicity receive a different mix of services compared to Caucasian children. Lower parental income decreases the likelihood of accessing a developmental pediatrician and speech/language therapy (Levy et al., 2003; Mandell, Listerus, Levy, & Pinto-Martin, 2002). Moreover, lower income families tend to use fewer information sources and are less likely to attend autism group meetings (Mackintosh et al., 2006). Factors posing a challenge to accessing services include: a child not being covered by public or private insurance; older children (Green et al., 2005; Kraus et al., 2003); and families living in rural areas (Thomas, Ellis, McLaurin, Daniels & Morrissey, 2007). In addition, increased levels of parental stress (Tobing & Glenwick, 2002), not subscribing to a major treatment approach, and lower levels of parental education make access to quality services less likely (TEACCH: Marcus, Garfinkle, & Wolery, 2001).

So how can the research community and autism experts assist parents in overcoming challenges in obtaining accurate information about autism and in accessing

evidence-based treatments? The logical place to begin is following diagnosis. Providing parents with assistance in sifting through the information they are accessing and also in forming support networks with other parents can be extremely valuable, as are developing programs to bridge the gap between the doctor's office and the autism community. The University at Albany's Center for Autism and Related Disabilities (CARD) has recently received a grant through the Office of People with Developmental Disabilities to implement a parent education program to meet this need. The program is offered at no-cost to families of young children recently diagnosed with ASD in the Capitol Region. The goal of the program is to offer accurate evidence-based information to parents in a timely manner (within 6 months to one year following diagnosis) on a variety of important topics such as how to choose treatment, medical/developmental issues, accessing resources and living with ASD. The program is delivered in a group format and sessions are led by both a clinical psychologist from CARD and a nurse clinician from CapitalCare Developmental-Behavioral Pediatrics. Program format was

selected to assist parents in deciphering information they are accessing from various sources (i.e., pediatrician, autism community, internet, etc.). Preliminary data on parents who have completed this program are positive; parents appear to be gaining knowledge about ASD and at the same time reducing their stress levels and improving their family's quality of life.

Assisting parents with obtaining accurate information following diagnosis is only one part of the battle. Autism professionals and researchers need to work with parents to overcome common barriers to accessing science-based treatment, particularly in families with lower socioeconomic status and families of minority race and ethnicity. Providers of evidence-based treatments need to reach out to these families by offering programs at no- and low-cost, and by providing stipends for access to transportation and/or childcare. In addition, the use of distance learning and telemedicine has promise as a solution to reach families that may not otherwise be able to access services. More and more families are using the internet as a quick and readily available means to find information and complete activities in their busy lives. A

recent study suggests that the majority of all households own a personal computer (88.9%). In addition, it is encouraging that internet access is available in the homes of most families (81.4%), including 60% of families with an annual household income of \$10,000-\$25,000, and 70% of families with only a high-school education (Carroll, Rivara, Ebel, Zimmerman & Christakis, 2005). Although the rapid increase in accessibility and use of technology can make it more difficult for parents to sort through information, it also opens the door for the scientific community to bring cutting-edge science-based treatments that were previously available mostly to families in city centers or university towns, to a more diverse group of children with autism spectrum disorders.

Kristin Knapp-Ines, PhD, BCBA is Research Scientist, Melissa L. Rinaldi, PhD is Research Coordinator, and Kristin V. Christodulu, PhD is Director at the Center for Autism and Related Disabilities at the University at Albany. To learn more about the University at Albany Center for Autism and Related Disabilities, please visit their website www.albany.edu/autism.

Brother from page 27

water slide. "Please, mom, can't he stay home?" I explained that we were allowed to bring siblings and Jack loves parties (and Daddy wanted to take a nap with the babies for the afternoon). You complained that I would "start talking to the other moms and you won't watch him, Mom. You won't!" (Note for future, young lad: I might have relented if you hadn't challenged my parenting. I dug my heels in.) Of course I would watch him! I'm his mother! Fast-forward to one hour later when I was relaxing with some other parents and looked up just in time to see Jack scale the large water slide sans bathing suit. Your angry glare was not lost on me.

