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FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

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Science Matters: The Latest Advances in Autism Research

New Trends in Brain and Tissue Banking for Autism Research

By Jerzy Wegiel, PhD,
Daniel Lightfoot, PhD,
Jane Pickett, PhD, and
W. Ted Brown, MD, PhD

Professor Giovanni Morgagni, of the University of Padua, published a book in 1761 entitled, "The Seats and Causes of Disease Investigated by Anatomy." This book described nearly 700 autopsies and demonstrated that disease is recorded in the pathology of organs in detectable ways. Dr. Richard Cabot's review of the autopsy records of thousands of patients at the Massachusetts General Hospital in the 1910's revealed that the given clinical diagnosis was wrong in about 40% of cases. These studies, which were also confirmed by many others, justified the central role of autopsies in medical education and in the quality control of clinical practice. They contributed to the growth of autopsy rates in hospitals and medical schools to approximately 50% in the 1940s (Dobbs 2005). This trend resulted in



remarkable progress in diagnosis, identification of new diseases, detection of disease mechanisms, and new treatments. However, the rate of autopsies declined toward the end of the past century and the current US rate is less than 5%. The major reasons for declining autopsy rates were

costs, changed diagnostic priorities, and decreasing clinical interest in the autopsy as a quality control of clinical diagnosis and therapy (Kretzschmar 2009). The decline in autopsy rates occurred during the same time that the diagnosis rate for Autism Spectrum Disorders (ASD) increased

from about 1/2,000 in 1980 to 1/110 in 2010 (The Center for Disease Control). This decline has had a detrimental effect on the progress of research on autism.

Clinical studies of thousands of autistic patients have resulted in improvements in early diagnosis, and behavioral and pharmacological treatments. Genetic studies are identifying gene mutations, single nucleotide polymorphisms, and copy number variations, as contributors to autism's etiology. However, the progress of clinical and genetic studies is not paralleled by a similar progress in postmortem studies of the brain. The brain of an autistic individual is the main source of information about developmental defects determining the cause of life-long disability and clinical phenotypes. The decline in autopsy rates and the number of brain donations for research coincide with an emerging need for application of modern methods of brain studies to determine the types and distribution of developmental alterations, the correlations between structural

see New Trends on page 26

Inhibition of Eye Blinking Reveals How Toddlers with ASD Attend Differently to What They Watch

By Sarah Shultz,
Warren Jones, PhD, and
Ami Klin, PhD
Marcus Autism Center

One of the central goals in autism research is to better meet the needs and experiences of individual children on the autism spectrum, even and especially children who may not be able to easily communicate those experiences. Researchers hope that doing so will provide an inroad into helping those children and also into understanding the condition as a whole.

That goal would initially appear to have very little to do with eye blinking. In fact, most people don't even notice when they blink. But without noticing it, we spend nearly 45 minutes of each day

blinking, with eyelids closed, not seeing the visual information in front of us.

Researchers at the Marcus Autism Center at Emory University, together with a graduate student in Psychology at Yale University, have discovered a new way to use this information to actually measure how engaged people are with what they're watching. And they can even use this technique to learn from children who, like those with autism, have difficulties communicating their interests to others. The results are reported in the December 12th online Early Edition of the Proceedings of the National Academy of Sciences.

The new method relies on measuring the precise timing of when people blink, and when they don't. The research reveals that people unconsciously inhibit their blinking at precise moments. Why would people blink at some moments but not at others?

"When we blink, we lose visual information," says Sarah Shultz, a graduate student in the Psychology Department at Yale University. "Our eyelids close. We're not conscious of the timing of our blinks, but they still impact the visual information we take in."

Shultz and her colleagues at the Marcus Autism Center, Ami Klin and Warren Jones, work with children with autism, studying how these children look at the world and how they learn from the things they pay attention to. While measuring what 2-year-olds look at when watching videos of other children playing, Shultz made an interesting observation: she noticed that the children blinked less while the videos were playing than they did before or after the videos.

"That initial observation opened the whole thing. It made us wonder if we

might see the same effect at a micro-scale: that is, not just for a whole video, but moment-to-moment, whether the rate of blinking might go down or up depending on whether viewers perceived a scene to be more or less important," says Jones.

The researchers tested the hypothesis by letting 93 two-year-old children watch a video. The video showed a simple scene of a boy and girl playing together. About half the children watching had Autism Spectrum Disorders. The researchers measured when children blinked and when they didn't, and the results were surprising.

"Typically-developing 2-year-olds inhibited their blinking at the same moments in the video. And they were more likely to inhibit their blinking when watching more emotional moments, and when looking at

see Blinking on page 13

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Spring 2012 Issue:

“Transitioning into Adulthood:
Navigating the Complex Changes Ahead”

Deadline: March 5, 2012

Summer 2012 Issue:

“Vital Supports and Services in the Community”

Deadline: June 5, 2012

Fall 2012 Issue:

“The Importance of Early Intervention Following Diagnosis”

Deadline: September 5, 2012

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“Exploring Educational Challenges and Opportunities”

Deadline: December 5, 2012

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— From the Publisher —

Science Matters Because Individuals with Autism Matter

By David H. Minot, BA
 Publisher
 Autism Spectrum News

The theme of this issue of *Autism Spectrum News* is, "Science Matters: The Latest Advances in Autism Research." We are truly inspired by the quality of articles and leaders in the field of autism who have collaborated with us to bring you this exciting issue. Our goal is to bring you the highest quality of science-based information and education in each issue of *Autism Spectrum News*.

Why is autism science so important? Through scientific research, we gain an increased knowledge and understanding of autism; who it affects, what causes it, when it begins, and how it can best be treated. Thanks to discoveries made through scientific research, we now know that early intervention utilizing proven evidence-based treatment methods will greatly increase a child's overall development. This is just one example of how research translates into knowledge used to improve the lives of individuals with autism and their families. As Kofi Annan, former Secretary General of the UN once said, "Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family."



David H. Minot, BA

At the beginning of the 20th century, infectious diseases were widely prevalent in the United States and took an enormous toll on the population. For example, in 1900, 21,064 smallpox cases were reported and 894 patients died. In 1920, 147,991 diphtheria cases were reported and 13,170 patients died (CDC MMWR April 02, 1999 / 48(12);243-248). By com-

parison, in 2010 there were no reported cases or deaths of smallpox or diphtheria (CDC MMWR December 16, 2011 / 60 (49);1681-1694). Thanks to knowledge gained through scientific research, vaccines were developed to eradicate these terrible diseases, improving our overall quality of life.

As we enter the year 2012, autism has become widely prevalent in the United States and is having an impact on society in many ways. The current US population is near 312,800,000, with one birth every 8 seconds (US Census Bureau). The latest prevalence data from the CDC is that autism occurs in 1 out of every 110 children. The lifetime incremental societal cost of autism per person is \$3.2 million (Arch Pediatr Adolesc Med. 2007;161(4):343-349). This data shows that autism is extremely costly and the prevalence is increasing dramatically. What these numbers do not show is the human effect autism has on the lives of children and adults with autism spectrum disorders and the family members who are struggling to care and provide for them.

Similarly to how scientific research led to the eradication of many infectious diseases in the early 1900s, science today is having an impact on autism. For example, through research, we are beginning to understand human genetics and neurology like never before. This increased knowl-

edge will translate into advances such as the development of new novel treatments and the ability for even earlier detection and diagnosis. The future of autism science is looking very promising.

Today, science matters more than ever as autism continues to raise more questions than we currently have answers for. We must continue to increase funding and further publicize the vital work our research scientists are doing for the autism community. The people who truly benefit from science are the young and adult individuals living with autism spectrum disorders. Ultimately, what matters most is providing individuals with autism with the best quality of life as productive members of the community. Science matters, because individuals with autism matter.

I urge you to share the articles in this issue of *Autism Spectrum News* with your professional colleagues and personal friends. You can view the entire issue and all previous issues on our website for free at www.mhnews-autism.org. In addition, please become part of our growing online autism community on Facebook (www.facebook.com/AutismSpectrumNews) and on Twitter (@AutismSpecNews).

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

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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

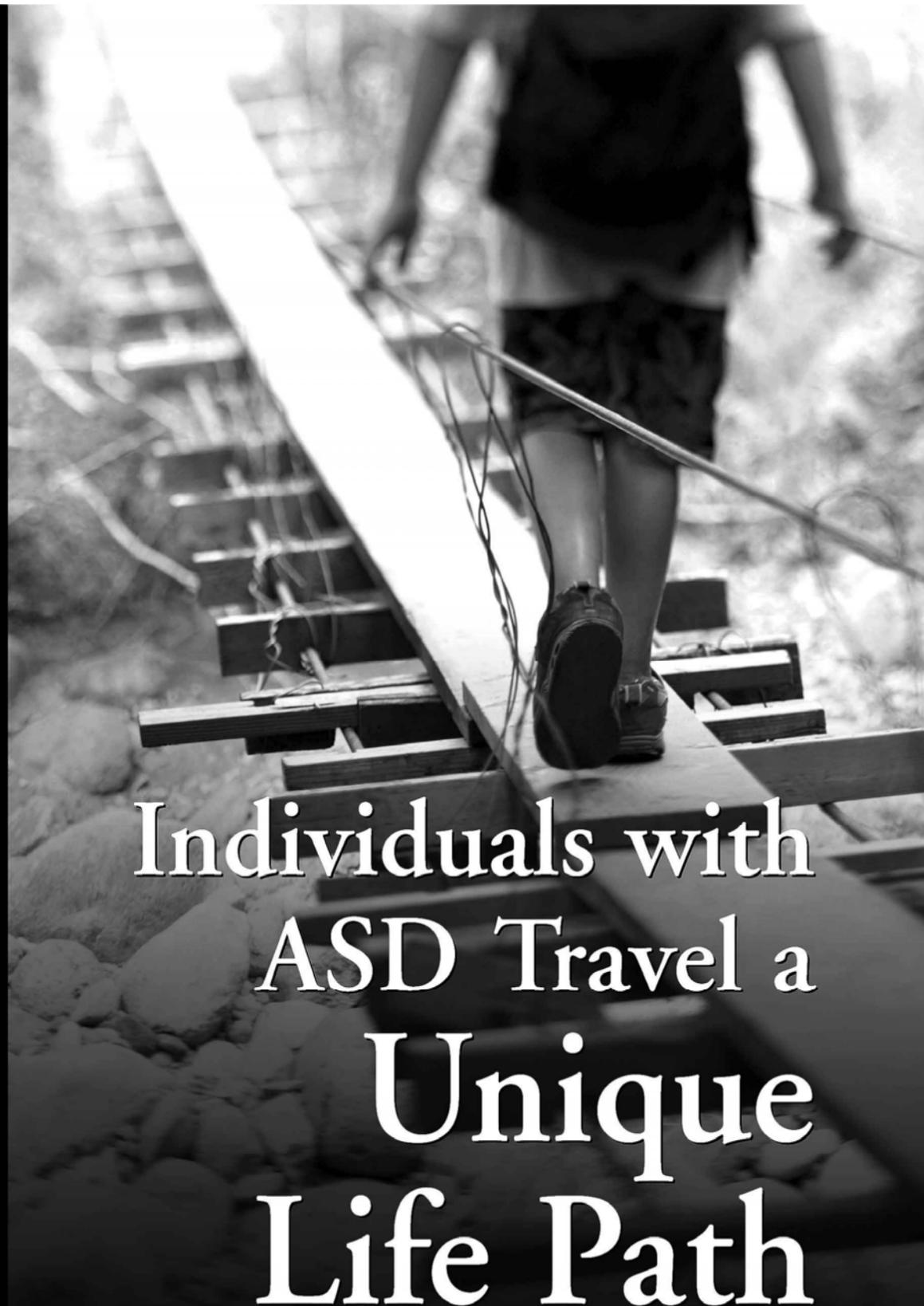
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AUTISM SPECTRUM NEWS DESK

NDAR Federation Creates Largest Source of Autism Research Data to Date *NIH-Funded Database Sets Standard for Collaboration and Data Sharing*

By The National Institute of Mental Health (NIMH)

A data partnership between the National Database for Autism Research (NDAR) (ndar.nih.gov), and the Autism Genetic Resource Exchange (AGRE) (agre.autismspeaks.org) positions NDAR as possibly the largest repository to date of genetic, phenotypic, clinical, and medical imaging data related to research on autism spectrum disorders (ASD).

"The collaboration between AGRE and NDAR exemplifies the efforts of government and stakeholders to work together for a common cause," said Thomas R. Insel, MD, director of the National Institute of Mental Health, part of NIH. "NDAR continues to be a leader in the effort to standardize and share ASD data with the research community, and serves as a model to all research communities."

NDAR is supported by the National Institutes of Health; AGRE is an Autism Speaks program.

NDAR's mission is to facilitate data sharing and scientific collaboration on a broad scale, providing a shared common platform for autism researchers to accelerate scientific discovery. Built around the concept of federated repositories,



NDAR integrates and standardizes data, tools, and computational techniques across multiple public and private autism databases. Through NDAR, researchers can access results from these different sources at the same time, using the rich data set to conduct independent analyses, supplement their own research data, or evaluate the data supporting published journal articles, among many other uses.

Databases previously federated with NDAR include Autism Speaks' Autism Tissue Program (www.brainbank.org), the Kennedy Krieger Institute's Interactive Autism Network (IAN) (www.ianproject.org), and the NIH Pediatric MRI Data Repository (www.nih-pediatricmri.org). AGRE currently houses a clinical dataset with detailed medical, developmental, morphological, demographic, and behavioral information from people with ASD and their families.

Approved NDAR users will have access to data from the 25,000 research participants represented in NDAR, as well as 2,500 AGRE families and more than 7,500 participants who reported their own information to IAN.

NDAR is supported by NIMH, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, the National Institute of Environmental Health Sciences, and the NIH Center for Information Technology.

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 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 www.nih.gov.

Studies of Early Development Reveal Immune Link to Autism

By Virginia Hughes

The molecular soldiers of the immune system affect brain development and may contribute to many cases of autism. That's the emerging hypothesis from five new studies that use different methods — ranging from screening blood samples of pregnant women to mathematical analyses of gene expression in the brain — published in the past few months.

One report shows, for example, that pregnant women whose babies later develop autism tend to carry rare antibodies in their blood. Another finds that they harbor an excess of certain signaling molecules of the immune system, called cytokines, in the amniotic fluid. A third study found that some autism risk genes expressed in the developing brain belong to networks of genes related to cytokine signaling.

"These studies further build the case for the relevance of the immune system in autism using totally different approaches," says Paul Patterson, professor of biology at the California Institute of Technology. Patterson has made animal models of the immune system's role in brain develop-

ment but was not involved in any of the new studies.

Many investigations of older children and adults with autism have uncovered signs of the immune system gone awry. The new studies are finding similar signatures in early brain development, from the womb through the first few years of life.

Still, no one knows much about the biological mechanisms that determine when, how or why immune molecules affect the fetal brain — let alone whether or why they might contribute to autism.

"Obviously the immune changes are there and are prominent. We just have to figure out what they're doing," Patterson says.

Maternal Influence

Developing babies can defend against infection thanks to immune molecules gleaned from their mothers. Maternal antibodies called immunoglobulin G, or IgG — produced after an individual is exposed to certain bacteria or viruses — pass through the placenta to the fetus, protecting it against those pathogens.

"It's a very important part of fetal health to have IgG circulating through the fetus," says Judy Van de Water, professor

of internal medicine at the MIND Institute of the University of California, Davis.

Sometimes, though, these antibodies can turn against the fetus, mistaking its proteins for foreign invaders. This happens, for example, in pregnant women with the autoimmune disease lupus, whose babies are sometimes born with heart abnormalities.

Van de Water's work suggests that these so-called autoantibodies may also contribute to autism.

In fact, she says, when pregnant women carry specific combinations of these antibodies, their chance of having a child with autism is close to 100 percent. "It's definitely a unique set of autoantibodies in these moms," she says. "We don't find these antibodies in control moms." A Sacramento-based biotech called Pediatric Bioscience is developing a commercial test for these markers that should be available within 18 months, she says.

On 20 October, Van de Water reported in the *Journal of Autism and Developmental Disorders* that about 13 percent of mothers of children with autism tend to carry one of two types of IgG antibodies that bind to fetal brain proteins in their blood. None of the mothers of typically developing children carry either of these IgG subtypes¹.

The study is based on 520 women, including 204 who have children with autism, who are part of a project called Childhood Autism Risk from Genetics and Environment, or CHARGE (<http://beincharge.ucdavis.edu/>). Launched in 2003, the project aims to collect genetic and environmental information — such as diet and chemical exposures in their homes — from 2,000 children with autism or developmental delay, and typical controls, ranging in age from 2 to 5 years.

Van de Water's team also found that the particular combination of antibodies carried by the mother relates to her child's behaviors. The researchers assessed the children using a variety of autism tests, including the gold standard diagnostic tests: the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised. They found that certain antibodies in the mothers' blood are associated with low scores for expressive language, whereas others correlate with increased irritability.

It's unclear why some women produce these antibodies and others don't, but Van

see *Immune Link* on page 34

AUTISM SPECTRUM NEWS DESK

Boys with Regressive Autism Have Larger Brains Than Age-Matched Health Counterparts

By Christine Wu Nordahl, PhD, and David G. Amaral, PhD
UC Davis MIND Institute

In the largest study of brain development in preschoolers with autism to date, a study by UC Davis MIND Institute researchers has found that 3-year-old boys with regressive autism, but not early onset autism, have larger brains than their healthy counterparts.

The study is published online today in the Proceedings of the National Academy of Sciences Early Edition. It was led by Christine Wu Nordahl, a researcher at the UC Davis MIND Institute and an assistant professor in the Department of Psychiatry and Behavioral Sciences and David G. Amaral, Beneto Foundation Chair, MIND Institute Research Director and University of California Distinguished Professor in the Department of Psychiatry and Behavioral Sciences.

“The finding that boys with regressive autism show a different form of neuropathology than boys with early onset autism is novel,” Nordahl said. “Moreover, when we evaluated girls with autism separately from boys, we found that no girls - regardless of whether they had early onset or regressive autism - had abnormal brain growth.”



Photo Credit: UC Regents

David G. Amaral, PhD with Christine Wu Nordahl, PhD

Brain enlargement has been observed in previous studies of autism. However, prior to this study, little was known about how many and which children with autism have abnormally large brains.

“This adds to the growing evidence that there are multiple biological subtypes of autism, with different neurobiological underpinnings,” Amaral said.

Autism is a neurodevelopmental disorder whose symptoms include deficits in language and social interaction and communication. The condition affects 1 in 110 children born today, according to the U.S. Centers for Disease Control and Prevention. It is diagnosed more frequently in male children than female children - at a ratio of 4 to 1.

The current study is one of the first published from data collected by the UC Davis MIND Institute Autism Phenome Project (APP). The project’s goal is to recruit and enroll as many very young children as possible in order to collect sufficient biological and behavioral information to characterize different autism subgroups and to explore different neural, immunologic, and genetic signatures of autism.

For the study, the authors enrolled a total of 180 children between age 2 and 4. One hundred and fourteen of the participants had autism spectrum disorder; the remaining participants were 66 age-matched typically developing controls. Of the children with autism, 54 percent were diagnosed with the regressive form and 46 with the non-regressive type.

The researchers collected magnetic resonance imaging (MRI) scans on 180 participants at age 3. To evaluate the rate of brain growth prior to age 3, they analyzed head circumference measurements taken from pediatric well-baby visits from birth through 18 months. Roughly half of the children with autism were reported by their parents as having experienced a regression, characterized by the loss of previously acquired language and social skills.

see *Regressive* on page 31

Autism Recurs in Families More Often than Previously Realized

By Autism Speaks

Research funded by Autism Speaks provides vital information on the need to screen baby siblings of children on the spectrum. Parents of children with autism are understandably concerned about the likelihood that subsequent children will be affected. New research, made possible by Autism Speaks, shows that the chances are considerably higher than previous estimates.

“These findings emphasize the importance of screening high-risk younger siblings,” explains Autism Speaks Chief Science Officer Geraldine Dawson, PhD, “because we know that early diagnosis and early intervention help children on the spectrum achieve their greatest potential.”

The study, the largest ever of its kind, was published in August by the respected journal *Pediatrics*. It found that in families with one or more children on the autism spectrum, the chances that a baby sibling will develop autism are around 1 in 5, more than double previous estimates of 1 in 10 to 1 in 30. The rate



Geraldine Dawson, PhD

was much higher among younger brothers (1 in 4) than among younger sisters (1 in 9). In families with more than one older child on the spectrum, 1 in 3 infants eventually developed autism. The

severity of the older sibling’s autism did not affect the risk to younger brothers or sisters, nor did other family attributes such as parental age, ethnicity, or birth order.

In all, the researchers assessed 664 infants, all of whom had at least one older sibling with a verified diagnosis of an autism spectrum disorder (ASD). They enrolled infants very early (two-thirds of them before 6 months) before symptoms of autism become obvious. The clinicians then followed the babies through 36 months of age. They used gold standard diagnostic methods and comprehensive assessments performed by expert clinicians.

“Previous studies were done in the 80’s and 90’s when different and more narrow diagnostic criteria were used,” Dr. Ozonoff says of the dramatic findings. “Previous studies also used different methods and some did not directly assess children.”

“The implications of the study are clear,” Dr. Dawson adds. “Baby siblings of a child with ASD need to be tracked carefully. Pediatricians and other medical professionals should work actively with parents to monitor developmental

milestones, especially those related to autism, and if needed begin intervention without delay.” Equally important, she adds, is the need to fund further research on how early intervention can be best used with infants and toddlers and whether it might be possible to develop preventive measures to help children not yet showing full symptoms.

Autism Speaks made the study possible by organizing the High-Risk Baby Siblings Research Consortium, an international network that pools and coordinates studies of affected families in 21 sites in the US, Canada, Israel and the UK. Alycia Halladay, PhD, Autism Speaks director of research for environmental sciences, and Andy Shih, PhD, vice president of scientific affairs, organized the consortium in 2003, in partnership with the Eunice Kennedy Shriver National Institutes for Child Health and Development. Autism Speaks funded the participation of lead authors Sally Ozonoff, PhD., and Gregory Young PhD, both of the University of California-Davis MIND Institute and also funded the study’s analysis of collaborative results. The National Institutes of Health provided overall funding.

An Overview of Strategies to Address Food Selectivity and Refusal in Individuals with Autism

By Christopher Perrin, PhD, BCBA-D, Amanda Guld, PhD, BCBA-D, and Mary Jane Weiss, PhD, BCBA-D
Melmark

Feeding difficulties are common in typically developing children (2-35%), and are even more common in children with developmental problems (33-80%; Babbitt, Hoch, & Coe, 1994; Burklow, Phelps, et al, 1998). Feeding difficulties in individuals with autism is one of the most challenging presenting problems faced by clinicians. These problems come in several forms, including food refusal and extreme food selectivity. Specific issues may include inadequate intake of food, inadequate range of foods consumed, refusal to consume food, and challenging behaviors. Often, individuals with these issues have had them for many years, have been treated unsuccessfully with a variety of strategies, and have developed health consequences as a result of the longevity and severity of the problem. Efforts to intervene may be met with escalations of challenging behaviors, and with increased refusal to eat. Documented health consequences of food selectivity in autism include rickets, vitamin deficiencies, bone loss, and stunted growth (Williams, 2010).



The effects on caregivers are also significant and family members often express extremely high stress surrounding eating and mealtimes (Singer, Song, Hill, & Jaffe, 1990). Parents and other caregivers often are extremely concerned, and may be genuinely worried about the health impact of the food refusal issues. In addition, they may themselves feel defeated from years of unsuccessful efforts to address the problem. Parental anxiety may also have led to some interactional patterns around eating that are also part of the current problem. For example, parents may often remove the item that is being refused, inadvertently

teaching the child that refusal will result in food removal. Also, they may cajole, beg, or otherwise encourage the individual in a way that provides undue attention for food refusal. In many cases, just to get their child to eat something, parents will provide access to preferred foods once attempts to get their child to eat a non-preferred food fail. Multiple researchers have confirmed that escape and attention are the two most common parental reactions that may maintain such behaviors (Piazza et al., 2003; Borrero et al., 2010; Casey et al., 2009). Caregiver training is therefore an essential aspect of treatment, as the protocols are

specialized and must be consistently implemented. Furthermore, intervention may initially increase problem behavior, increasing caregiver worry.

Clinicians faced with these issues must possess an impressive set of skills in order to successfully treat feeding problems. Professionals who lack specialized training may not have the skill set to meet these needs, depending on the nature of the problem. It is imperative that clinicians evaluate their ability to intervene effectively and obtain needed expertise when the behavior exceeds their skill level.

Furthermore, these problems are often multifaceted, and may require the expertise of medical doctors, speech and language pathologists, and behavior analysts. It is often the case that feeding issues interact with medical issues, most notably reflux and motility issues (see Williams et al., 2010 for a review of the etiology of feeding problems). The resulting persistent problems may require both medical and behavioral interventions, and treatment should be designed in combination with a simultaneous medical assessment and/or a medical treatment plan.

In this article, we will briefly review some of the specialized strategies that have been shown to improve feeding. The strategies are behavior analytic, and have been empirically shown to reduce refusal,

see Food on page 28

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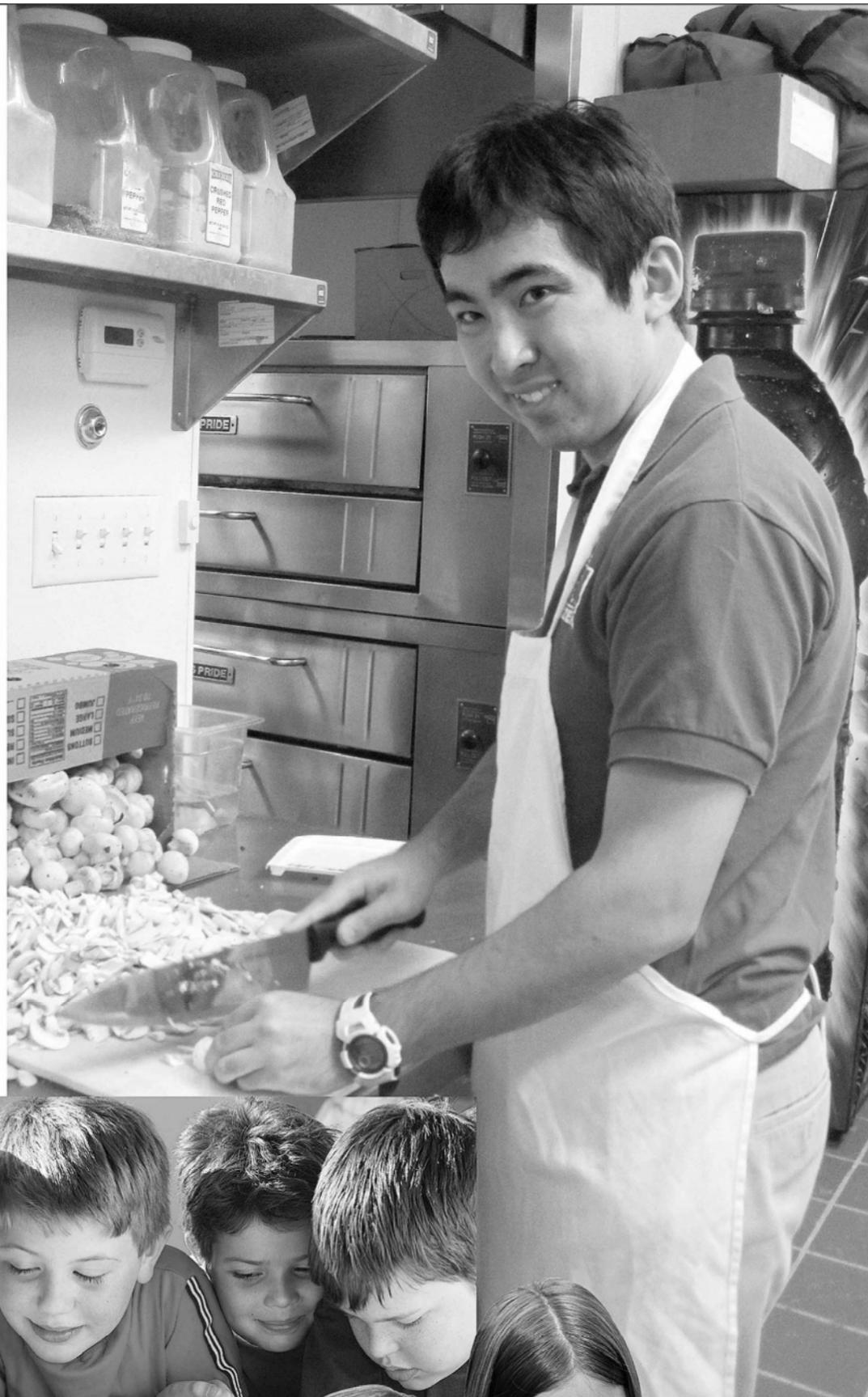
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Future Directions in Medication Treatments for ASD

By Evdokia Anagnostou, MD,
Joel D. Bregman, MD, and
Latha V. Soorya, PhD, BCBA

There has been enormous growth over the past 10-15 years in research attempting to identify effective medications for children and youth with ASD. A few classes of medications have been shown to be effective for treating specific symptoms associated with autism. There is accumulating data to support the use of stimulants and non-stimulants for hyperactivity and attention deficits, and of atypical antipsychotics (risperidone, aripiprazole) for irritability and impulsive aggression. There is disappointing data regarding the use of SSRIs (citalopram, fluoxetine) for repetitive behaviours but several issues related to possible subgrouping may not have been addressed adequately. However, the work done to date is based on the premise that if a symptom domain is shared by multiple neurodevelopmental disorders, then its biology must be common across such disorders. As such we "borrowed" medications from other such disorders (e.g. ADHD, OCD) and tested them in autism. Although the results have been sometimes fruitful, the predictability and degree of clinical benefit has been lower among those with autism. In addition, this approach has not adequately addressed either impairments in core social and



Evdokia Anagnostou, MD

communication development or in key learning and cognitive domains essential for skill development. Previous studies have focused primarily on behavioural symptoms shared by other disorders, rather than on weaknesses in cognitive and motor domains of functioning (e.g., fine and gross motor impairments, poor motor coordination, memory weaknesses, sensory issues).



Joel D. Bregman, MD

As our understanding of the molecular genetics and basic neurosciences of ASD grows, the field is considering new treatment approaches. We are for the first time in a position to identify novel molecular targets based on molecular genetics, neuropathology and animal model work. This cutting edge research facilitates the translation of basic science findings into treatments that target core ASD symptoms and



Latha V. Soorya, PhD, BCBA

potentially facilitate learning. There are currently several brain pathways and neurochemical mediators identified as potentially important targets for treatment in ASD. In this article, we focus on the glutamate signalling system, oxytocin and immune function, although other models arising from single gene disorders such as

see Future Directions on page 29



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Excessive Folic Acid Supplementation: A Cause for Autism Spectrum Disorders?

By Mohammed Junaid, PhD
New York State Institute for Basic
Research in Developmental Disabilities

Autism spectrum disorders (ASDs) are a group of phenotypically heterogeneous neurodevelopmental disabilities characterized by impairments in three core functional domains: reciprocal social interactions, verbal communication and stereotyped, repetitive patterns of behaviors. The ASDs are phenotypically heterogeneous, in that affected individuals have varying degrees of deficits. Recent prevalence data indicate a marked increase in ASDs throughout the United States and the world, the causative factors of which remain largely unknown. ASDs are complex disorders, with the probable involvement of both dysregulation of multiple genes and environmental factors. Although ASD are labeled as highly heritable, extensive genome-wide analyses of linkages, copy-number variations, and single nucleotide polymorphism approaches have identified genetic causative factors in only less than 10% of the total cases. Therefore, there is a need for greater emphasis on studies of environmental factors that contribute to the etiology of ASDs. The primary targets for such studies would be factors to which pregnant women and their developing fetuses are exposed and that have the abil-



Mohammed Junaid, PhD at his High Performance Liquid Chromatography (HPLC) system analyzing metabolites in response to Folic Acid treatment

ity to modify gene expression. The New York State Institute for Basic Research in Developmental Disabilities (IBR), located in Staten Island, NY, is studying such factors that contribute to modification of the genome, affecting normal gene expression. These factors that do not change

the primary DNA sequence but instead cause dysregulation of gene expression due to covalent modification of the building blocks of the DNA are termed epigenetic factors.

Folic acid (FA) is an essential vitamin that is prescribed to every woman who is

pregnant or is planning to achieve pregnancy, and hence can be considered an environmental factor. There are mandatory recommendations for FA supplementation of foods to prevent the occurrence of neural tube defects (NTDs) in newborns. In addition, the guidelines recommend that all women planning or capable of pregnancy take a daily supplement containing 0.4 to 0.8 mg (400 to 800 µg) of folic acid per day, which is increased to 4 mg/day for women with a history of a prior child with NTDs. Because neural tube closure in human fetuses occurs within the first trimester, the question is raised of the rationale for FA supplementation for the entire duration of the pregnancy. A primary function of FA is to act as a co-factor in enzymes that synthesize nucleic acid and facilitate transfer of 1-carbon methyl groups to DNA and proteins. Methyl groups added on cytosine residues in promoter regions' CpG dinucleotides in the genomic DNA are responsible for the regulation of gene expression. The IBR research team led by Mohammed Junaid, PhD, head of the Structural Neurobiology Laboratory, hypothesizes that excessive FA supplementation during pregnancy will lead to altered gene expression during the crucial development of the fetus and may be responsible for the behavioral changes evident in the ASDs. Epigenetics plays a crucial role in

see *Folic Acid* on page 32



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Assessment and Understanding of Fear in Children with an ASD

By **Laura B. Turner, MS** and
Raymond G. Romanczyk, PhD, BCBA-D
Institute for Child Development
SUNY Binghamton

Intense fears and phobias have been reported in up to 64% of children with an ASD (Muris Steerneman, Merckelbach, Holdrinet, & Meesters, 1998). In comparison, only 5% of typically developing children present with intense fears (Ollendick, King, & Muris, 2002). Children with an ASD also have an atypical presentation and express greater amounts of fear as compared to children with other developmental or intellectual disabilities (Evans, Canavera, Kleinpeter, Maccubbin & Taga, 2005; Rodgers, Riby, Janes, Connolly & McConachie, 2011). For example, children with an ASD express more fear of medical procedures and less fear of dangerous and harmful objects or situations than children without an ASD. It is interesting that given this lowered fear of dangerous and harmful objects or situations, research at the Institute for Child Development has indicated a threefold increase in unintentional injuries for children with an ASD compared to typically developing children (Calavari and Romanczyk, 2011). Although deficits in emotion perception, expression, and regulation in children with an ASD are well recognized, the understanding of specific emotional states, such as fear, is in its infancy.



Laura B. Turner, MS with Raymond G. Romanczyk, PhD, BCBA-D

Much of the current understanding of fear in children with an ASD has been through caregiver report, which is also common practice in the assessment of fear in typically developing children, along with self-report. Given that self-report can pose significant limitations for most chil-

dren with an ASD, caregiver report has been the primary tool. However, interpreting emotional states in children with an ASD is a challenge for caregivers as well as service providers and researchers. Common deficits in ASD such as poor communication skills and difficulty with

emotion identification and labeling, along with atypical reactions to the environment, limit the ability of even those that are closest to the child to accurately interpret the child's behavior as fear-related. Children with an ASD often are not able to effectively identify or communicate their emotions or even dislike of an object or situation to their caregivers. Because of many of these challenges, there are currently no comprehensive, accurate, or standardized methods to assess fear in children with an ASD.

Comprehensive Assessment of Fear

Recent research at the Institute for Child Development utilized a comprehensive assessment method involving both caregiver report of children's fear and direct observation of children's fear responses. The purpose was in part to determine the correspondence between caregiver report of children's fear and direct observation of children's fear responses and to assess the utility of a comprehensive technique.

To directly assess children's fear reactions, children viewed photographs of common natural stimuli (e.g., animals, car, boat, insects, medical procedures) on a 42-inch high definition monitor. Caregivers completed a questionnaire that assessed their knowledge of their child's

see Fear on page 33

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Sarah Shultz

Blinking from page 1

the faces of onscreen characters,” said Shultz. Toddlers with autism, however, were more likely to inhibit their blinking when looking at physical objects, and at physical objects in motion.

The results show for the first time that eye-blinks are inhibited at precise moments so as to minimize the loss of visual information that occurs as the eyelids close during a blink. Importantly, exactly when that inhibition occurs depends on how important the visual information is to a viewer. The more important the visual information is to a viewer, the more likely he or she will be to inhibit blinking. While the children in each group blinked at about the same overall rate, and blinked less during the video than before or after, the timing of blink inhibition varied between groups: typically-developing toddlers stopped blinking to watch emotional facial expressions and actions, while toddlers with ASD stopped blinking when watching objects move. Each group of toddlers inhibited their blinking, but did so during moments that they perceived to be particularly important to process (and they actually increased their blinking during moments perceived to be less important).