One time I asked you if you ever felt embarrassed by Jack at school, and I braced myself for your answer. Would it be the time he held up the entire bus, kicking and screaming because he didn't feel like getting on? Or maybe the day he whirled through the school-wide book fair like a tornado? Perhaps it's Jack's latest habit of asking everyone what color their shampoo is. You thought for a minute and said yes; sometimes you are a little embarrassed by something he does. As the pit in my stomach grew you casually explained you wished he wouldn't give you such a huge hug and kiss whenever you passed each other in the hall because it made your friends laugh.

I know it can't be easy to be Jack's brother. It can't be easy to have a sibling who has a breakdown at the mere sight of a four-legged animal, or greets you at the end of the drive-



way after school with only his underwear on screaming the lyrics to Michael Jackson's "Man in the Mirror". Although I know you suffer to some degree because one of your siblings has autism - yes, Disney World is on hold until Jack gets a grip on people in costume - I'm confident there is a flip side to our family's dynamic for both of you.

For starters, I don't feel sorry for you because you have a brother with autism. (You're talking about the same mother who refuses to buy you a Nintendo DS or whatever that thing is because I gave you siblings to play with. I'm not a softie.) Jack brings a richness to your life that all those so-called normal families miss out on, and you are learning as much from him as he from you. Because of Jack, you are learning how to anticipate other's

needs before your own - like warning us when a dog is approaching the bus stop - and how to communicate more creatively. For the longest time you would come to me to tell Jack things or ask something, now we're at the point where you know how to elicit answers from him. ("Jack, look at me. Look in my eyes. Now where did you hide my gum?")

Nothing gives your father and me more pleasure than to hear the two of you converse, play a game, or make mischief together. Last week Jack asked me what he should do if "my friends are mean to me," referring to some kind of game at lunch time. Without any cue from me, you hopped off your stool, went over to him and at eye level explained the type of game the kids were playing in the cafeteria and how to avoid their taunting.

Just this afternoon we were preparing to head out and see Kung Fu Panda 2, and Jack suddenly refused to go. I was astounded - he loves movies - but you explained he doesn't like the main character, Po because he's scary. I turned and asked him if this was true and he said "Yes, Po scares me. I'm staying home." Sometimes you understand him better than I do, simply because you're his big brother.

And Jack benefits from you. Without even knowing it, you push him to be a better version of himself all the time. With your example, he works hard to communicate at your level and achieve the goals you've accomplished. I don't think we can fully understand the importance a boy barely a year older plays in Jack's development, but I'm certain it's nothing but positive. The evidence is the love in his eyes and those big embarrassing bear hugs at school.

I wonder if one day you're going to look back on your childhood with Jack and feel bitter, like you were shortchanged in some way. But I doubt it. I think you'll appreciate the value of Jack's brotherhood as you continue to grow your relationship and mature together. He may not be "normal," and he may like a certain flavor of pancake, but he's making each one of us a better person in his own way. On behalf of Jack, I'd like to thank you for being such an extraordinary brother - I know if Jack could, he'd thank you himself.

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

Trust from page 19

professional will take into consideration additional matters such as:

- Protecting the parent's or guardian's ability to fund the trust
- Balancing their concerns for the individual with special needs along with the financial goals for the rest of the family.

When thinking about funding a trust, it's

important to include the financial goals of the entire family in addition to those for the dependent with special needs. An experienced financial representative will take a holistic approach to your planning to ensure your ability to achieve your goals for your loved one with special needs in addition to planning for your own retirement, establishing income protection and perhaps college funding in situations where there are other children to consider.

It's not surprising that most parents or guardians of dependents with special needs are challenged to find the time to

focus on their own needs or those of the rest of the family. By working with an experienced financial professional you can make an important difference in how you map out a future of financial security for your entire family including your loved one with special needs.

The fact is, when you overlay a plan for funding the long-term financial security of someone with special needs, virtually everything and everyone is affected.

This article prepared by Northwestern Mutual with the cooperation of

Stephen A. Ehrens. Stephen A. Ehrens is a Financial Advisor with Northwestern Mutual Financial Network 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.nmfn.com/stephenehrens.

Scale from page 28

disorders today is based on his painstaking research and groundbreaking discoveries.