Toddlers with autism also inhibited their blinking after actions happened, whereas typically-developing toddlers inhibited their blinking early. This suggests that typically-developing toddlers were anticipating the unfolding of the social interactions they watched, while toddlers with ASD were reacting, after the fact, to physical actions that had already happened.

“While we knew about young children with autism paying less attention to social cues and information, this is a new insight into understanding what kids engage with and what they perceive to be most important,” said Jones. “Even if they’re looking at the same thing, different children may perceive it differently. For a two-year-old with language delays, or even an 8 or 10 year-old who struggles to communicate, this kind of measure can tell us about that child’s experience and, with that information, hopefully improve our efforts to help that child learn.”

In addition to allowing unique insights into how children with Autism Spectrum Disorders engage with and experience the visual world, Shultz says that the finding is of broad relevance to understanding perception in general. “It’s remarkable that eye-blinks, a seemingly simple physiological function, should be inherently linked to something as complex as the subjective assessment of what content in the visual world



Warren Jones, PhD

is or is not engaging. This means that we can measure not only what a person is looking at, but also how important and engaging that thing is to a person,” says Shultz.

This method is now being applied to investigate the experiences of other children with ASD. When children with ASD look at different kinds of visual information, or at faces and eyes and information that might be useful when trying to understand other people’s actions, are children with ASD actually engaged with those stimuli to the same extent as their typical peers? Do children with ASD perceive those stimuli and their adaptive value in the same way? Because engagement with socially relevant stimuli may be critical for other aspects of neural and behavioral development - such as the acquisition of speech and language skills, and the specialization of brain function - this is a critical question. And the timing of when children blink may hold new answers.

The eyes are a window to the soul, but now it seems that the way that window opens and closes offers a deeper look inside.

References

Shultz, Klin, & Jones. (In Press). Inhibition of eye blinking reveals subjective perceptions of stimulus salience. *Proceedings of the National Academy of Sciences*.

The study was funded by the National Institute of Mental Health and the Simons Foundation.

Sarah Shultz is a graduate student in the Department of Psychology at Yale University. Ami Klin, PhD, is the Director of the Marcus Autism Center, Children’s Healthcare of Atlanta, and Chief of the Division of Autism & Related Disorders at the Department of Pediatrics at Emory University School of Medicine. Warren Jones, PhD, is the Director of Research at the Marcus Autism Center and Assistant Professor in the Department of Pediatrics at Emory University School of Medicine.

The Marcus Autism Center, in Atlanta, Georgia, is the largest center for clinical care of children & adolescents with Autism Spectrum Disorders in the country, providing comprehensive diagnostic and needs-based evaluations, and a wide array of treatments programs spanning severe behavior, language and communication, school-based and in-home programs, and feeding disorders. From 1991, Marcus has served more than 40,000 individuals and their families. For more information, visit www.marcus.org.



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Autism and Asperger's: Two Distinct Disorders or One Disorder of Varying Symptom Severity

By Sam Goldstein, PhD, and Jack A. Naglieri, PhD

Autism has been conceptualized as a biologically determined set of behaviors occurring with varying presentation and severity that is likely as the result of varying cause (for review, see Goldstein, Naglieri, & Ozonoff, 2008). The disorder occurs significantly more often in boys (Smalley, Asernow, & Spence, 1988) and is found across all social classes (Gillberg & Schaumann, 1982). Recent surveys have suggested the incidence of autism in the general population may be as high as 1 per 113 (Center for Disease Control, 2007). Autism is a disorder in which individuals can present problems ranging from those that cause almost total impairment to others that allow the individual to function but not optimally. Children on the Autism Spectrum or continuum experience a wide range of developmental difficulties involving communication, socialization, thinking, cognitive skills, interests, activities and motor skills (Goldstein, Naglieri, & Ozonoff, 2008).

The Diagnostic and Statistical Manual IV – Text Revision (DSM-IV-TR) of the American Psychiatric Association (APA, 2000) criteria include a group of Pervasive Developmental Disorders under which Autism and Asperger's are consid-



Sam Goldstein, PhD

ered two distinct conditions. The criteria for Autistic Disorder include three sets of behavioral descriptions to qualify for the diagnosis. A child must show evidence of symptoms from at least two of the first set of criteria and one from each of the second and third sets of criteria. The first set of criteria features qualitative impairment and social interaction manifested by problems related to non-verbal behaviors including eye contact, facial expression,



Jack A. Naglieri, PhD

body posture and gestures of social interaction; failure to develop peer relationships appropriate to developmental level; markedly impaired sharing of emotional states or interests with others; expression of pleasure in other people's happiness and a lack of social or emotional reciprocity. The second set of criteria must reflect a qualitative impairment in communication as manifested by a delay or total lack of the development of spoken

language without efforts to compensate through gesture; marked impairments in the ability to initiate or sustain conversation despite adequate speech; repetitive or stereotyped use of language or idiosyncratic language; lack of varied, spontaneous, make believe play or social imitative play appropriate for the child's developmental level. The third set of criteria involves repetitive and stereotypic patterns of behavior, restricted interests or activities including preoccupation in certain patterns of behavior that would be considered abnormal in intensity or focus; compulsive adherence to specific non-functional routines or rituals, repetitive motor mannerisms (self-stimulatory behavior), or persistent preoccupation with parts of objects. The second two sets of criteria include delay prior to the age of three in social interaction, language as used for social communication or symbolic, imaginative play.

Though considered a distinct disorder in the DSM-IV-TR, Asperger's provides criteria identical to the Autism diagnosis for qualitative impairment in social interaction and restrictive, repetitive and stereotypic patterns of behavior. There is, however, no requirement for a qualitative impairment in communication. Specifically, this diagnosis requires an absence of clinically significant delay in language, acquiring single words by two years of

see *Autism and Asperger's* on page 27

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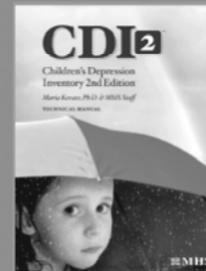
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Training Peers Improves Social Outcomes for Some Kids with ASD

By The National Institute of Mental Health (NIMH)

Children with autism spectrum disorders (ASD) who attend regular education classes may be more likely to improve their social skills if their typically developing peers are taught how to interact with them than if only the children with ASD are taught such skills. According to a study funded by the National Institutes of Health, a shift away from more commonly used interventions that focus on training children with ASD directly may provide greater social benefits for children with ASD. The study was published online ahead of print on November 30, 2011, in the *Journal of Child Psychology and Psychiatry*.

"Real life doesn't happen in a lab, but few research studies reflect that," said Thomas R. Insel, Director of the National Institute of Mental Health (NIMH), a part of NIH. "As this study shows, taking into account a person's typical environment may improve treatment outcomes."

The most common type of social skills intervention for children with ASD is direct training of a group of children with social challenges, who may have different disorders and may be from different classes or schools. The intervention is usually delivered at a clinic, but may also be school-based and offered in a one-on-one format. Other types of intervention focus on training



Thomas R. Insel, MD

peers how to interact with classmates who have difficulty with social skills. Both types of intervention have shown positive results in studies, but neither has been shown to be as effective in community settings.

Connie Kasari, PhD, of the University of California, Los Angeles, and colleagues compared different interventions among 60 children, ages 6-11, with ASD. All of the children were mainstreamed in regular education classrooms for at least 80 percent of the school day.

These children were randomly assigned to either receive one-on-one training with an intervention provider or to receive no one-on-one intervention. The children were also randomized to receive a peer-mediated intervention or no peer-mediated intervention. The two-step randomization resulted in four intervention categories, each with 15 children who had ASD:

- Child-focused: direct, one-on-one training between the child with ASD and intervention provider to practice specific social skills, such as how to enter a playground game or conversation
- Peer-mediated: group training with the intervention provider for three typically developing children from the same classroom as the student with ASD; the affected student did not receive any social skills training. The participating children were selected by study staff and teachers and were taught strategies for engaging students with social difficulties.
- Both child-focused and peer-mediated interventions
- Neither intervention

All interventions were given for 20 minutes two times a week for six weeks. A follow-up was conducted 12 weeks after the end of the study. After the follow up phase,

all children with ASD who had received neither intervention were re-randomized to one of the other treatment categories.

Children with ASD whose peers received training - including those who may also have received the child-focused intervention - spent less time alone on playgrounds and had more classmates naming them as a friend, compared to participants who received the child-focused interventions. Teachers also reported that students with ASD in the peer-mediated groups showed significantly better social skills following the intervention. However, among all intervention groups, children with ASD showed no changes in the number of peers they indicated as their friends.

At follow-up, children with ASD from the peer-mediated groups continued to show increased social connections despite some of the children having changed classrooms due to a new school year and having new, different peers.

According to the researchers, the findings suggest that peer-mediated interventions can provide better and more persistent outcomes than child-focused strategies, and that child-focused interventions may only be effective when paired with peer-mediated intervention.

In addition to the benefits of peer-mediated interventions, the researchers noted several areas for improvement. For example, peer engagement especially

see *Training on page 28*

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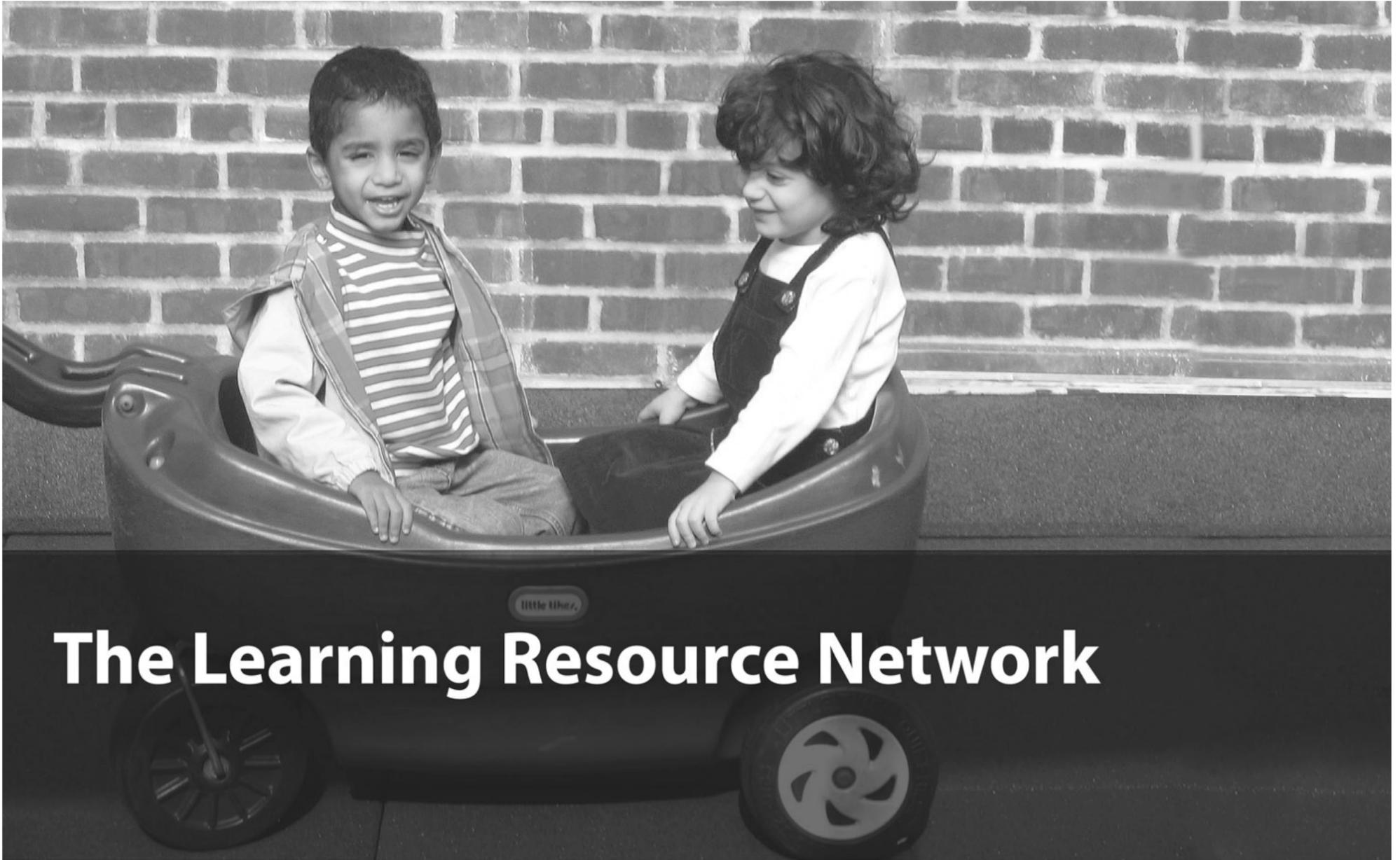
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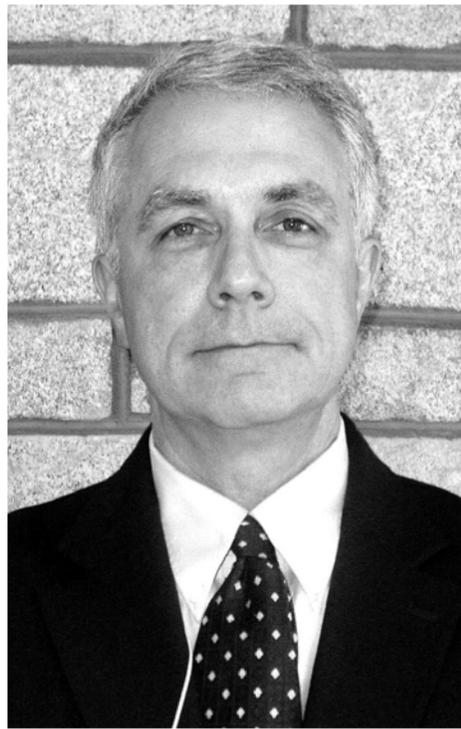
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How Science and Evidence Won Out Against Auditory Integration Therapies

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

There are many ways of learning about our world. One way is through science and the scientific process. There is a growing belief that the methods of science and scientific inquiry are the standards that should be employed when designing and evaluating autism treatments. Ideally, by adhering to common scientific criteria for acceptable empirical evidence, professionals across disciplines would study a phenomenon and all arrive at the same conclusion as to its "truthfulness" or veracity. A conclusion about, say, the efficacy of an autism treatment would be much more powerful given the adherence to the scientific method by professionals from varying disciplines all examining the same treatment from different perspectives.

Autism is known as a "fad magnet" because of the plethora of treatments available to treat the condition (Jacobson, Foxx, & Mulick, 2005). Because of the varying levels of believability and evidence supporting many of these treatments, there is a duty to be skeptical about any particular autism intervention until some minimal level of quality scientific evidence exists suggesting that a particular treatment has demonstrated positive results. The story of Auditory Integration



Thomas Zane, PhD, BCBA

Therapy (AIT) is a useful model for how, through adherence to the scientific method and process, professionals from different disciplines can examine an autism treatment and make a judgment about whether that treatment has evidence of effectiveness and should be promoted to consumers.

Researchers have reported that persons with Autism Spectrum Disorders (ASD) show higher incidences of sensory processing difficulties than the general population (e.g., Baranek, Foster, & Berkson, 1997; Gillberg, et al., 1990). Some of these sensory problems consist of abnormal responses to auditory stimuli, which could translate into learning and behavioral challenges (e.g., Dahlgren & Gillbert, 1989). As a result, Berard (1993) and others have proposed a therapeutic approach aimed at reducing or eliminating auditory sensory processing challenges.

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

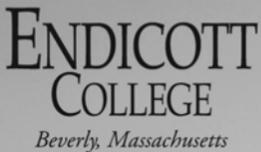
The advocates of AIT claim that there is scientific evidence to support this therapeutic approach. Indeed, all of the web-

sites devoted to AIT have references to research studies that purportedly confirm that AIT is causally related to improvements of behavior and learning. For example, at the AIT Institute (2010) website, there can be found a list of 23 research studies that purportedly support the effectiveness of AIT.

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

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

see Evidence on page 30



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Planning For Your Child With Special Needs

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



Stephen A. Ehrens, CPA, CLTC

One of the most challenging issues facing parents of a child with special needs is planning for their child's future without them. Financial planning for families with a child with special needs often requires the development of a plan that honors the future needs of their loved one, with sensitivity to the rules regarding government eligibility for programs and services. The child's parents, grandparents and other relatives may desire to coordinate their planning to best serve the interests of the child. With ever-changing laws and legal procedures, it's important for families to regularly revisit their financial plans to ensure their child with special needs is well prepared for the future.

At the heart of this planning is the desirability to preserve the child's eligibility for most publicly funded disability related programs. Maintaining eligibility for basic government programs can be vitally important, although sound financial planning will also take into consideration the fact that government benefits likely will not meet all the child's needs.

Special Needs Trusts

Many families are unaware that the receipt of an inheritance may cause eligi-

bility problems for the child. An inheritance worth as little as a few thousand dollars could disqualify an individual with disabilities from most federal benefits, such as supplemental security income (SSI) and Medicaid, as well as risk qualification under some state programs. This is an enormous loss for many, reports the National Information Center for Children and Youth with Disabilities (NICHCY), since critical services such as supported employment and vocational rehabilitation

services, group housing, transportation assistance and personal attendant care could be jeopardized.

For this reason, an effective estate plan should include a *special needs trust* – a legal document in which the family leaves chosen resources, such as money or property, directly to the special needs trust, which is managed by a trustee on behalf of the person with the disability. The trustee is given absolute discretion to decide when and how distributions are made from the trust for the benefit of the trust beneficiary, thus ensuring that government benefits are preserved. Grandparents and other relatives may also choose to designate the trust as the beneficiary of a portion of their estates. There are several types of *special needs trusts* that serve different purposes and laws affecting trusts vary from state to state. It is imperative that the family work with a knowledgeable attorney and a financial professional in creating and maintaining a special needs trust.

Funding the Trust

Building a proper roadmap for all of the family's financial goals and objectives is extremely important. For some families funding a trust may require a reallocation of the assets they already have, while others may seek to ensure that there are additional funds available for their child upon the death of the pri-

mary caregivers. For many families, permanent life insurance is the solution. By naming the special needs trust as the beneficiary of a life insurance policy, the family can rest assured that the trust will be funded with the resources necessary to provide for the future financial needs of their loved one with special needs.

Planning Considerations

There are important considerations parents can make when planning the financial future for children with special needs. Here are a few suggestions:

Prepare, review and revise legal documents - Parents should regularly monitor legal documents such as wills, trusts, power of attorney documents and healthcare proxies to make sure they are relevant and properly worded.

Develop a clear vision of how you want your child to live if both parents are no longer around - The family's planning efforts should reflect their hopes, dreams and aspirations for their loved one.

Develop a written Letter of Intent that will assist future caregivers - Having a blueprint that provides vital information regarding the child's physical and mental status, likes and dislikes, medications,

see *Planning on page 32*

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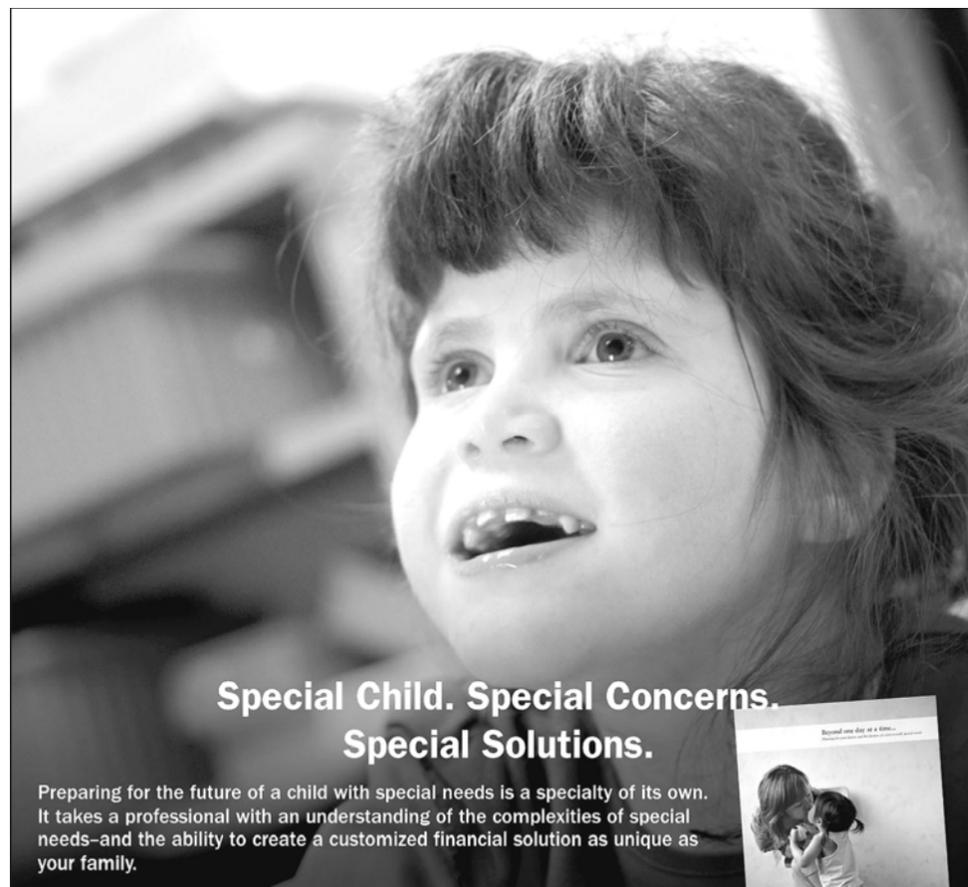
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Learning Style Preferences of Students with Autism

How They Align or Differ From Their Typical Peers

By **Dr. Diana Friedlander**
Special Education Teacher

Developing successful educational opportunities for students with autism has long been a challenge for educators. This challenge may well be due to the fact that students with autism have unusual intellectual and academic skills profiles making it difficult for teachers to accurately assess students and align curriculum. The rise in the incidence of a diagnosis of autism is a pressing call to educators to develop a better understanding of the unique profiles these students present and to carefully plan educational opportunities which have been thoughtfully created with mindful consideration of student preferences. All learners have a preferred learning (Dunn & Dunn, 1992). Educators must become more proficient in assessing learning styles as they strive to differentiate instruction based on their students' needs. This paradigm neither classifies learners based on ability nor disabilities but, rather, on their individual preferences and therefore bodes well for students with unique skill sets such as those seen in students with autism.

Several researchers have documented the positive effects of teaching to all students' preferred learning-style and their work served as a foundation for this investi-



Dr. Diana Friedlander

gation (Burke & Dunn, 2003; Dunn, Beaudry, & Klavas, 1989; Dunn & DeBello, 1999; Dunn, Denig, & Lovelace, 2001; Dunn & Dunn, 1992). Based on the knowledge that individual instructional preferences exist and can be reliably measured, this study extended previous research to include a population of students with autism who were not specifically identified in previous research and found the uniqueness of its findings for this population to be in con-

cert with that of other students identified as having other special needs such as Attention Deficit Disorder or Emotional Disturbance (Braio, et al., 2001; Brand, 1999; Fine, 2002; Greb, 1999; Majewski, 1990).

The similarities and differences in the learning preferences of students with autism in comparison to their typical peers was investigated and the possible uniqueness of their learning preferences as a group was examined by responding to the following questions: Are there common learning-style preferences among students who are diagnosed with autism, and are there significant differences between the preferred learning-style preferences of students with autism and the learning-style preferences of their typical elementary level peers?

Data on student learning-style preferences were collected from student responses to questions on the Elementary Learning Style Assessment (ELSA) (Dunn, Rundle, & Burke, 2007), a comprehensive diagnostic instrument that considers 25 different variables in each individual's environment, sociological, and cognitive processing traits as described in the Dunn and Dunn learning-style model. The model consists of 20 elements, measured by the 25 variables in five strands: Environmental, Emotional, Sociological, Physiological and Psychological.

A sample of 52 students attending a private school in a large metropolitan area

whose academic performance was at an elementary level and who had a diagnosis of Autism Spectrum Disorder self-reported their preferred learning styles using the ELSA computer-based self-assessment. The findings, as related to these five strands, indicated that there were significant commonalities in the manner in which students with autism preferred to learn (Friedlander, 2010).

Students respond to a number of environmental factors when learning. This research showed that students with autism indicated a preference for learning in environments which included background noise. However, 40% of the students tested indicated they preferred a quiet environment. Students also indicated a strong preference for bright light while learning compared to dim light and a significant preference for a warm environment, with almost 50% of the students preferring warm temperatures over cooler temperatures while learning. It should be noted that the element of Design which considers a formal or casual arrangement of the classroom, such as a conventional desk and chair as opposed to a bean bag chair or large pillows, did not meet the more stringent level of significance (.025) chosen for this study. However, the level of significance was found to be .035, which had the researcher opted for a more

see Learning Style on page 34

Supporting Academic Success with Assistive Technology

By **Lorianne Hoenninger, MS, ATP**
Accessible Learning Technology Alternatives

Schools are challenging environments for all learners, especially those with disabilities. Students with Asperger's Syndrome are particularly vulnerable, as they often bring a strong intellect to the classroom, but deficits in social, language and motor skills negatively impact their success. Fortunately, improvements in technology have resulted in a variety of commercial products that can help students compensate for their disabilities.

For students who experience difficulty with note taking, the LiveScribe Echo SmartPen (about \$150 from BestBuy or Amazon) may be beneficial. This tool links audio to the written word and is of value for students who cannot write notes efficiently, and/or for students who would benefit from re-listening to information at their own pace. With the Echo SmartPen, students can focus on the content of the presentation while they jot keywords and drawings for later search. Similarly, students can create their own audio notes for studying, by writing down vocabulary words and recording the definition. For students who find it difficult to focus for the entirety of each class, use of the Echo SmartPen allows them to re-listen to the class discussion at a later time, catching up on any information they may have missed.

Audio notes can also be uploaded to



Lorianne Hoenninger, MS, ATP

the computer and to mobile devices and saved as "pencasts" for independent study and review. Since pencasts replay step by step, exactly as they were written in the LiveScribe notebook, they are also very useful for teachers for the creation of review materials. For example, a teacher could write out all the steps in a math problem, verbally explaining the process as it is written, then save the resultant

pencast to the class webpage. Students can replay the pencast video at home, to support their mastery of the material.

While the Echo Pen is an excellent solution for students who handwrite, for students who prefer to type, the Apple iPad can be a resource. There are applications (apps) or programs that provide a similar function to the Echo SmartPen on the iPad. "PaperDesk" by WebSpinner, LLC and "AudioNote" from Luminant Software, Inc. both synchronize audio to typing so that later, users can tap any typed word and jump to that portion of the recording.

For students who need to type their responses on worksheets, the Apple iPad 2 has a camera that can scan worksheets into the device. Apps such as "GoodReader" by Good.iWare Ltd. provide students with the option to snap a picture of a worksheet, annotate it with their typed responses, and then email or upload their completed work.

Students with strengths in the auditory modality, who often benefit from text-to-speech supports, will appreciate the "ZoomReader" app by Ai Squared. Similar to desktop computer applications such as Kurzweil 3000 or Read and Write Gold, ZoomReader snaps a picture of print, changes it into text and reads the words aloud.

Bookshare (www.bookshare.org) is a web-based resource that is available for free to all school districts in the USA. Eligible students with reading, physical or visual deficits can enroll with Bookshare and re-

ceive access to digital versions of novels and textbooks. Once registered, the included free "Read:OutLoud" app will read the books aloud to the student, with word by word highlighting, facilitating reading comprehension. Bookshare also has an iPhone app called "Read2Go," which enables students to see and hear their downloaded books on their iPad, iPhone, and iPod touch.

Many students benefit from access to online resources to support learning at home. There are many free, online tools that could be used to support study skills, while providing an alternative to the manual production of flash cards.

Khan Academy (www.khanacademy.org) is a website with a library of over 2,400 free videos demonstrating various math and science concepts. Similar to a pencast approach, these videos can be replayed as needed to master new concepts.

Study Blue (www.studyblue.com) is one of the newest online flash card websites. Flash cards can be created on the computer, with text, audio and graphics, and then uploaded to mobile devices for on-the-go studying and practice.

Evernote (www.evernote.com) is a free online service available for computers and mobile devices that allows students to store and organize information including notes, websites, audio, pictures, etc. that they gather from the internet for research projects or personal reasons. Captured information

see Technology on page 25

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

By Carrie Cariello



Our Story

People often ask me how I knew something was wrong with Jack, and how old he was when we noticed warning signs. Obviously autism unfolds differently for each individual; some demonstrate symptoms very early on, while others grow and interact normally until a particular age and then they seemingly morph into another person altogether.

From what I've read and heard from other parents, the development of this tricky disorder is as unique as the minds of autistic people themselves. And so this is our story with a little boy named Jack.

Jack is my second son, and he was born 13 months after our first son, Joey (Public service announcement: You can get pregnant while breastfeeding). My pregnancy and delivery were very normal and he arrived on Mother's Day; one day later than his due date. A whopping nine pounds, three ounces, he was pronounced healthy and we took him home a day later.

Those of you who know Jack personally may be surprised to learn he did not spring from the womb demanding to



Jack (second from left) and his siblings

know the obstetrician's birth date or the color of his radio. What he did come out doing was coughing, sneezing, and fussing. He developed congestion around three weeks and battled a seal-like bark and dripping nose from that point forward. Repeated visits to an ear, nose, and

throat specialist revealed reflux and eventually landed us in the operating room having tubes placed in his ears and his adenoids removed when he was five months old.

Once he had surgery we were hopeful things would get easier with Jack, and

that his constant fussiness would subside along with his perpetual ear infections and reflux. Little did we know the fun was just beginning.

People usually want to know when we knew something was wrong. Back in Buffalo, NY, Joe and I once took the two boys to an Italian restaurant we loved called Rizzo's. Joey was about a year and a half and Jack around six months. I distinctly remember them both dressed in matching snowflake pajamas, and Jack was sitting up in a high chair for the first time. As we enjoyed a nice meal people stopped to comment on their likeness and closeness in age. All in all, a lovely evening. So why does this memory make me so sad? Because it's the last time I remember not worrying about Jack.

The next six months were some of the most trying times in my life as a mother. I can't say there was a light bulb moment where we knew with absolute certainty that he had autism, but I always had a gnawing pit in my stomach and a strong sense that something was just not right. His language wasn't developing normally. He never pointed or gestured, and he had a difficult time managing solid

see Our Story on page 24

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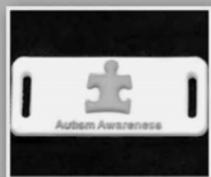
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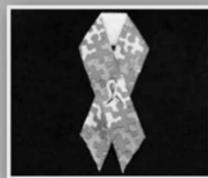
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Show Me The Science - Advice for Parents Seeking Treatment

By Robin H. Morris
Freelance Writer

Merriam Webster's Medical Dictionary defines science as: "knowledge or a system of knowledge covering general truths or the operation of general laws especially as obtained and tested through the scientific method and concerned with the physical world and its phenomena." The Scientific Method asks a question followed by research, hypothesis, experiment, analysis and conclusion. Ironically, the internet, which is often a stunning source of cutting edge ideas, can also be a conduit of misinformation, inciting rogue theories.

Willard Duncan Vandiver, the Congressional Representative from Missouri, made a statement in 1889 to express that Missourians were particularly astute and not easily fooled. "I'm from Missouri; you've got to show me." Duncan 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" attitude. Parents of autistic children are so very vulnerable that



Robin H. Morris

we are often willing to plunge into any intervention. The conflict of Science vs. Sentiment is almost tangible. My one caution and caveat is that there is money in autism these days. It is the most practical

message to be aware of snake oil or quack remedies.

Our son is now 24 years old, and we are seasoned veterans, living with autism. I can share over 20 years of interventions and I believe that evidence-based practice is our best hope.

The Science, Not the Sentiment, Must Prevail

I remember that when my Dad was succumbing to colon cancer in 1996, 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 an auspicious group, we parents of autistic children. Full disclosure: my initial venture into the world of rogue treatment for autism was when I

packed up our 4 year old autistic non-verbal son and traveled to Montreal to attempt auditory training. I had read *The Sound of a Miracle* by Annabel 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 tear them from his ears) for 2 solid weeks. We returned to the US, without regret, but there were no whistles or bells that rang to say "eureka, it's a miracle!" Ironically, another more pressing issue intervened. Our son developed a type of parasite condition (we were told that it was possibly due to his drinking the lake water in Canada) 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!"

see Show Me on page 27

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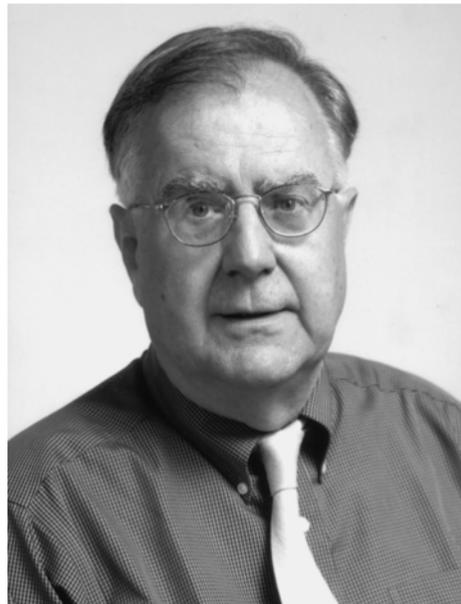
The Cybility Jobs Program Story

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

Last July, Scott's mother called us advocating for her son to be enrolled in our seven-month-old Cybility Jobs Program: "He just aged out of Special Ed. He receives SSI (\$769/mo), is twenty-two years old, types 45wpm, is very bright, spends hours on the internet, but he cannot find any kind of work. He is Autistic, nonverbal, has ADHD, is anxious and will not look at you; he covers his mouth and grunts. He is 6'2" and 250lbs. I think some employers may be afraid to hire him. I have not been able to find any NYS funded jobs program for adults on the spectrum, only Day Treatment, which is glorified 'babysitting.' I know he could earn money using his computer skills but I don't know how. I don't want him spending the rest of his life in a Group Home after I die. Can you help us?"

Sadly, Scott's story was familiar. According to the NYS Office of People with Developmental Disabilities (OPWDD), there are over 20,000 persons diagnosed on the Autism Spectrum in NYS and some 8,000 of these are adults. According to the CDC, 1 in 110 boys are diagnosed with ASD (about 1,000,000+ in the U.S.), and about 40% are nonverbal.

Whether or not an individual has a developmental, mental or physical disability,



Donald M. Fitch, MS

federally funded education stops at age twenty-two. And while there are Vocational Rehabilitation (VR) Programs and Community Colleges with programs for many with disabilities, we have found none for folks like Scott in New York or New Jersey.

As a nonprofit NYS ED licensed Business School and a certified Microsoft Office Training Center, we have taught Microsoft Office job skills to over 2,000 adults with disabilities over the past fourteen years with mixed success. While we are generally effective with persons diagnosed with psychi-

atric issues (e.g. Schizophrenia, Depression, Bipolar Disorder, PTSD, etc.), we have not been very effective with persons diagnosed on the Autism Spectrum.

Our traditional Instructor-led small classes require students to maintain their concentration for fifty minutes, three times per week, for twenty-two weeks (a total of sixty-six class hours) to become proficient in just one Microsoft Office Software Program, (e.g. Word, PowerPoint or Excel). It is very expensive and time consuming to staff a school using a traditional instructional modality for a special needs population teaching a NYS ED approved Microsoft curriculum.

In our classrooms, our staffing includes a Microsoft (MS) certified NYS ED Licensed Master Instructor and two MS Certified Assistant Instructors, almost two hundred-fifty hours of staff time per course, for eight students. The problem is, while there are plenty of folks who want to learn MS Office Skills and get a well paying \$12-\$15/hr job, there aren't enough MS qualified Instructors who are experienced teaching special needs students. Even if we could find them, we don't have the funds to pay them.

We knew this perpetual lack of funds and experienced staff would always limit how many students we could serve. In business terms, our instructional model was not scalable. It had to be radically restructured, but how?

Because many of us had years of experience in the world of business, we

knew which work skills were essential to generating quality letters, tables and charts, internet research, data entry, billing and many other office tasks. We felt our challenge was to transform what Microsoft's software engineers and NYS Ed's academics thought our students needed to learn to get a job into what employers said our students needed to get hired!