Riva Ariella Ritvo, PhD is a clinician and a biomedical researcher specializing in children and adults with Asperger's and Autistic Disorders. She was the director of the Ritvo Clinic

and is clinical instructor at the Yale Child Study Center at the Yale University School of Medicine. Max Ritvo is attending Yale University. Max is a co-investigator on the inter-

national multi-center RAADS-R study. He was a co-investigator and co-author on the published RAADS articles in JADD and Comprehensive Psychiatry journals.

Lessons from page 31

- A good sense of humor goes a long way. We love to laugh and Khery has a great sense of humor. Being able to laugh has helped us survive many near disasters.
- Accept help whenever and wherever you need it. Find a knowledgeable behaviorist, psychiatrist, medical doctor, social worker, lawyer and other therapists to be a part of your team.
- Take time for yourself. Nurture the physical, emotional and spiritual self. This is advice that every care giver needs to hear. But it is very difficult to put into regular practice. Prayer, meditation, yoga and massages work wonders. There are cds and videos that make it easier to do it yourself. Whenever I can I work self-care into my schedule.

- Find a "joy buddy" or two. There needs to be someone who makes you happy, can make you laugh and is available to listen when you need it. This can be your spouse but does not have to be. He or she may benefit from a "joy buddy" too.
- Acknowledge that I view the world differently. My daughter most certainly does. It may get us called weird or unusual but we have learned the value in seeing things from a slightly different perspective.
- Prioritize. Learn to "let go" most household chores, and just about everything else will wait.
- Life is a little bit easier if you always make provisions for plan "B". When our children were young we learned to have several diaper bags packed and ready to

go. Though we no longer need diaper bags, the same mentality works here. Each ready to go bag needs to have items that will come in handy if we are away from home unexpectedly and /or do not return home as quickly as planned. Since our bag always contains electronics of some sort, batteries are one essential item in our ready to go bags.

- Make time for your spouse. The stress and challenge of parenting a child with autism can be lethal to marriage. Cry on one another's shoulders. Laugh, love and work together.
- Accept your role as doctor, lawyer, teacher and chauffeur. This is not to imply that I have more knowledge than anyone who has been professionally trained in any of those positions. I do

have expertise, however, which will aid any of these genuine professionals in their work with my family.

- My job description as parent, includes the possibility of being kicked, scratched, hit, bitten and spit upon (This is not a complete list). This can occur whether your child is 3 or 33 years old.

Khery is not an autistic girl. She is a young woman who is diagnosed with autism. I like this description of our daughter far better than calling her autistic. In 16 years I have learned that she is much more than an autistic girl. She loves to travel, has a wonderful singing voice and enjoys the pool. She is still growing and learning and showing us who she is. Autism does not fully explain who she is. This is my greatest realization.

Positive from page 16

team will develop a “behavioral intervention plan” (BIP) for the child, which will include positive strategies to address the behavior. The BIP can include a variety of program accommodations, modifications, supports, and services to improve the child’s behavior. The BIP should be designed to accomplish four outcomes: (a) improve environmental conditions to prevent problem behaviors; (b) teach the student new skills to enable the student to achieve the same function in a socially appropriate manner; (c) reinforce desired behaviors, including newly-taught replacement skills; and (d) use strategies to defuse problem behavior effectively and in ways that preserves the student’s dignity” (Education Law Center, 2008).

Applied Behavior Analysis (ABA) is an evidenced-based treatment for improving the functioning of children diagnosed with autism. It addresses the core deficits of ASDs including verbal and non-verbal communication, social interaction, restrictive repetitive behaviors, inflexibility, daily living skills, and peer relationships to name a few. ABA has been successfully used for over 30 years. Today, the techniques and strategies of ABA have created a new look for behavioral interventions and the treatment of autism in homes, schools, and community settings.

Today, Applied Behavior Analysis (ABA) is supported by research as being

effective in increasing social competencies of individuals diagnosed with Autism and behavioral challenges. ABA can modify behavior through the processes of assessment, intervention, data collection, and responsive programming.