We decided to take our direction from the marketplace because, at the end of the day, the employers were the ones who decided who to hire and who to fire. Whatever skills they would pay for are the skills we had to teach our students. Using the employer as the final authority, we worked backwards, eliminating everything in our MS curriculum that didn't apply to the job. We were able to reduce the amount of material taught and class time by 70%!

Our next challenge was to figure out how to teach an ASD population that preferred computers to instructors. They also preferred visual learning over reading pages of text or listening to someone talk for fifty minutes. After weeks of trial and error we were able to identify the essential work skills and then, to illustrate each step using a "comic book" format (see Publisher Tutorial on pg. 31).

Then, we tested and refined each Tutorial among three populations, Autistic, Psychiatric and "Neurotypical" until the Tutorial could "stand alone." That is, the student

see *Cybility* on page 31

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Difficulty Finding Appropriate Education Leads to the Creation of a School for Students with ASD

By Michael J. Kondor, MA
Executive Director
The Ridge School

Seven years have gone by. When I look back and see that I now have a school full of happy students who have become lifetime friends it makes me realize the importance of starting our school for children with Asperger's Syndrome. As a teacher I have come to realize that Asperger's is not a disability, it is a true gift. Our students are happy because they have been allowed to learn using the abilities they have been born with.

An Asperger's student can visualize projects designed in their heads. They tend to be visual and auditory learners; most often they are like recorders in that they process material slowly auditorily and then are able to repeat this by visually reproducing the knowledge they have been presented. These students exhibit creativity and think outside the box. Many famous people, inventors, artists, and even presidents of the United States probably had Asperger's Syndrome.

Starting a school is not easy. The biggest obstacle is MONEY, the second is proving that what you are doing is right for the students, and the third is to teach the rest, especially other educators, what



Michael J. Kondor, MA

to do to understand and enter the world of an individual with Asperger's.

The money issue was not easy, but the one thing my wife and I had was that, through hard work, we had been able to pay off our home. Home equity loans

were not hard to get at the time, so we applied and were granted a \$100,000 loan within a couple of weeks. Although I felt it was risky, I knew in my gut that both of us had to do this and use this money to start the school.

We next approached the Hyde Park United Methodist Church to rent space for our school, which has 501(c)(3) not for profit status. They had just finished a beautiful new education wing and were glad to have us join them. It was important to set the school up like this because my wife and I were approaching 60 years of age and we wanted to be sure the school would be here for future generations.

History and Inspiration

The Ridge School was started because of my nephew JM, of whom my wife and I are legal guardians. JM was diagnosed with Asperger's Syndrome when he was about 7 years old. He attended early intervention programs in which his providers felt he had a mild form of autism.

In pre-kindergarten, we enrolled him in a private school because the local public school only offered a half day program. All other local private schools rejected him because of the diagnosis of mild autism.

The pre-kindergarten program worked out well, so we enrolled him in the same school for kindergarten, again an all-day

program; however there were 37 students in his class. It was a Montessori-based program. The size of the class was too large and confusing for JM. In the spring, we removed him from that program and went to our local public elementary school. JM seemed to finish the year well and it was recommended he enter a regular first grade class. The students in this class were integrated with a second and third grade class so JM spent a great deal of time with older children.

At the end of the year the teacher, my wife, and myself decided that the program was too hectic and confusing for JM so he went into a traditional second grade class with one of the most wonderful teachers JM could have ever had. She recognized that JM had Asperger's and did everything in her power to accommodate his needs. This teacher fought hard to get him the services that were in his IEP which included Speech with language pragmatics, Occupational Therapy, Social Skills, and counseling. The district was unable to provide these services because they claimed they were unable to locate providers.

The last two weeks of school he received speech, after which his teacher decided speech was no longer needed! When I mentioned to the school psychologist that it was important for him to

see Education on page 32

Our Story from page 21

foods. As commonly found with autistic children, Jack had limited eye contact and didn't babble or coo. He rarely seemed content in his own skin and fussed constantly - I dubbed him "Tuggy" because every morning I woke to the sounds of his nasally whine.

Early on people were almost tools to Jack. He would take my arm and lead me to the refrigerator or toy he wanted, placing my hand on the desired object. We'd play a game at mealtimes where Joe would point to me and repeat, "Mommy! Jack, look at Mommy! This is Mommy." He seemed to have no idea who we were. It was chilling.

And tantrums? Whew. All I can say is I should've done commercials for Secret Antiperspirant because it was the only thing standing between me and a drenched shirt each time I had to take him to the grocery store or couldn't figure out that he wanted milk. He could rage and bang on the floor for what seemed like hours out of frustration. And really, who could blame him?

When Jack was about eight months old our pediatrician referred us to early intervention services for an evaluation and we started to become acquainted with terms like "joint attention" and "self-directed." After many, many painful sessions where I watched through double-sided glass as a speech therapist tried to coax language from this boy, we were offered in-home services for speech and occupational therapy. At this point he was 16 months old.

In the midst of all this, many, many

people were adamant that we were over-reacting. We heard explanations of how Jack's older brother was talking for him, of how children develop at their own pace, how he was fine, just fine, and to let it go. During this time I learned a very valuable lesson; I am the only advocate for my children, and if we didn't fight for Jack no one would. If I succeed at nothing else for my entire life, I will be content knowing I did everything I could for him from the very beginning. It wasn't easy.

Right about this time our third son, Charlie, came along and when I returned from the hospital after his delivery, Jack strode past me as if I were a floor lamp (OK, a chubby floor lamp in stretch pants, but you get the idea...). My sister came to visit and for the first time someone in my family validated my fear. As she watched him trace the same grout line with his finger she gently agreed that yes, maybe there was something off.

I worked four days a week in those days, and both Jack and Joey were in childcare. One day the center had a photographer come in for class pictures and I went in to see if I could help. Jack was about two at this time, and I remember sweating as I chased him around the playroom, trying to get him to listen to me and sit still. The photographer - a stooped man in his sixties - tried to reassure me by saying "Don't you worry! I work with autistic children all the time!" It stopped me cold. Although no one from early intervention or the doctor's office had uttered that term yet, I knew in my bones that's what we were

looking at. Not long after the kindly man from Teddy Bear Portraits connected the dots, our developmental pediatrician also made her assessment: Autism.

Or more specifically, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), a stop on the slippery bell curve of autism. In a nutshell, PDD-NOS is characterized by delays in socialization and communication.

I've heard parents of an autistic child describe a period of grieving and bereavement immediately following a diagnosis, a time where they mourned the loss of a normal child. While very understandable, I never experienced sadness in that way, I think because I always knew with certainty something was wrong and that he wasn't developing normally. Frankly, I was relieved. It was a relief to have a name to the behavior, to be able to explain why he insisted on taking the vacuum apart over and over during play dates. It was a relief that I wasn't crazy - that something was wrong with my adorable little boy and we needed help. We accepted his diagnosis and forged ahead, getting him as many early services as we could.

Sometimes after I explain our path to his diagnosis, people will ask me what life is like with Jack now. I wish I could say after nearly six years of services, IEP meetings, paraprofessionals, and therapies that he's shed his diagnosis like a second skin and is cured, but that is not the case. While he's outgrown many of his earlier behaviors like whining and non-communication, they've been replaced by other issues such as

anxiety and obsessions. The old saying, "little kids, little problems - big kids, big problems" seems to apply tenfold to Jack. But there is a very bright side to all of this.

The bright side is that Jack is extraordinary. He's traveled so incredibly far since those early days of tantrums and non-verbal communication, and is steadily reaching goals we once thought impossible. Now I actually hold conversation with the very boy I didn't expect to speak full sentences. I listen to him play with his siblings and read books aloud, and my heart soars.

As his language improves I get a little peek inside his remarkable mind. Last week he asked me what color I see for Monday. I explained that I don't see days as colors and asked if he did. Almost confused, he replied that every day was a color and rattled off which colors he associated with which day. I was astounded.

Saying that I'm lucky to know Jack doesn't do it justice. And the things he's taught me? Well, that's almost another essay. He's taught me to trust my instinct in the face of challenge, to never give up on him, and that Thursday is purple.

So that's the entire history of Jack....all seven years, seven months, and three days of his beautiful life. I can't wait to see how the rest of his story unfolds.

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.

Acting Makes the Aspergers Go Away

By Julie Reuther
Mother

It was the third night of production of Albany's Park Playhouse Kids' *Annie Jr.* when eleven little girls, ages 9-12 who landed sought-after orphan roles, found themselves in a bit of a predicament. They were up on the outdoor stage for the "Hard Knock Life" reprise in scene one after Miss Hannigan had just stormed off because Annie got away in Mr. Bundles' laundry bin. As written in the script, the girls would laugh and sing praises about Annie's escape from the orphanage. But then there were technical difficulties and their musical cue didn't turn on. The little girls improvised extra laughs and giggles in the hopes they would soon here the music. The clock ticked away but still no music and some people in the audience just began to catch on to an issue. Then all of a sudden the orphan standing on the end, eleven year old Phoebe, playing the role of "Duffy" sang out loud and clear, "Lucky kid she got away." While singing this line she focuses her eyes on Belle playing "Molly" who then knew to sing her line a capella too, "Running free in NYC!" It seemed as if Park Playhouse had a hero that night. Phoebe "saved the show" by leading the



Phoebe may have Aspergers, but musical theater has allowed her to achieve success and build self-confidence

girls through an unexpected situation. What many parents and audiences members did not know is that little girl playing Duffy has Aspergers.

The next night, Park Playhouse held a special ceremony before the show to award two cast members the Carol Butler Simmons Memorial Scholarship. Months prior, after a competitive audition of over 100 children and being informed of her role, Phoebe applied for the scholarship. The scholarship asked cast members to write about their challenges and how theater helps them

with these challenges. We made sure that the application would be confidential so she would not be labeled by the other parents and children. I sat down with Phoebe and asked her the questions and we discussed them and this is what she wrote:

Please tell us about the challenges you face: "I have Aspergers. It is hard for me because I pace when I am bored and it's kind of hard for me to take interest in other people. I am also not good in school sports like the other kids."

What have you done to overcome these challenges? "I try to act normal when I'm around other people. To fit in better with other kids, I have found comfort in singing, acting, and dancing. When I'm up on stage singing for my schools Variety or Follies show, the other kids in my school actually think I'm cool."

Please explain why acting and/or theater is important in your life: "Theatre is important in my life because it is fun and I get to pretend to be a character. When I play a character I am not myself, Phoebe with Aspergers. Theatre also helps me to be more social. I take a lot of interest in all the kids and their characters in the play."

Realizing that it is still very early in your life, please tell us about your greatest dreams and goals: "I want to be a famous actress and singer for other kids when I'm around 15 years old and I've been really trying to work up to that. I always want to be involved in theatre. Someday, I hope to help other kids that face the same challenges that I do."

Then about three weeks later, she received a letter in the mail from Park Playhouse's scholarship committee. Congratulations! it read. Phoebe accepted the award on stage proudly. Carol Butler's husband had driven from NYC to hand

see Acting on page 30

Technology from page 20

is automatically processed, indexed, and made easily searchable. Users can add tags and organize notes into different virtual notebooks.

Study Stack (www.studystack.com) is a website where students can create stacks of electronic cards that can be reviewed online, printed or exported to PDA, cell phone and/or iPod. Each stack can be viewed in flash card mode, in match mode, as hangman games, crossword, word find or bug match. Flashcarddb (www.flashcarddb.com) is a similar site, but with a more extensive selection of premade flash cards. These cards can only be reviewed or printed. Other sites such as Flashcard Machine (www.flashcardmachine.com), Brain Flips (www.brainflips.com) and Quizlet (www.quizlet.com) enable students to add graphics and sound to their study cards, then play games and quiz themselves. Finally, Flashcard Exchange (www.flashcardexchange.com) is a site that is particularly teacher-friendly, as it saves statistics on the student's use of the study cards, presenting the student's right/wrong responses in a pie chart.

Technology can also support social skill development. One very interesting use of the Apple "i-devices" is as a source for social "crib notes." The Fraser Child and Family Center in Minneapolis (www.fraser.org/our_services/by_location/fcfc.htm) have created a series of short videos and slide shows that they distribute through Apple app called QuickCues (\$4.99). If a student is unsure of how to answer the phone, engage in small talk or

ask for help, they can read the "crib notes," mentally rehearse the procedure, and then confidently engage in the activity.

If QuickCues does not contain the exact social script a particular student requires, customized social cues can be created with the aforementioned online flash card apps, then uploaded to inexpensive apps such as "Talking Flash Cards" by TheraTech Solutions, LLC, "Touchcards" by Steven Romej, and "Flash Cards" by Resolute Digital, LLC. Check with each online flashcard maker as to which i-device or android app they are compatible with.

For further information on apps for social skill development, check with the autism directory at blog.autismspectrumdirectory.com/2011/01/14/ipad-ipod-touch-and-iphone-apps-social-skills-social-stories-and-scripts/.

Finally, no discussion of current, inexpensive technologies would be complete without mention of the Google Docs. Google Docs includes an online "Cloud" word processor. Compositional writing begun in Google Docs can be accessed from both home and school, facilitating difficulties with paper management. If a student forgets to print out, transport or simply loses an assignment, he/she can easily access the assignment from any internet-connected computer.

The previous mentioned technologies are just a sampling of what is available for students with disabilities. With their support, students can be more successful than ever.

To learn more, please contact Lorianne Hoenninger by email at accessiblelearning@verizon.net. This article was originally published in the AHA Fall 2011 issue of "On the Spectrum."

A Possible Cause of Autistic Disorder: Non-Coding mRNA

By Edward R. Ritvo, MD
UCLA Medical School

The new field of Molecular Genetics is on the verge of unraveling the mystery surrounding the cause of Autistic Disorder.

For many years it has been known that genetic influences exist in some cases of Autistic Disorder (AD). For example, if one child in a family has autism there is a 10 percent chance that each of their following children will also have autism; this is called the sibling recurrence risk estimate. Also, if one twin, identical or not, has autism, there is a significantly higher chance that the other one will also have AD.

It has also been known for many years that there are two types of genetic instructions carried in our genes (DNA). The first type of instructions direct, or code for, the building of the specific parts of the body, such as bones, blood vessels, nerves, etc. These coding instructions take up only about two percent of our DNA. Efforts to identify abnormalities in non-coding parts of genes in Autistic Disorder have met with little success. And while some cases have been traced to specific abnormalities of DNA coding parts of genes, they account for less than 5 - 10% of all AD cases.

The second type of instructions directs when the parts of the body develop and where they get placed. These instructions



Edward R. Ritvo, MD

are located on the other ninety-eight percent of the DNA - the part that does not code for specific proteins. This is called non-coding DNA. They are copied, or transcribed, in the nucleus of cells by non-coding RNA which, when it goes to work in a cell's cytoplasm, is called messenger or mRNA.

see mRNA on page 34

New Trends from page 1

changes and clinical phenotypes, the link between genetic factors and brain structural and functional alterations. It is anticipated that the integration of genetic and clinical studies with neuropathological and biochemical studies of the brain will help in the discovery of the mechanisms that lead to the autistic phenotype and in the design of mechanism-oriented targeted treatments.

Our knowledge of the clinical phenotype and genetic factors in autism is based on the examination of thousands of individuals with autism. However, a review of the world literature revealed that between 1980 and 2003, only 58 brains of individuals with idiopathic autism were examined postmortem (Palmen et al 2004). This low rate of brain donation for research is the major obstacle in research progress. Neuropathological studies are usually limited to a few brains. Due to the very low rate of brain tissue donations for autism research and the etiological and clinical diversity of autism, the pattern of detected changes is incomplete and inconsistent, and neuropathological diagnostic criteria of autism have not yet been established (Lord et al 2000, Pickett and London, 2005).

Research on Autism Requires New Standards of Tissue Banking, Handling, Distribution and Sharing

Brain banking is a particularly important tool for making progress at a time when new technologies in molecular biology, biochemistry and confocal microscopy are opening up new avenues of research on autism. However, autism spectrum disorders are so different than other targets of postmortem studies that they require appropriate research design, and standards of tissue acquisition, preservation and distribution:

1) Autism affects the entire life of an individual with modifications of the phenotype during childhood, adulthood and aging. To detect and characterize developmental and aging associated changes, the cohort examined must represent the entire lifespan and the number of examined individuals must provide statistical power to detect significant differences.

2) Clinical and neuropathological studies reveal a broad spectrum of inter-individual clinical manifestations, most likely as a cumulative effect of genetic and epigenetic factors determining both structural and functional alterations. This heterogeneity requires large enough cohorts to identify and characterize major autism phenotypes and mechanisms shaping these phenotypes.

3) Autism is diagnosed in association with other syndromes/disorders, including fragile X syndrome, chromosome 15 duplication, Down syndrome, seizures, and intellectual deficits. It requires parallel studies of reference cohorts.

4) Qualitative developmental abnormalities are usually undetectable by routine neuropathological examination. However, modification and expansion of neuropathological evaluation methods reveals a broad spectrum of defects of neurogene-

sis, migration and cytoarchitecture (Wegiel et al 2010a). A majority of developmental changes are mainly quantitative and only unbiased morphometric methods can detect significant changes of brain development.

5) Changes in the developing and the aging brain of autistic individuals have a global character with brain region, neuronal population, neuronal circuit and neurotransmitter system specific alterations. Therefore research on autism requires the combining of localized models into global models of brain developmental defects, keeping in mind that each autistic patient is unique and all statistical strategies are dealing with heterogeneity.

Age Associated Alterations in the Brain of People Diagnosed with Autism

In contrast to majority of human illnesses, autism is a life-long disability with age-specific alterations. The global marker of age-associated alterations is abnormal acceleration of brain growth in autistic children 1 to 2 years of age (Courchesne et al 2001, 2003, Dawson et al 2007), slower rate of brain growth at age of 2 to 4 years (Courchesne et al 2001, Hazlett et al 2005), and a decrease to control levels in the middle to late childhood period. The period of accelerated brain growth rate precedes and overlaps with the onset of detectable behavioral changes, and the period of deceleration coincides with worsening of autism symptoms (Dawson et al 2007). Recent data indicate that these changes are associated with an increase of the total number of neurons (Courchesne et al 2011). Our studies reveal that in the majority of examined brain regions, the volume of neurons is less than in normally developing children, but these differences are almost undetectable in the brains of teenagers/adults (Wegiel et al 2010). Identification of the self-regulatory mechanisms that can lead to brain size and neuron size normalization in early childhood may result in treatments that reduce or eliminate developmental delay and restore correct trajectory of brain development and function. Altered brain development suggests that the aging autistic brain will be also modified, but late age-associated changes are almost unexplored.