ABA is characterized by more naturalistic techniques whose emphasis is making meaningful changes in the lives of individuals. More recently, there has been a trend to move away from using highly structured and rigid environments towards natural settings (home, school, community). ABA interventions are designed to not only change the behavior of the targeted individual, but also changes the behaviors of those in direct contact with the individual (parents, educators, peers). Naturalistic methods of ABA that incorporate other individuals include modeling, incidental teaching (IT), pivotal response training (PRT).

Modeling is valuable technique if an individual is capable of imitation. It can be useful in the initial phases of instruction when a skill is just being acquired. A significant amount of literature exists supporting the role of peer models and their ability to bring about socially appropriate behaviors in children with autism.

Incidental teaching (IT) methods can be used in the natural environment to help a child expand their verbal repertoire. Initiations put forth by the child are met with response that typically requires an additional

interaction, prior to being reinforced with the desired item.

Pivotal response training (PRT) is characterized by a set of instructional strategies that are brief, specific, and focus on activities chosen by child. The method also utilizes contingent reinforcement directly related to the desired behavior, and attempts at the desired behavior. PRT has recently been shown to cause significant improvement in the communication and interactions of toddlers.

Innovative uses of technology are a “new look” in the treatment of autism. One such device Technology Assisted Classroom Teaching (TACT) and Technology, Observation, and Parent Support (TOPS), developed by the Center for Neurological and Neurodevelopmental Health (CNNH), located in Gibbsboro, NJ, is a remote behavior capture system. The system allows access to professional support and expertise.

This technology utilizes a small camera and computer to efficiently record target behavior, antecedents, and consequences. Behavior and teaching can be viewed in real time over Health Insurance Portability and Accountability Act (HIPAA) compliant Internet portals. Behavior can also be captured and reviewed at a later date by a Board Certified Behavior Analyst (BCBA) or other clinicians if needed.

The technology approach reduces reactance effects and distractions of an extra observer in the physical environment. It is

cost effective, as there are no travel expenses, or expenses of a consultant traveling to the setting when the target behavior may not occur. TACT/TOPS also allow for regular data collection and feedback to foster education, progress, and success.

Techniques such as direct observation, antecedent-based strategies (what to do before the behavior occurs), modeling, shaping, use of peers, positive behavior supports (visuals, incentive systems), and functional communication interventions foster natural, practical learning across settings. Emphasis is placed on utilizing the individual’s preferences and activity choices. Focus on adaptive and functional skills aide methods in generalizing across environments and individuals.

Prior to understanding the practical uses of ABA in treating autism spectrum disorders, it is important to understand what constitutes normal and aberrant behavior, as well as what behavior is exactly. Behavior can only be exhibited by living organisms and provides a function such as: 1) attention, 2) access to preferred items/tangibles, 3) escape, 4) avoidance, and 5) automatic reinforcement (an internal reinforcer).

Laura Henderson, MA, BCBA and Nicole Pellicciari, MS, BCBA are Behavior Analysts at the Center for Neurological and Neurodevelopmental Health. For a list of references from this article, please contact Laura at lhenderson@thecnnh.org.

Undiagnosed from page 10

prevalence of ASD among the total study population was 2.64 percent. Among the children attending regular schools, the prevalence was 1.89 percent and boys were 2.5 times more likely to have ASD than girls. Among the high-probability group the prevalence of ASD was 0.75 percent and boys were 5 times more likely to have ASD than girls.

Of the 2.64 percent of all ASD cases, 0.94 percent met diagnostic criteria for autism and 1.7 percent met criteria for other types of ASD, including Asperger's disorder and pervasive developmental disorder not otherwise specified.

Opportunities from page 33

and support - and most importantly - THE RIGHT TYPE OF EMPLOYMENT - can transform the work experience for people on the autism spectrum.

Aspiritech harnesses the strengths of autism such as focus, attention to detail and strong technical skills to provide training and then employment in software testing (quality assurance or QA). Aspiritech provides its clients with reliable, secure, effective testing and communications. Through our operating procedures, we ensure the quality and consistency of our work and give employees the structure and direction they need to do their best.

Testimonials from our satisfied clients attest to the quality we deliver. For example, David Fisher, CEO of optionsXpress said, “Aspiritech allows us to scale our QA and QC resources up and down... and do it efficiently.” Sara Winter at Squag writes, “It’s easy to recommend... Aspiritech was on time and on budget... providing excellent service...”

In addition to the first-rate, quality QA

Significance

Unlike previous studies that analyzed health records and registries, the researchers attempted to look at each child in every school in a particular community, even children who did not have a record of any special education need. According to the researchers, this method unmasked cases that could have gone unnoticed if they had relied solely on health records. As a result, this study's estimate of ASD prevalence is higher than previously reported estimates, which range from 0.6 percent to 1.8 percent.

However, according to the researchers, the prevalence in the high probability group is similar to reports in other studies that have focused on the same target populations. The major difference in this

study was that two-thirds of ASD cases were identified in the general population among children who never had contact with care systems. This particular finding highlights the importance of screening mainstream school populations as well as clinical populations in future studies. The researchers also suggest that the highly structured educational system in South Korea may allow children with less severe ASD symptoms to manage in general education settings, despite their impairments.

What's Next

More research is needed to find out whether these results can be repeated in other populations in Korea and other countries. The researchers note that more rigorous ASD

services they are providing, we’ve found that our testers thrive in Aspiritech’s environment. When we have regular, consistent work we see a huge impact on the testers’ mood, sense of pride and confidence. Our own son has demonstrated an increase in initiative and self-awareness. Other parents are reporting renewed pride and self-confidence too!

And the surprises don’t stop there! When they detect a “bug” (a suspected software error) or a process that can be improved, they are told to double-check it with someone else. At first, each worked in separate corners of our office and they all checked their errors with the manager who had trained them. Guess what? Within a very short time, almost all began to work together around the main conference table and to double-check their bugs with one another! We are seeing teamwork and cooperation amongst our staff, all of whom have some form of autism. In recognition of their leadership and technical skills, two testers have just been promoted to project leads and given raises!

At Aspiritech, our testers appreciate each other and are comfortable with them-

selves because we value them and acknowledge their incredible abilities and their work. We also are understanding and accepting of their individual “quirks.” Incidents that are unacceptable in other places (and are not customer-related) are often ignored and our autism specialist, graciously funded by grants from Autism Speaks and Healthcare Foundation of Highland Park, handles them later.

Our continuing challenge is securing enough contractual work to provide a consistent, predictable work schedule for our testers. And although software testing is a great match with the strengths of autism, we are exploring other types of work where their extreme focus and attention-to-detail will be an advantage.

Today, most experts agree that at least 85-90% of adults with autism are either unemployed or severely under-employed. Of those who work, many are overqualified - stuck working in low-paying jobs that are not a good fit with their skills and abilities. In sharp contrast, Aspiritech’s work is intellectually challenging. In addition to a pay check, it provides socializa-

screening may provide a more accurate estimate of the number of people with ASD, and that this number may exceed previous prevalence estimates. Additionally, this study only addressed ASD prevalence, or the current number of people with the disorder. Incidence studies - those that focus on the numbers of new cases - are essential to examine possible environmental and other potential causes of the rising ASD prevalence.

Reference

Kim YS, Leventhal BL, Koh YJ, Fombonne E, Laska E, Lim EC, Cheon KA, Kim SJ, Kim YK, Lee HK, Song DH, Grinker RR. Prevalence of Autism Spectrum Disorders in a Total Population Sample. *Am J Psychiatr*.

tion, self-fulfillment, self-esteem and structure to our testers’ lives.

It boils down to finding the right fit in the employment world. We must stop trying to pigeonhole people with autism into available jobs and begin to looking at what jobs (such as software testing) align with autism’s strengths. If we can transform how we view employment for adults with high functioning autism, just think how much of the lost productivity and other incremental costs - and estimated \$3.2 million per person - we could reduce, redirect or avoid.

As a society, we can do better. And we must do better before the tidal wave of 500,000 children with autism reach adulthood in the next decade or so! We cannot afford to waste their talents and have capable individuals fall through the cracks as our son once did!

For more information about how Aspiritech can meet your company’s quality assurance/software testing needs, please contact Moshe Weitzberg, PhD, at moshe@aspiritech.org or check us out at www.aspiritech.org.