Brain Only?

Major research efforts are focused on the brains of autistic individuals. However, clinical records suggest that immune, digestive and peripheral nervous system alterations are also present in autism. One abnormality is of particular interest. Hyperserotonemia in autism, identified as an increase in the serotonin level in blood platelets by up to 50% is a frequent finding. A significant amelioration of obsessive-compulsive rituals and routines, and anxiety and aggression in subjects with autism treated with selective serotonin reuptake inhibitors, such as fluoxetine (deLong et al 1998, Kolevzon et al 2006) confirms the hypothesis that the serotonergic system is altered and that modulation of these developmental alterations produces clinical improvements.

Blood serotonin is produced by enterochromaffin cells of the intestinal epithelium whereas brain serotonin is produced by neurons of the raphe nuclei projecting from the brainstem to all cortical and sub-

cortical subdivisions. However, in spite of evidence (a) that the development of the serotonergic system of autistic individuals is altered, (b) that these alterations contribute to the clinical manifestations of autism, and that (c) pharmacological interventions result in significant benefits of some autistic patients, enterochromaffin cells of the intestines, the source of blood serotonin, and the raphe nuclei, the only source of serotonin supporting the entire brain function and contributing to autistic phenotype were not examined. These examples of gaps in our knowledge of the pathology of autism indicate that changes in standards of tissue preservation for research are necessary.

The Role of Brain and Tissue Banks

One of factors contributing the low rate of tissue donation is the limited knowledge of the general public about legal and technical aspects of donation as well as the important role of postmortem studies of the brain and other organs in research progress on autism. Banks play a critical role in cooperating with families and in obtaining clinical records. Brain and tissue banks services for families are free of any charges to them. Tissue samples as well as clinical data are distributed to qualified researchers in a coded and anonymous form. The next of kin, who signs the donation document, is eligible to receive a neuropathological report based on examination of the brain and histopathological sections, also without charges. To match to the complexity of modern research, the banks adopt complex protocols of tissue collection, clinical data acquisition, clinical and neuropathological diagnosis, tissue quality evaluation, tissue preservation, processing, storage, and distribution. One brain provides hundreds of tissue samples dissected with anatomical precision to obtain information about specific brain structures or neuronal populations and samples are distributed to dozens of projects (Vonsattel et al 2008). Estimates of the brain bank cost per brain preserved for postmortem studies is in range between \$10,000 to \$30,000 in US and 10,000 to 15,000 euros for the BrainNet Europe consortium (Hulette 2003). However, brain and tissue banks efforts reduce the risk of inclusion in dozens of research projects and publications a case with an incorrect genetic, clinical, neuropathological classification or affected by postmortem degradation distorting biochemical and neuropathological studies. As a result, tissue banks contribute to elimination of false results, increased quality of research and reduce the costs of the individual research project. Autism tissue banking is supported by the Autism Speaks/Autism Tissue Program and new initiatives of the New York State Autism Consortium.

Autism Tissue Program

In response to both families and researchers, requests to the Autism Tissue Program of Autism Speaks provides information and support for families donating tissue for research and concentrates on enhancing the availability of brain tissue for research (www.autismtissueprogram.org). To advance research on autism and related disorders, ATP coordinates tissue recovery, storage, cataloging, preservation, and distribution of brain and other tissues to quali-

fied investigators. The tissue collection includes samples from normal individuals (a control cohort) and individuals with developmental disabilities other than autism.

New York State Autism Consortium

New York State Office for People with Developmental Disabilities (OPWDD) supports more than 16,000 people diagnosed with autism and ASD, and the number of autistic subjects increases every year. In response to the growing autism crisis, in 2008, the OPWDD created a New York State Autism Consortium under the leadership of the Institute for Basic Research in Developmental Disabilities (IBR). The aim of the Consortium is to establish the infrastructure, resources and collaboration necessary to advance basic and applied research on autism. The consortium collaborates with affected families, advocacy organizations, research institutions and public agencies to implement new research on the causes, mechanisms and treatment of autism. One of tasks of Consortium is support and expansion of tissue donation and banking, including brain, and other tissues and organs.

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Autism and Asperger's from page 14

age and communicative phrases used by three years of age. Because of the significant overlap in the diagnoses of these two conditions, most medical and mental health professions consider Asperger's as a milder form of autism or even "high functioning autism" despite the fact that it is not delineated this way in the DSM-IV-TR. In fact, proposals for the Pervasive Developmental Disorder categories for DSM-V have recommended the elimination of the distinction between these two conditions and instead propose to refer to the combined conditions as Autism Spectrum Disorder (American Psychiatric Association, in press).

The new proposed diagnostic criteria contain four parts focusing on (1) social communication and social interaction, (2) restricted, repetitive patterns of behavior, interests and activities; (3) symptoms present in early childhood; and (4) symptoms that limit and impair everyday life. This approach suggests that the distinction between these two conditions is one of symptom severity rather than symptom type as first proposed by Goldstein and Naglieri (2009). As part of a standardization process for the Autism Spectrum Rating Scales (ASRS; Goldstein & Naglieri, 2009), we obtained approximately 6,000 protocols containing parent and teacher observational reports of children in the general population as well as those with specific developmental disorders such as Autism and Asperger's and related conditions. Data were collected by 70 site coordinators throughout the United States and Canada. Efforts were made to guarantee that diagnoses were made in a standard fashion across all sites. As part of this process a group of children with a specific diagnosis of Asperger's Disorder was collected. This study provided the opportunity to study the presence of autistic

symptoms in a normative population of school children, as well as compare those diagnosed with Autism and Asperger's.

The results of our study summarized in Figure 1 (see the ASRS Manual for more details about the methods and results) allows for a comparison between a group of children diagnosed with Autism and a group diagnosed with Asperger's syndrome. The total ASRS score, three empirically derived scales, the DSM symptom score, and eight treatment scales containing behaviors specific to certain areas of functioning are shown. The ASRS T-scores are set to have a normative mean of 50 and a standard deviation of 10 based on a large representative sample of individuals in the US. Recall that a score of 60 falls at the 84th percentile and a score of 70 at the 98th percentile. As this instrument measures atypical or problematic behaviors, higher scores are indicative of greater number of symptoms.

Figure 1 provides a visual means of observing the differences between children with Autism and those with Asperger's. As can be seen, the individuals with Autism and Asperger's syndrome had nearly identical profiles which do differ on elevation. Figure 2 provides a comparison of each of the ASRS mean T-scores expressed as an effect size, that is, the difference between each mean expressed in standard deviation units. In addition to all of the differences being statistically significant ($p < .01$) the effect sizes ranged from a low of 0.43 (considered a small effect size) to 0.85 (considered a large effect size). The ASRS Total T-score effect size was 0.78. The largest difference was found for the ASRS Social/Communication scale. This is consistent with the current conceptualization of and diagnostic criteria for Asperger's as a condition characterized by normal early language development. These findings strongly suggest that the difference Autism

and Asperger's syndrome is based on severity not a different composition of symptoms like, for example, the difference between individuals with Autism versus those with Attention Deficit Hyperactivity Disorder (see Goldstein & Naglieri, 2011).

Despite widely held belief over the past twenty years that youth with Asperger's as a condition distinct from Autism have a better life outcome than those with Autism (Klin, Sparrow and Volkmar, 2000), the life course and adult outcome for youth currently diagnosed with Asperger's may in fact be better than those with Autism simply because their symptom profile is milder and they develop functional language at a much earlier age, typically demonstrating the ability to use language to communicate despite pragmatic problems. At this time, these data strongly support the decision by the DSM-V committee to eliminate the Asperger's and Pervasive Developmental Disorder – Not Otherwise Specified diagnoses and instead provide a single diagnosis of Autism Spectrum Disorder.

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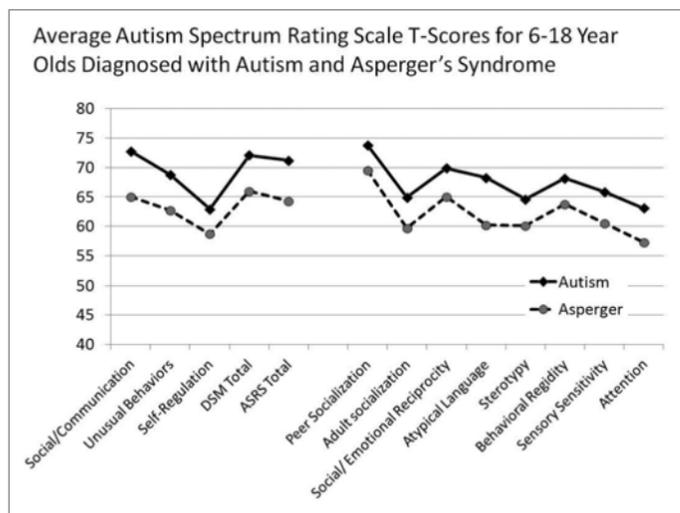


Figure 1

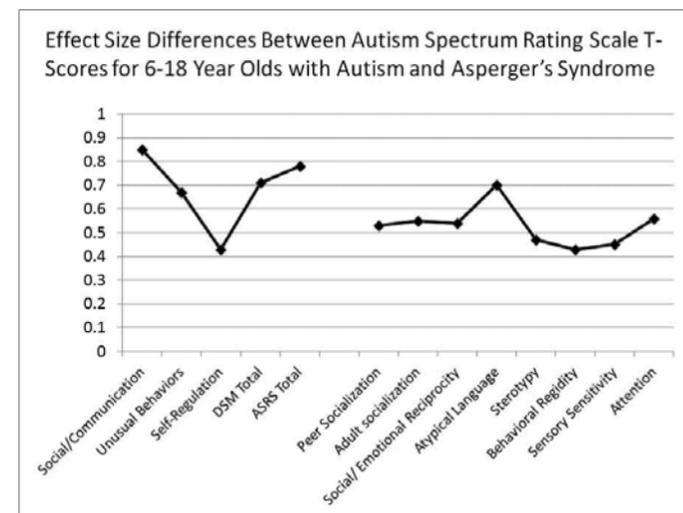


Figure 2

Show Me from page 22

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

We were not comfortable with 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 began selling secretin injections charging thousands of dollars for doses. Recent studies have disputed the claim of secretin's efficacy in the treatment of autism.

Chelation is another intervention used 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 bypass was recommended, and given that it was major surgery, a cousin suggested we try chelation first. We chose not to

take that route, as it did not make sense to us. We believed that the science made sense. Clogged arteries need to be repaired surgically.

We even allowed our son, then 17 years old to try the Hyperbaric Oxygen Chamber therapy. I decided to interview him about the experience. I do value his perception, as it is he is the one who has autism and it is he who got inside that machine. His response was, "It was an 'okay' deal... It did make me dizzy...I think it's not good, it made my ears hurt, like an airplane." When I asked him what he meant by "airplane," was it loud or was it the pressure, he indicated "both." Initially, when he first tried the chamber he

told me that it calmed him. I asked him recently if it was calming or not. His response was that, "In the beginning it was okay, but then it wasn't."

We can circle the drain or move forward with purpose. 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 hope.

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increase acceptance, and widen the variety of consumed foods.

Summary of Effective Interventions

One of the hypotheses in behavior analytic intervention for food refusal is that escape is often a maintaining factor. Children who protest and refuse food often have food taken away (and the expectation to eat is thus removed). The most commonly utilized clinical intervention is positive reinforcement and escape extinction (e.g., Ahearn, Kerwin, et al., 1996; Piazza, Patel, et al., 2003). The positive reinforcement generally involves access to preferred stimuli for desired eating, while the Escape Extinction (EE) contingency involves no longer permitting escape or avoidance.

The EE procedures take a variety of forms. A commonly used procedure is the Non Removal of the Spoon (Hoch et al., 1994), in which the spoon remains by the individual's mouth until the bite is consumed. In other words, the individual can not avoid the presentation of the bite. Sometimes, physical guidance is used in this procedure as well, to facilitate consumption. Behavioral escalations are common in this approach, especially when first implemented. These experiences can be both messy and stressful for caregivers prompting some to suggest that it may not be feasible for all settings or with inexperienced/untrained caregivers.

Alternatives to EE have been developed to address the issue of behavioral escalation. Differential Reinforcement of Alternate Behavior (DRA) procedures provide reinforcement for accepting food or swallowing bites. Non Contingent Reinforcement (NCR) Procedures provide continuous access to preferred stimuli. These procedures work best if highly preferred items can be easily identified, and if the individual can be deprived of those items prior to the sessions. DRA and NCR are often used in combination with EE helping to mitigate the characteristic behavioral escalations (see Piazza et al., 2003 and Reed et al., 2004).

Some clinicians have altered the antecedent conditions (as opposed to focusing on consequences). For example, there is some evidence that simultaneously presenting preferred and less preferred foods can effectively increase the range of accepted foods (e.g., Ahearn, 2003; Buckley & Newchok, 2005). At times, the ratio/concentrations of nonpreferred foods can be systematically changed, to slowly build tolerance for nonpreferred foods. Finally, high probability behaviors are sometimes used to build behavioral momentum and increase the occurrence of low probability behaviors. For example, a child may accept several presentations of an empty spoon, and then accept food presented on a spoon (e.g., Kerwin et al., 1995).

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helped children with ASD to be less isolated on the playground, but it did not result in improvement across all areas of playground behavior, such as taking turns in games or engaging in conversations and other joint activities. Also, despite greater inclusion in social circles and more frequent engagement by their peers, children with ASD continued to cite few

Clinical Application to Increase Taste Exposure

As we noted, one of the many problems associated with feeding is a restricted range of preferred foods. Recently, it has been suggested that repeated taste exposure may be a helpful strategy for this problem (e.g., Casey, Perrin, et al., 2008; Paul et al., 2007). A number of researchers have found that repeated exposures to foods has led to increased acceptance and a wider range of consumed foods, and that multiple taste exposures are essential for the effects. These sessions are in alignment with what is generally necessary to build ranges of food acceptance; typically, people must try foods 10-12 times before they start to like them. The taste exposures are brief sessions with one bite of food and once consumed, the session/demand is terminated and the child is given a break.

Williams has recently suggested the use of a Plate A/Plate B protocol, in which tiny bits of 2 or 3 new or nonpreferred foods are contained on Plate A and Plate B contains 2 or 3 preferred foods. The child must eat a small bite from plate A to get a food item (or a drink) from Plate B.

In a recent extension of Williams' work conducted by clinicians at Melmark, an approved private school and residential facility for children diagnosed with developmental disabilities, a Plate A/Plate B procedure was used with two individuals diagnosed with autism, both with a long history of food refusal. One participant was treated previously in an inpatient feeding clinic and prior to treatment received the majority of his daily calories from a gastronomy tube, as he only consumed 3-5 foods consistently. The second participant also had history of severe food selectivity resulting in a diagnosis of Failure to Thrive and was at risk of requiring a gastronomy tube. Both participants had a history of an intervention including escape extinction. The Plate A/Plate B procedure was selected for these participants because it was presumed to be easier for staff to implement with a high degree of procedural integrity and less restrictive as an intervention for the children treated, as it did not contain escape extinction. The Plate A/Plate B procedure was compared with a condition consisting of the Plate A/Plate B with the addition of taste exposure sessions in an alternating treatment design to determine if the taste exposures would enhance the effectiveness of the Plate A/Plate B intervention.

Although one participant showed some progress with both conditions, the Plate A/Plate B intervention did not produce clinically significant results for either participant, regardless of the addition of the taste exposure sessions, probably due to the low frequency of taste sessions. Once escape extinction in the form of non-removal of the spoon was added to the intervention, bite consumption increased for both participants. The intervention was so success-

ful for one student, that he currently eats meals of adult sized portions containing a variety spanning at least 30 foods, and will likely be able to discontinue the need for the gastronomy tube in the near future. This was a significant replication because it extended the Plate A/Plate B research to non-vocal participants with a diagnosis of autism in a private school/residential setting. Future research is needed to determine when escape extinction is necessary.

Summary

Feeding issues are among the most resistant to intervention efforts, but can be successfully treated by highly trained clinicians. Expertise in feeding/food selectivity issues is essential, particularly for more complex and long-standing difficulties. All treatment must be coordinated with family members and caregivers across settings, to ensure that treatment effects are generalized and maintained. There are several behavior analytic treatments that have been demonstrated to be successful in ameliorating these issues. Successful interventions include the use of escape extinction, the use of reinforcement for appropriate eating, the use of stimulus fading procedures to gradually increase the ratio of nonpreferred foods presented in combination with preferred foods, and the use of behavioral momentum to build tolerance for eating nonpreferred items. Procedures that increase the number of taste exposures have also been shown to increase the range of items consumed. Feeding problems are among the most compelling target behaviors to address, as quality of life changes can be dramatic for both the individual and their family. In addition, the health consequences of improved feeding, enhanced variety of foods, and improved nutrition are substantial.

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friendships. Further studies are needed to explore these factors as well as other possible mediators of treatment effects.

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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, re-

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tuberous sclerosis or Shank3 mutations are also of great interest.

The Glutamate Signalling System

The glutamate system has recently become the focus of potentially translational work. Research in the Fragile X model of autism has demonstrated that manipulating aspects of this system can produce autism-like features. In addition to the mGluR5 pathway, there are other possible molecular targets within the glutamate signalling system that may be modified by medication. Several different avenues of research have found impairments in the glutamate system in people with ASD. Studies of glutamate levels in blood suggest that individuals with ASD have increased levels of glutamate compared to typically developing controls (Rolf et al 1993, Moreno-Fuenmayor et al 1996, Aldred et al 2003, Shinohe et al 2006). Multiple pathology studies have documented aberrations in enzymes and receptor density important in glutamate related systems (Fatemi et al 2002, Purcell et al 2001). Emerging genetic findings have either implicated glutamate related genes or genes involved in the structure and function of synapses important for glutamate signalling (Phillipe et al, 1999, Serajee et al, 2003, Barnaby et al 2005, ADD).

A few medications targeting glutamate pathways have preliminary data to support the notion that manipulation of glutamate/GABA related systems offer promise for novel therapeutics. Both a new GABA agonist and mGluR5 inhibitors are currently in trials. Medications with effects relevant to the NMDA receptor (a receptor involved in the glutamate signalling system) also suggest promise (e.g. Amantadine, King et al 2001; dextromethorphan, Woodard et al, 2005, Welch et al 1992, Phillips et al 1999). Of particular interest is memantine, a non-competitive NMDA inhibitor. In a series of four open label studies involving 186 children with autism, memantine was suggested to improve irritability, social withdrawal, hyperactivity, inappropriate speech, stereotypy, memory, and language (Owley et al 2006, Chez et al 2007, Niederhofer et al 2007, Erickson et al 2007). Current studies of memantine include a large randomized trial looking at core symptom domains

sponsored by Forest Labs and a trial targeting motor functioning, expressive language, and memory sponsored by Autism Speaks.