Typical from page 12

on the spectrum are not only more motivated to learn, they are also empowered to boost their classroom participation and social interaction with their typically developing peers. These skills are vital to the development of social competence, are desirable within the family context, and are an essential ingredient in helping children with ASD

Employment from page 25

In school they were often being pushed into college when they were either not adequately prepared or had no career endgame in mind if they graduated. In addition to this confluence of conflicting issues, transition services were becoming more important to head off this steamroller of events. For students with both high and low significance of disability an emphasis on the transition process from school is now one of the key solutions.

Despite the vortex of issues that surround this social ill there are some solutions. First should be an awareness of what is transpiring in the workplace and an end to the reluctance to look at this disability and employment issue clearly. Employment is the ultimate outcome education is designed to provide and most individuals want and need employment for personal dignity and livelihood. Transition services, when properly and effectively implemented, are more effective in addressing some of these issues. Schools

Law Enforcement from page 26

They realize that the "Command and Control" approach learned as Cadets in the Academy is unlikely to be successful in contrast to respecting personal space, being calm, empathetic and "thinking outside the box."

To date, there has not been a single known police force that has instituted CIT policing that has abandoned maintaining the program. Given the degree of initial skepticism and resistance to change along with shrinking funding, this is truly a tribute to the strength and utility of Crisis Intervention Team training. Several jurisdic-

Advice from page 29

it came and the leaky gut was no more.

Through the years we tried brushing therapy (with a corn husking brush), for tactile defensiveness, occupational therapies, always speech therapy, behavioral therapy, and RDI (Relationship Development Intervention), but the trials stopped at invasive procedures.

We were not comfortable with attempting the secretin trials. Secretin (a drug administered during endoscopy to determine gastrointestinal problems) became a newsworthy item when a mother discovered that her child became verbal after secretin was given to her child. The idea of putting a drug into our child that could potentially harm his liver frightened us. Nevertheless, given that there is always money to be made when people are vulnerable, specialists jumped on the bandwagon selling secretin injections for thousands of dollars in treatment. Studies determined that administering secretin for improving symptoms of autism

build meaningful, long-lasting relationships.

References

McConnell, S.R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for education intervention and future research. *Journal of Autism and Developmental Disorders*, 32, 351-372.

can provide a clear view of the workforce by analyzing, promulgating and tracking employment trends and training needed to coincide with those trends. Encouraging and enabling work experiences for special education students during high school is a critical component, not only for college bound students, but for students considering technical school or employment upon graduation as well. Families often believe that exclusive focus on academics is the prescription to success when, in fact, students with disabilities who work during high school have demonstrated a higher rate of staying in college and not dropping out.

Experiencing work is critical for students with disabilities since their greatest challenges include overcoming the barriers of their disability not just in school but in their ultimate goal of being in the workforce. Starting work or internships in high school enables them to have a better idea of the impact of their disability in real work situations with a cadre of highly skilled professionals, i.e. special education teachers, psy-

chologists, social workers, transition coordinators etc., to assist in the development of strategies to overcome their disability. Preparing students for the non-academic issues that their disability impacts is crucial as well. Social skills, executive functioning skills, self-advocacy and self-determination are all critical in the college, technical school and work arenas. Being able to fully understand their disability, its etiology, impact, barriers and strategies needs to be taught and inculcated as fully as multiplication tables would be in math.

Technical schools and colleges need closer scrutiny as a potential post-secondary means to career outcome since most of them have a placement requirement as part of their mandate. Why these options are not given the fullest attention by guidance counselors is usually not because of their effectiveness or reliability, but due to their specialty status. They are off the beaten track of the usual "college" pathway and therefore not given the same level of attention as the typical four-year college, or even two year community college.

and resources of that particular region. Clearly, the program will succeed only if it is home grown, uses the expert faculty to teach evidence-based curriculum and involves all stakeholders at the same table during the creation phase. It becomes "more than training," it becomes reality. Having family members with disabilities, I say it's about time. Consider becoming proactive if your community lacks a CIT program and remember to request response from a CIT trained officer if a program already exists where you live in case of an emergency or crisis.