Oxytocin System

There is also accumulating data to suggest that oxytocin related systems should be explored for potential therapeutics in ASD. This and related peptides have been documented to be involved in aspects of social perception and cognition as well as the development of repetitive behaviors in animal models. Insel et al. suggested that abnormalities in the neural pathway for oxytocin could explain some deficits shared by autism, such as the early onset, high prevalence in males, genetic loading, and neuroanatomical differences. Although the data implicating oxytocin in the pathophysiology of ASD is still limited, early work suggests lower blood level of oxytocin in children with ASD compared to typically developing peers (Modahl et al 1998), and aberrant maturation of this system (Green et al 2001). Recent genetic studies suggest a genetic association between the OXT receptor gene and autism (Wu et al., 2005; Ylisaukko-oja et al., 2006; Jacob et al., 2007) and intravenous administration of oxytocin may facilitate aspects of social perception in ASD (Hollander et al 2007) in ASD. Single dose studies of intranasal oxytocin in both typically developed adult volunteers and youth with ASD have also supported the role of oxytocin in social perception/cognition and randomized trials of this compound are currently underway.

Neuroinflammation

Early neuropathology studies have implicated neuroinflammatory processes in the brain of children with ASD. (Vargas et al 2005). Activation of neuroglia cells can produce brain changes consistent with those seen in autism. Reported findings (Vargas et al., 2005; Pardo et al., 2005; Zimmerman et al., 2006) suggest a dysregulated immune response. Many studies have documented either elevated levels of proinflammatory cytokines such as TNF-alpha/IL-12, tumor necrosis factor receptor II, interferon - gamma among others (Jyonouchi et al, 2005a, 2005b,

2001(Croonenberghs et al., 2002a), Croonenberghs et al., 2002b), or lower levels of IL-10 which is a counter regulatory molecule. There is also evidence of immunogenetic differences (Pardo et al 2005, Torres et al 2006 and Ashwood et al 2006) and a family history of autoimmune disorders in individuals with ASD than in the general population (Sweeten et al., 2003). There are currently multiple compounds that have the potential to modulate the central nervous system immune system in favourable ways; however, their side effect profiles vary. It is of note that nutritional supplements may have a role to play. For example, omega 3 fatty acids at high enough doses have been noted to decrease microglia activation in the brain (ADD). Still the need for large randomized trials is urgent.

The advancement of research practices, from borrowing medications from other conditions, to a focus on translating findings from molecular genetics and neuroscience into treatment may finally give us therapeutic options for treating core symptom domains and facilitating learning. The great advantage of such an approach is the potential of these medication treatments to facilitate progress in psychoeducational and behavioural interventions. To date, behavioural interventions are the mainstay of intervention programs for children with ASDs, but are faced with the problem of variable treatment responsiveness and high cost structures. Translational treatment options such as oxytocin, memantine and other glutamate/GABA modifying agents as well as potentially immunomodulators have the potential to modify neurobiological impairments that may impede progress in behavioural interventions, and thus, may facilitate skill acquisition. For example, drugs that manipulate Glutamate/GABA to facilitate memory and learning may be used in children making slow or stagnant progress in behavioural interventions. Oxytocin has also been suggested as a potential treatment for improving the social attention and motivation to potentially facilitate response to socialization interventions. Both early intensive behavioral interventions and computerized technologies targeting cognitive skill acquisition are potentially great models for such an approach as such interventions facilitate the formation of new connections. The

hope is that such medications may improve the neural substrate for skill acquisition in ASD.

In summary, recent findings from neuroscience and molecular genetics are giving us the opportunity to start translating such data to novel therapeutics. In addition, one should not underestimate the potential that clinical trials have to inform our understanding of the disorder. For example, a trial of a compound manipulating the glutamate system has the potential to also inform our understanding of what is different in this system in ASD. Thus, it is now imperative that these novel treatments are tested in clinical trials and that the autism community supports such initiatives to help advance our knowledge of neurobiological impairments and translate this knowledge into novel effective treatments.

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

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

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

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

Lastly, even some proponents of AIT recognize the limitations of the research base. After each study listed at the AIT Institute website (2010), a comment from the Institute is posted, critiquing the

strengths and weaknesses of each article. Of the 23 studies listed, only one study received a positive comment suggestive of any positive findings of AIT using an acceptable research design. The comments made for the remaining 22 studies noted that the validity of each was considered problematic due to a variety of potential methodological problems, such as small number of subjects, no control group, or the use of unreliable survey data (AIT Institute, 2010).

Conclusion

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

However, apparently, there are still those who continue to use AIT. Green, Pituch, Itchon, Choi, O'Reilly, and Sigafos (2006) conducted an Internet survey of parents of children with ASD, to learn what treatments exist and which ones parents admit using. The authors categorized the treatments by type, such as medications, educational/therapy, and alternative therapies. The results showed that almost half of the respondents indicated they were using a “physiological” – based treatment, which included specific treat-

ments such as sensory integration, conductive education, and auditory integration (AIT), the 3rd-most cited treatment in this particular category.

However, the professional community has come to the conclusion that AIT has no credible scientific evidence to support the belief that such procedures result in any positive and measurable impact of any aspect of ASD. This skepticism cuts across researchers, educators, and professional organizations. It presents an interesting example of how, by adhering to the methods of science and understanding the definition of quality evidence, the professional communities can speak with one voice about a particular treatment in question. There are many other therapies currently being used for which we could apply the same standards of evidence. Hopefully, this will be done so that in the future, consumers will be able to select from a menu of treatments that all have an empirical basis of support discovered through the scientific process. Employing the methods of science is a slow, plodding, and careful process, but we must remain true to it, for, ultimately, it is our best hope for solving the puzzle that is autism.

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out the scholarship awards. While Park Playhouse played a track of one of Carol's song in the background he presented a framed certificate to Phoebe saying, "I only ask that you continue your love of singing in Carols loving memory."

How Phoebe Discovered Theater

When Phoebe was about four years old she would sing songs that she made up in her head while pacing or staring at objects she held in her right hand. Everyone noticed once Phoebe started to sing that she actually had a beautiful voice. Then when she was in second grade her elementary school held auditions for a Variety Show where children can perform on stage. Phoebe seemed interested. So within a

week I had her memorize an easy song, ironically "Tomorrow" from Annie. This was all an experiment. Although the children have to audition, most of them get to be in the show. So the night of the show, the curtain opened and there she stood in front of the microphone in her floral dress, pink sweater and headband in front of about 70 people. The karaoke music started and so did Phoebe. It was loud, confident and flawless. She had a huge smile on her face and later reported how much fun it was to be up on stage and that she wasn't even nervous. Parents in the audience gave praise of her voice and performance. It was the start of something wonderful for Phoebe and we felt lucky to have found her niche. By fifth grade she built enough confidence to audition for her competitive school districts' Follies Show. By this time she had been in thea-

ter classes enough to really entertain and not just stand behind the microphone. She got in to the Follies, singing "Love Will Keep Us Together" dancing, snapping and twirling with great energy.

When Phoebe is on stage she is like a completely different child. It is as if someone flicks a switch and the Aspergers disappears. She gets immersed in any role she is playing and has this ability to stay in character. After the Annie production ended she got the male role of "Papa Ge" in *Once on This Island* in Saratoga Children's Theater summer camp program. She was so expressive and believable in this role that little children in the audience were afraid to approach her after the play for the meet and greet the actors. She gets confidence from working with the other kids in the cast and succeeding to the final product, the

show. I suspect children with Aspergers may have an edge to excel in the theater world. I hope other parents will read this story and it will inspire them to find their child's niche too. Incidentally, when Phoebe auditioned for Park Playhouse's *Annie Jr.*, I thought to myself when I saw all the little girls sitting and waiting their turn "what have I done to my daughter?" I thought I was setting her up for rejection and disappointment and I could have never been more wrong!

Julie Reuther is a mother of an eleven year old daughter with Aspergers.

I would like to give special thanks to Dr. Gina Cosgrove at the Campbell House, Schenectady, NY and Shirley Arensberg, Director of Education at the Park Playhouse in Albany, NY for their love and support.

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was able to perform the task (e.g. type a letter, create a table or create a business card) using just the Tutorial all by themselves – without the Instructor in the room.

To determine if the Tutorials could also be effective among special needs students enrolled in High School Transition Programs, we partnered with public schools in Newark and Jersey City, New Jersey and in New York City and Westchester County. These field trials are ongoing. The feedback these remarkable teachers provide is invaluable. Most have been trained in Applied Behavioral Analysis (ABA). The goal is to make the field tested Cybility Microsoft Tutorials available online and in hard copy, to teachers of Transition Programs for special needs students, everywhere.

In our learning lab, when we observed that Scott and other ASD students preferred to learn from their computer, rather than their Instructor, we installed webcams and Skype software so the Instructor could teach through the screen. This “assisted technology” enabled Scott and our non- and minimally verbal students to communicate, thereby opening up their world to learn and work through the computer (see Skype chart below).

A three month research study among eleven students conducted at our Center found all were able to complete five office work tasks in significantly less time and with fewer errors than our 1:1, face-to-face instruction. We coined the term “Cybility” (Cyber + Ability) to describe this special talent. We concluded that the

further away our Instructors were from their students, the more comfortable and efficient our students became. Apparently, we were part of the problem and were unwittingly contributing to our ASD student’s sensory overload!

We are now testing live, interactive distance learning classes using Cybility Tutorials and Skype onsite in our classrooms and in group and individual homes. We plan to videotape these lessons to make them available to everyone 24/7 on www.cybility.org in the spring of 2012.

We are blessed to have a number of very accomplished and innovative professionals to guide the development of the Cybility Business Model. This diverse team represents a unique blend of three cultures and skill sets; 1) Direct Care Providers 2) Special Needs Educators, and 3) Corporate leaders, which combine to create Cybility’s unique approach to job development. View mini bios of the Cybility team at www.cybility.org/about-us.html.

These Corporate Leaders have also educated us in identifying which job skills are required to survive in a hyper-flat, hyper-connected world where more and more jobs are automated, digitized or outsourced. To prepare our students for these future jobs, we have chosen to focus on “white collar,” routine skills jobs that utilize Google, Wikipedia and other databases to perform many standardized repetitive tasks, such as Number Crunching, Data Entry, Charts, PowerPoint Production, Internet Research, Sales Prospecting, and of course Peer-to-Peer Teaching.

We believe that, not only will a new classroom model be required to provide

these tools and applications, but also a new role will be required for the teacher; as an orchestrator, facilitator, inspirer, challenger and listener. The Corporate Leaders have also enabled us to incorporate concepts of ROI, Scalability, Continuous Learning, Crowd Sourcing, and Added Value into the Cybility Jobs Program.

Cybility’s learning lab environment provides an exciting opportunity to test new ways to learn and instruct. For example, because the Tutorials contain only the essential work tasks in an illustrated form, they enable the more advanced students to become effective peer-to-peer Instructors, thereby providing them with a well paying job and to significantly reduce our professional labor costs.

Similarly, we have invited several of our student’s moms with office skills to volunteer a few hours a week to learn how to teach students using our Tutorials and Skype distance learning methods.

We would welcome inquiries from interested parent’s groups who would like to start their own Cybility Learning Jobs Centers. Please contact Don Fitch by email at donfitch@freecenter.org.

After six months in program, five of our seven students are earning \$8/hr part-time for conducting internet searches, data entry, creating special occasion cards and as Skype Technicians and Peer-to-Peer Instructors

Our goal is for graduates to earn at least \$3,000 per year for an estimated lifetime earnings total of \$120,000. At a per student investment of \$10,000, about half the cost of a Day Program, the breakeven point would be a little over three years.

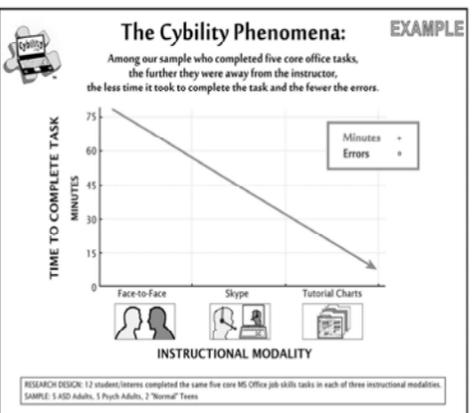
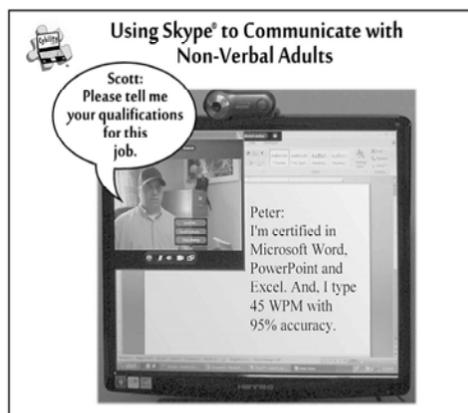
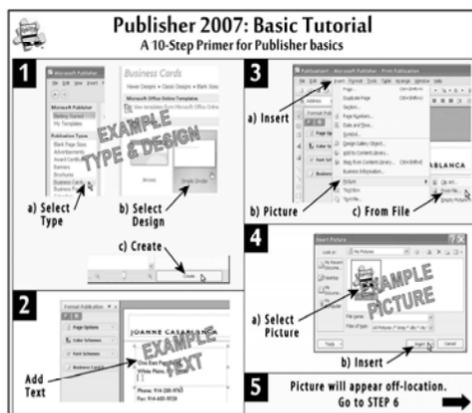
The Cybility Team has been generous in opening doors at several Foundations for “seed money.” We anticipate long term funding would be a blend of government (OPWDD/DDSO, DOE), Corporate and Private Donors and sales of 99¢ Tutorial Apps for iPads and toolkits for middle and high school Special Ed Programs throughout the U.S. Our goal is a new facility serving 20-30 students each year by 2013.

Scott and his Mom helped inspire the Cybility Team to restructure our curriculum and method of instruction to create a new model of teaching real world job skills at less cost, in less time, and to provide virtually universal access. Their needs and the lack of funds for adult ASD Jobs Programs has transformed the Center into a “Social Enterprise,” a hybrid non- and for-profit business model, in order to achieve financial viability and create life sustaining jobs for our neighbors-in-need. We believe Cybility is a model that is scalable worldwide using today’s technology for a fraction of the cost of traditional classroom instruction.

To learn more about this pioneering program and how you can help, please visit www.cybility.org.

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Regressive from page 7

The MRIs were carried out on study participants during natural, nighttime sleep using protocols developed specifically for the Autism Phenome Project by Nordahl.

“Obtaining MRI scans in 3-year-old children without the use of sedation may seem quite challenging. But, by working closely with the parents, we actually were successful more than 85 percent of the time. Patience on the part of everyone and the dedication of the families was critical for our success,” Nordahl said.

The study found that accelerated head growth and brain enlargement was consistently observed only in the subset of children diagnosed with regressive autism. Specifically, total brain volume in 3-year-old males with regressive autism was more than 6 percent larger than that of age-matched typically developing peers. Twenty-two percent of boys with regressive autism, as opposed to 5 percent of boys without regressive autism, had enlarged brains, the study found.

Changes in brain size were not appar-

ent in boys who did not experience a regression. Girls with autism, regardless of autism onset status, also did not show abnormal brain growth. The study findings suggest that abnormalities in overall brain growth are specific to male children with the regressive type of autism, and that rapid brain growth may be a risk factor for regression, the researchers said.

While brain size was clearly larger at age 3, the study also determined when the precocious growth began, by examining records of head circumference that provides a reasonable estimate of brain size in young children. These analyses clearly indicated that brain growth diverged from normal at around 4 to 6 months of age. This is of particular interest, because many families believe that the trigger that led to their child’s regression took place close to the time that the regression happened. But the data reported in this paper indicate that the process leading to the enlarged brain, which presumably also is associated with the onset of autism, started when the child was a newborn.

Much remains to be elucidated regard-

ing brain changes associated with autism, the authors note. In the current study, not all boys with regression demonstrate the precocious brain growth. The investigative team also continues efforts to define the underlying brain pathology in children with early onset autism and in girls with autism.

“It is not clear how many different types of autism will be identified,” Amaral said. “The purpose of defining different types of autism is to more effectively study the cause of each type and eventually determine effective preventative measures and better, individualized treatments. This is a first step in defining autism subtypes based on the data from the Autism Phenome Project, but it certainly will not be the last. There are already indications that other subtypes of autism will be more closely associated with immunological differences or genetic alterations.”

The study’s other authors are Nicholas Lange of the Department of Psychiatry and Biostatistics at Harvard University Schools of Medicine and Public Health McLean Hospital; Deana D. Li, Lou Ann

Barnett, Aaron Lee, Tony J. Simon, Sally Rogers and Sally Ozonoff of the UC Davis MIND Institute and the Department of Psychiatry and Behavioral Sciences in the UC Davis School of Medicine; and Michael H. Buonocore of the Department of Radiology, UC Davis School of Medicine.

The study was funded by grants from the National Institute of Mental Health and the University of California, Davis Medical Investigation of Neurodevelopmental Disorders (MIND) Institute.

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

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gene expression during gestational development. The development of a fetus is controlled by precise regulation of gene expression. Certain genes are turned on and off at particular time intervals, and any disruption of such highly orchestrated gene expression will likely have persistent deleterious effects. In a fertilized egg, global DNA demethylation, followed by remethylation, occurs to reprogram the maternal and paternal genomes for efficient regulation of gene expression. A number of imprinted genes with the potential to undergo hypermethylation at CpG islands are expressed in human brain in addition to large regions of partially methylated genomic

DNA within neuronally expressed genes that can undergo methylation in response to epigenetic agents such as FA.

Our preliminary results with human lymphoblastoid cells in culture have revealed that FA supplementation causes widespread changes in gene expression, as measured by expression microarrays and further confirmed by Western blot analyses [M.A. Junaid, S. Kuizon, J. Cardona, T. Azher, N. Murakami, R.K. Pullarkat and W.T. Brown. (2011). Folic acid supplementation dysregulates gene expression in lymphoblastoid cells—implications in nutrition. *Biochem. Biophys. Res. Comm.* 412 (4): 688-692]. A prominent gene whose expression is inhibited by FA is *FMRI*, which encodes the protein FMRP. In hu-

mans, reduced protein levels of FMRP cause Fragile X syndrome, the most common known cause of inherited intellectual or developmental disability as well as the most common known single-gene cause of autism. These results provide evidence of abnormal gene expression in response to excessive FA supplementation due to cytosine residue hypermethylation. Studies of dietary FA supplementation in female C57BL/6J mice are underway to determine whether such supplementation modifies the behavior of the progeny.