Further information can be obtained by visiting www.citinternational.org or www.nami.org. Special thanks to: Chicago Police Department, Cook County Sheriff's Training Institute, Young Adult Institute, New York, NY, Anixter Center, Chicago, Illinois, Leeda Services, Chicago, Illinois, Jane Addams School of Social Work and Department of Disability and Human Development, University of Illinois, Chicago.

Bruce Handler, MD is Clinical Adjunct Assistant Professor of Medicine at the College of Medicine at University of Illinois, Urbana-Champaign, and is the Course Director of Crisis Intervention Team Training at the Cook County Sheriff's Training Institute in Chicago, Illinois.

was no more effective than placebo. I have worried about the criticism of conventional medicine. It is the tease for fact from "yarn" that begs consideration. The notion of a "one stop shop" to tempt parents living with autism is seductive. I bear no umbrage toward individuals who integrate hands on therapy with a data-taking trial process for behavioral intervention. I worry about the potions and anecdotal testament of success. Conflict of interest is the operative term. We know the obvious answer to who benefits from vaccine sales, and drug sales. The next question is who benefits from book sales and bio medical sales, and vitamin sales, and hyperbaric oxygen chamber sales, etc. Chelation is another intervention that has been championed to combat autism. It is a process where heavy metals, such as mercury and lead, are removed from the body. I was introduced to chelation when my Mother had a heart attack 26 years ago. Cardiac by-pass was recom-

ended, and given that it was major surgery, our cousin suggested we try chelation first. We chose not to take that route, as it did not make sense to us. We heeded the advice of surgeons who indicated that clogged arteries needed to be repaired surgically. Parents need to be clear-headed while living with the pain of autism. Perhaps my "Missouri" ethic has been a guiding force, but for our son and his autism, it has given us solid ground to stand on. "Show me" is all we can say, and feel safe.

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

where, and it is advisable to ask as many questions as you deem necessary. We need to be educated consumers. Be pro-active! Make a list and create a hierarchy of what about autism impedes the lives of your child and your family. Establish your priority needs. Look for resource websites (e.g., Autism Speaks resource guide: www.autismspeaks.org/community/fsdb/search.php). Investigate services within your state and learn what your child's rights are. Ask questions about success with evidence (data) and inquire about references. Research the scientific studies - Autism Science Foundation is a valuable source (www.autismsciencefoundation.org). Remember, no question is too insignificant. You are the driver here!

Robin Hausman Morris is a freelance writer and can be reached at RobinHausman-Morris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/autism-and-parenting-in-national/robin-hausman-morris.

ders. *Education and Training in Autism and Developmental Disabilities*, 46(1), 62-77.

Jill Krata, Ph.D., is Associate Chief of the Premier HealthCare Autism Research and Treatment Institute and Manager of Clinical Services at the YAI Autism Center. Premier HealthCare is a member of the YAI Network. For more information or for services, call 1-888-YAI-Autism or visit yai.org.

Realistic and effective transition programming by schools for students with disabilities, no matter the level of disability, may be the best way to affect the social ill of under- or unemployment for people with disabilities. The current economic crisis tells us that state funding through their adult service providers alone cannot meet, nor are they capable of meeting, that need. Schools can and should address this issue since they have the resources, the legal mandate and the skilled professionals needed to implement the necessary services in a committed way. Through transition in schools we can change this social ill, not manage it.

Career and Employment Options, Inc. (CEO) is a company dedicated to providing quality transition services and employment for people with disabilities on Long Island and New York City. They are located in Hauppauge NY and in Manhattan NY, within the Spectrum Services offices. They can be reached at www.CEOincworks.com or 631-234-6064 or 212-686-3535 ext. 212.

Bruce Handler, MD is Clinical Adjunct Assistant Professor of Medicine at the College of Medicine at University of Illinois, Urbana-Champaign, and is the Course Director of Crisis Intervention Team Training at the Cook County Sheriff's Training Institute in Chicago, Illinois.

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Robin Hausman Morris is a freelance writer and can be reached at RobinHausman-Morris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/autism-and-parenting-in-national/robin-hausman-morris.

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