About the Laboratory of
Structural Neurobiology

The major research focus of the

Laboratory of Structural Neurobiology is to identify the causative factors responsible for children's neurodevelopmental disorders, understand the molecular mechanisms involved, and ultimately develop blood-based biomarkers for early identification and prevention. Currently, we are working on three different disorders: autism, late-infantile neuronal ceroid lipofuscinosis (LINCL), and ataxia telangiectasia (A-T).

Mohammed Junaid, PhD, is the Head of the Laboratory of Structural Neurobiology at the New York State Institute for Basic Research in Developmental Disabilities in Staten Island, NY.

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history, etc., will be invaluable to future caregivers... and the child.

Surround yourself with a team of knowledgeable professionals who have experience working with families with special needs - Core members of this team should include an attorney, a social worker and a financial professional. Together this group can help you manage the legal, government benefits, and financial solutions for your loved one with special needs.

Provide funding for quality of life for a lifetime - Special needs trusts should be regularly checked to make certain that

they are adequately funded for quality lifetime care and quality of life.

Resources for Parents

There are many government and non-profit agencies to contact for more information on planning for the financial future for dependents with special needs and related issues. Following are some starting points for identifying local contacts:

- The Arc of the United States: www.thearc.org
- National Dissemination Center for Children with Disabilities: www.nichcy.org

- Special Needs Alliance: www.specialneedsalliance.com (A resource to help identify local legal counsel with expertise in special needs)

- National Care Advisors: www.nationalcareadvisors.com (Consulting firm that provides quality of life planning necessary to meet the challenges of living with special needs)

Whether a family has substantial means or few assets, a young child or adult child with disabilities, planning for the financial future of a loved one is critically important. How parents and

other relatives leave their assets after death may greatly affect the quality of life for their family member with special needs.

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

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continue services in third grade because of his diagnosis of Asperger's Syndrome, the school psychologist became upset and told us that JM could only have the diagnosis of "other health impaired."

At the end of the school year the Committee on Special Education (CSE) chairperson and the psychologist recommended out of the blue that JM be removed from his home school, placed in a different school in the district in a self-contained class of 15 students. This was his third school placement in 14 months; different building, different students, and different staff.

The teacher for third grade was wonderful. After several months she called my wife and I in for a conference. She informed us that she felt JM was not properly placed because 10 of her students were emotionally disturbed and he did not fit the profile of the rest of her students. He was also picking up and mimicking the behaviors of the other students.

Unfortunately the teacher was retiring after 44 years. We again started looking at the private schools in the area and were not able to find a suitable placement. Accordingly, we left him with the same class and a new teacher.

Fourth grade started and JM went back to school. By 10:00 am, we would receive a call that he was having a rough day and would be picked up from school. Next he started to get suspended.

I remember one morning in which he was suspended where the principal called to tell me he was to stay home because he was suspended. JM overheard the conver-

sation and yelled out, "Is she trying to take away my suspension? It's mine and I earned it, she can't take it back!" The rest of the year he had no transportation to or from school so we drove him 17 miles each way to and from school each day.

In June we had his CSE meeting. I was informed he was "regressing" in school. My wife and I were told the district did not have a placement for him and that he would be placed on home instruction until an appropriate program could be found.

On July 1st, the entire Special Education Department resigned, with the exception of one individual who was hoping to become the new head chairperson. Throughout the summer and fall, we visited at least 20 out-of-district placements, most of which were at least 45 miles one way from home. All these programs rejected him as he was considerably higher functioning than the student population they served, and in several cases he would "age out" in less than a year.

When September came along, the district was not able to find an appropriate placement, a home instructor, or a new CSE chair person. In November the district hired a woman who was given the title Director of Pupil Personnel. Five days after she was hired she invited my wife and I in for a meeting with her. We so hoped she would have a solution for us, instead she informed us that she was told to be prepared as we were going to be "her worst nightmare." After that meeting we left determined to create The Ridge School. We had already visited programs in 4 counties, none of which were appropriate for our child.

The Ridge School Opens Its Doors

On January 18, 2005 we opened our doors with 4 students. JM finally had a placement and was starting to make friends. In no time, four more students were enrolled - all either already diagnosed with Asperger's, high functioning Autism, or on the road to such a diagnosis. Suddenly my wife and I did not feel so alone. We met parents with similar situations and similar diagnoses. All this time the district led us to believe we were the only family in the district with a child with this disability. It soon became apparent that there was a large population of students and families who were being ignored, their children disenfranchised, home instruction was the only education available, and all families felt they were alone in this path. Some were on home instruction, some home schooled, and others staying home because parents could not get their child out the door. Many of these students we later realized were bullied in school and on transportation.

Within three weeks, we had 14 students apply from our local school district alone. We were told JM was the "only" student with this Asperger's Syndrome, and we soon found out that there were many students with this diagnosis; some were doing ok, others were out of school altogether. We were made to feel so guilty for this diagnosis and for requesting the education and services he deserved. Now we find out we are NOT alone!! The names and school districts are different, but the stories are almost identical. These families have been out there all along.

The Ridge School has now been around

for 7 years. We run a hands-on program and incorporate a lot of social skills daily. Our curriculum includes English, Social Studies, Science, and Math. Our lessons are reinforced by students building extraordinary projects. It is wonderful to see them working as a team creating an inventive world within this new school.

Our students and their families have traveled to New York City for Broadway, Colonial Williamsburg, gone to see whale watching, visited Plymouth Plantation, and seen many historic sites in the Hudson Valley and Philadelphia. We have been invited on research vessels studying the effects of pollution on the shell fish and fishing industry on Long Island Sound. We go on a trip each week. These trips support our socialization skills, encourage us to look around at the different jobs we see along the way, and support the academics in the classroom. We also study how to use the public transportation that is available to us. Supporting our educational program through vocationally oriented trips using social skills and public transportation provides the visual and "hands on" experiences these students relate to.

To date we have students in college placements that keep in touch with us and return when they can to visit. I tell them, "Once a Ridge School Kid, always a Ridge School Kid."

It is my hope that the readers of this story will realize our students are the inventors, the free thinkers, and most of all an important part of the future of our country and our world.

For more information, please visit www.ridgeschool.org.

Fear from page 12

amount of fear (i.e., none, some, much) to the same stimuli that were viewed by the children. The photographs were presented gradually, such that the opacity of each, from absent to normal, increased in one-second intervals to attenuate possible startle responses. That is, the visual stimulus was gradually faded in to full view. If the child showed a fear response, the photograph was terminated and after a pause the next photograph was presented. Behaviors associated with fear were systematically observed as the children viewed each photograph (i.e., verbal complaints, looking away, body rigidity, fearful facial expression) as well as approach and positive behaviors. Notably, as the research literature does not present accepted parameters for assessing fear in children with an ASD, the current procedure was chosen to allow observation of the common fear responses expressed by typically developing children.

During the assessment, many children displayed positive affect (e.g., smiling), indicating the utility of many of the photographs to generate an emotional response from the children. Children also attended to the photographs, often labeling what they were presented on the monitor (e.g., "A car!"). In contrast, the data showed a limited utility of the photographs to evoke typical fear responses. The majority (i.e., 67%) of children with Autistic Disorder did not demonstrate a typical fear response to any of the photographs, whereas 100% of the children that did demonstrate typical fear responses had a diagnosis of PDD-NOS or Asperger's Syndrome. However, to fully interpret these results it is important to consider the children's ability to demonstrate a typical fear response. As many children with an ASD evince difficulties with affect and may be less likely to display emotions in a typical manner, the fear-related responses measured in this assessment may not be characteristic of children with an ASD. For example, research suggests that individuals with an ASD are generally less expressive and often show neutral or idiosyncratic expressions (Loveland, Tunali-Kotoski, Pearson, & Brelsford, 1994).

Taken together, these findings highlight the complexity of assessing fear in children with an ASD and suggest that a more individualized assessment technique may be needed in identifying fear responses.

Results were interpreted that children with PDD-NOS or Asperger's Syndrome may be more responsive than children with Autistic Disorder to non-invasive assessment procedures involving pictorial representations and measurement of the presence of typical fear responses. These results underscore the difficulty in making conclusions based on samples of children with an "ASD" (i.e. generic diagnostic descriptor). When considering the assessment and presentation of fear in children there are meaningful distinctions between the specific diagnostic groups that comprise the autism spectrum disorders.

With respect to correspondence between caregiver report and children's reactions, overall correspondence was poor, with overlap on only 63% of photographs. Variation was seen among the three diagnostic groups that comprise the autism spectrum disorders. Specifically, average correspondence between caregivers and their children with PDD-NOS was 78%, whereas correspondence was 48% for children with Asperger's Syndrome and 59% for children with Autistic Disorder. Of the children who did display typical fear responses, an even lower correspondence was seen with caregiver report, suggesting that, as would be expected, caregivers have difficulty interpreting the emotions and behaviors displayed by their child, illustrating the complexity of the relationships between display of affect, fear response, and caregiver interpretation.

Caregiver Modeling – Implications for Teaching Social-Emotional Skills

Social learning models have been used to explain the development of fear in typically developing children (Dubi, et al., 2008, Gerull & Rapee, 2002; Rachman, 1977). In fact, much research has shown that typically developing children quickly learn to fear various objects and situations via their mother's reaction (Dubi, Rapee, Emerton & Schniering, 2008). Many typically developing children also present

with similar fear and anxiety symptoms to those of their caregivers (Kendall, Ellsas, Kane, Kim, Kortlander, Ronan, et al., 1992; Silverman, Cerny, & Nelles, 1988; Windheuser, 1977).

However, additional recent research from the Institute suggests that caregiver's report of their child's fear and caregiver's report of their own fears were *not* related. In other words, unlike typically developing children, children with an ASD are not modeling fear reactions (and appropriate coping responses) from their caregivers. This finding is understandable in light of the pervasive deficits in many social communication skills, such as eye contact, imitation, and the use and understanding of gestures and facial expressions, which are characteristic of individuals with an ASD. These skills are key factors in the ability to learn about emotions from others. More specifically, a lack of social comprehension skills may hinder the development of appropriate fears (e.g. strangers, harm) and spark the development of socially inappropriate fears (i.e. either in content or intensity) – which, described above, is a pattern often noted in the literature.

These results highlight the importance of direct instruction for teaching coping skills and emotion recognition, interpretation, expression, and regulation as part of a comprehensive service model for children with an ASD. Children must be directly taught the social coping skills needed to appropriately regulate and mitigate their expression of fear.

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Immune Link from page 6

de Water reported some clues in a study published 18 October in *Translational Psychiatry*². Her team showed that mothers carrying certain common variants of the MET gene have an abnormally high risk of producing these autism-linked autoantibodies.

One of MET's many functions is to help suppress a pregnant woman's immune system so that it does not reject her fetus, whose DNA is half foreign. Van de Water's study found that women carrying these common variants — in which there is a cytosine nucleotide in a specific part of the MET gene — produce less MET protein and less interleukin 10, a type of cytokine, in their blood. Both of these are molecular signs of the immune system in overdrive.

Pregnant women who carry these MET variants may be primed for an excessive immune response if, for example, they acquire an infection, Van de Water says. Epidemiological studies over many decades have shown that flu epidemics trigger a spike in the number of babies who go on to get autism or schizophrenia.

"This genetic susceptibility sets you up for the wrong event at the wrong time," Van de Water says.

Cytokine Storms

Explanations of how maternal antibodies may push the fetal brain toward autism

are murky. But more and more studies are implicating cytokines, the ubiquitous signaling molecules of the immune system.

A flurry of neuroscience research in the past couple of years has overturned the dogma that the nervous and immune systems are generally independent. Instead, many teams have shown that there is a two-way cross talk between them.

Cytokines, for example, are produced by brain cells in response to infection, but they also help neural stem cells differentiate and mature neurons change the strength of their connections³.

"There's a growing body of evidence that says immune processes are not simply defense processes, but play a role in the plasticity and connectivity of the brain during development," notes Owen Rennert, head of developmental and clinical genomics at the National Institute of Child Health and Human Development.

In September, Rennert reported an autism-immune link using an unusual computational model⁴. With data from a freely available atlas of gene expression, his team showed that 32 autism candidate genes are highly expressed in the developing human brain. Pathway analyses of these genes showed that many are involved with immune system regulation and, specifically, cytokine signaling.

This fits with studies of blood, cerebrospinal fluid and postmortem brain samples that have turned up abnormal cytokine levels in individuals with autism⁵.

In September, researchers took a look at the immune picture earlier in development by measuring cytokines in amniotic fluid. Drawing from hundreds of samples stored in a large Danish biobank, the researchers reported that pregnant women whose babies develop autism have elevated levels of a chemokine — a particular class of cytokine — called MCP-1 in amniotic fluid⁶.

This could mean that an altered immune state from the beginning of life causes autism — but that's only one of many possibilities.

"We don't have sufficient evidence that this is a causal relationship," says lead investigator Morsi Abdallah, a researcher at the Statens Serum Institute in Copenhagen. "It could reflect some other distortion going on in the fetus or stemming from the mother."

All of these researchers agree that pinning down biological mechanisms will require cell and animal models, in which researchers can measure the effects of specific tweaks to the immune system.

"Sorting out cause and effect — we're a ways away from that," Van de Water says. "But each piece of information that we get on which systems are dysregulated takes us that much closer to figuring out the commonalities."

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Learning Style from page 20

traditional level of significance (.05) would have been a consideration. Students with autism indicated a preference for a more structured environment.

Student preferences for varied sociological learning opportunities were also examined. Students with autism report that they learned best in a variety of social settings. While the social makeup of a classroom is usually teacher directed, peer collaboration and interaction in one-to-one and small group settings were important to these students with autism as was working with authoritative adults in a variety of different ways.

Physiological elements that influence learning include perceptual elements such as material being presented in a visual, auditory or tactual manner, time of day (morning, noon or afternoon), intake (snacking or not snacking while working), and opportunities for mobility during learning, such as taking short breaks. This study revealed that students with autism preferred not to snack while learning. While fewer than expected students expressed preferences for learning at specific times of the day, those that did express preferences stated they learned best in the afternoon. They also expressed preferences for material to be presented to them through various perceptual modalities. Although students with autism are often offered visual supports for their

learning, they stated their preferences for learning through a variety of different modalities which include tactile, visual, auditory and kinesthetic.

There are commonalities among the emotional needs of students with autism as well. They reported a strong need for structure and authority and felt they were motivated by others. This analysis also showed that students with autism were more multi-task persistent than single-task persistent, desiring frequent breaks during work periods rather than sticking to one task until completion.

Students with autism see themselves as more global than analytical learners. Global thinkers prefer to develop an understanding of the concept and then develop the details. The data analyzed in this study revealed that students with autism have commonalities in learning-style preferences. These commonalities have implications for students and teachers in the inclusive environment of a general education classroom as well as the more specialized, smaller group classroom. When students and teachers alike have a deep understanding of how students learn best and are willing to make simple changes to their everyday classrooms or routines to accommodate student preference, more active and engaged learning can occur.

In addition, this study found that students with autism prefer to learn in ways that are sometimes significantly different from their typical peers (Friedlander,

2010). This difference was apparent in four of the 25 preferences tested. Data revealed students with autism, when compared to their typical peers, reported a significant preference for learning in an environment which included bright light, and required them to listen to the teacher. In comparison, the responses of their typical peers were fairly evenly distributed across responses in choosing low, no preference or bright light (18, 23, and 19 students respectively). Also, 22% of their typical peers reported no preference for learning in an auditory manner, while no students with autism chose "no preference" as their response. They also differed significantly in that they preferred to learn with an authoritative adult as opposed to their typical peers who, although they also "preferred" to learn with an authoritative adult, 30% said they had "no preference" whereas only 4% of students with autism chose this response. Students with autism also felt themselves to be impulsive (56% as opposed to 20% of typical peers) rather than reflective students, while their typical peers made choices which indicated they felt they were more reflective (72% as opposed to 35% of students with autism).

When educators understand that all students have individual needs and preferred learning styles they can create learning environments that ensure maximum success. The learning-style researchers have found that students who are considered to be high-risk have benefited significantly

from instruction that was matched to their particular style of learning. As educators continue to search for more effective teaching strategies for students with autism to address their academic, social, and behavioral achievements, a consideration of students' preferred learning styles is essential.

Students with autism should feel increasingly more comfortable in their general education classrooms when their emotional, sociological, psychological, physiological, and environmental needs are met. Educators must develop proficiency in carefully evaluating profiles of ability for children with autism as their unique strengths and weaknesses may not always be supported within the general education classroom. With more data to support student learning preferences, the inclusion process can be specifically tailored to meet student needs and support success in the classroom when used for instructional planning and teacher training. The results of this study offer valuable insight into the learning styles of students with autism, enabling teachers to create classrooms which are welcoming and enriching, in turn leading to a more comfortable and successful school experience.

Dr. Friedlander is a special education inclusion teacher in elementary education in Ridgefield, Connecticut. She is currently working on a book about learning styles for teachers and their students with autism. She can be contacted at dfriedlander@ridgefield.org.

mRNA from page 25

The hypothesis proposed here is that the symptoms of autism (be they severe or mild) are due to an abnormal rate and sequencing of brain development which is due to abnormal non-coding RNA instructions.

The good news is that if this hypothesis proves to be true, technology could possibly be developed to correct or counter the abnormal timing and placement instructions contained in the non-coding RNA. Such technology could prevent and/or treat AD. However, it must be stressed that any preventive or

therapeutic measures based on non-coding RNA research are, at best, many years away.

Edward R. Ritvo, MD is Professor Emeritus at the UCLA School of Medicine. Edward R. Ritvo, MD is an internationally recognized medical expert, re-

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

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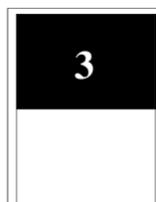
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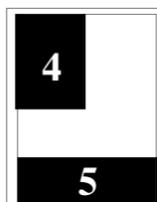
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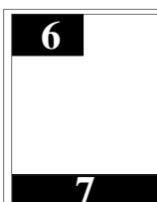
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