

The Promise of Research

The National Strategic Plan for Autism Spectrum Disorders

By **Thomas R. Insel, MD, Director
National Institute of Mental Health
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The Combating Autism Act of 2006 mandated the reestablishment of the Interagency Autism Coordinating Committee (IACC) to coordinate all efforts concerning Autism Spectrum Disorder (ASD) across the Department of Health and Human Services (DHHS). IACC membership includes an individual with an ASD, representatives from several advocacy groups (Autism Speaks, Autism Society of America, SafeMinds), and officials from most of the federal agencies that deal with autism research or services (including Centers for Disease Control and Prevention, the Department of Education, the Centers for Medicare and Medicaid Services, the Office on Disability, Substance Abuse and Mental Health Services Administration, and five Institutes of the National Institutes of Health). One of the first tasks of the IACC is to develop a strategic plan



Thomas R. Insel, MD

for ASD research that will be updated yearly. The Strategic Plan for ASD research is an opportunity to take stock of recent progress, identify needs for new

research, and plan for scientific initiatives that can be supported by either federal agencies, private foundations, or public-private partnerships.

The mission of the IACC Strategic Plan is to “focus, coordinate, and accelerate high quality research and scientific discovery in partnership with stakeholders to answer the urgent questions and needs of individuals on the autism spectrum and their families.” Toward this end the IACC received over 500 responses to a public request for information (RFI) published in December, 2007. In January, 2008 over 60 scientists, clinicians, and advocates participated in scientific workshops to identify research opportunities within the areas of: risk factors, biology, diagnosis, and treatment. Recently, the IACC held the first of a series of town hall meetings to gather additional public input.

An important part of the strategic planning effort has been the first comprehensive analysis of autism funding from both public and private sources. The NIH official funding commitment for ASD-related research in 2007 was approximately \$127

million (<http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/nih-initiatives/fy-2007-nih-asd-research-portfolio-summary-by-research-area.shtml>). When combined with CDC, Department of Defense, Autism Speaks, and the Simons Foundation commitments, 2007 ASD-related research funding exceeded \$188 million. How are these funds distributed by research area? While not every project fits into a single category, approximately 28% was dedicated to investigations of risk factors, 27% to biology, 17% to diagnosis, 14% to treatment, and 14% to other areas such as training and infrastructure. By matching research support across these various areas and across funding sources to the research needs highlighted in the strategic plan, the IACC will identify opportunities for new investments as well as for leveraging current support.

What specific research initiatives will be recommended by the Strategic Plan? The various ideas gathered from the response

see Strategic Plan on page 50

OMRDD Announces Statewide Autism Platform

Initiative Includes Research Consortium and Interagency Task Force

Staff Writer
Autism Spectrum News

When Diana Jones Ritter took office last spring and became the Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), she adopted the agency motto, “Putting People First.”

Ever since, Ritter and her leadership team have worked hard to integrate the slogan throughout the agency and its programs of services and supports. This year, OMRDD is celebrating 30 years of service, and the new motto speaks of Ritter’s goal: to help the world see people with developmental disabilities as people first, instead of just a disability. Under her guidance, the agency’s new mission is to help individuals with developmental disabilities lead richer lives.

For OMRDD, this translates into giving people with developmental disabilities as much individual control and choice over their own lives as possible, the chance to live in a home of their choosing



Diana Jones Ritter

within their community; opportunities to work and engage in activities that allow them to contribute to their communities; meaningful relationships; and good health.

OMRDD has re-examined its current supports and services, its ongoing initiatives and its internal structure to align every part of its system and its workforce with this singular mission and these specific outcomes. Within this new reorganization, the agency has launched numerous initiatives that respond to the needs of New Yorkers living with developmental disabilities with more individualized service, personal choice, community-based services, fiscal accountability and efficiency. In each initiative for improvement, OMRDD is committed to two principles: providing services to individuals, that is, to people who are not alike, but who are unique in their need for services and their choices, and responding to the needs of individuals with developmental disabilities of all kinds and their families.

OMRDD Autism Platform Initiative

OMRDD’s newly developed Autism Platform does just that. Within a service system that exists on behalf of more than 125,000 individuals with different diagno-

ses and unique needs, the Platform responds to the growing number of individuals and families faced with the particular challenges of Autism or an Autism Spectrum Disorder. The Platform is comprised of a collection of activities, some new and some well underway, that will affect the services OMRDD provides to individuals and families living with ASD. In keeping with OMRDD’s inclusive mission, the Autism Platform is built largely – though not entirely – on initiatives that serve individuals who need services, not merely individuals with a diagnosis of Autism or ASD. It responds with a comprehensive “platform” of initiatives embodied in five major areas:

- Increasing research;
- Translating research results into improved treatment options;
- Uniting public, private, and nonprofit interests to establish statewide research, evaluation and treatment capacity;
- Networking across State Government

see OMRDD Platform on page 49

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Autism Spectrum News Upcoming Theme and Deadline Calendar

Winter 2009 Issue:

“Understanding and Treating Autism Spectrum Disorders”
Deadline: September 15, 2008

Spring 2009 Issue:

“Helping Parents and Family Members Cope with ASD's”
Deadline: December 15, 2008

Summer 2009 Issue:

“Education for Children & Adults with Autism Spectrum Disorders”
Deadline: March 15, 2009

Fall 2009 Issue:

“Addressing the Needs of Adults on The Spectrum”
Deadline: June 15, 2009

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From The Publisher

You Are Not Alone:

Autism Spectrum News - The New Voice of the Autism Community

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

Welcome to our first issue of *Autism Spectrum News*. We want to thank everyone who helped us bring this issue to the community, a vision that began two years ago when we were inspired by a parent of a young adult on the spectrum. Because of her, we devoted an issue of *Mental Health News* to *Understanding and Treating Autism Spectrum Disorders*. Following its release, we heard from many readers who suggested we bring our award-winning format to a new publication devoted entirely to the autism community. We listened, and the seeds to develop *Autism Spectrum News* began to take shape. Over the next two years we went out into the community and met more inspirational parents and leaders of many wonderful organizations that are making a difference in the lives of people with autism spectrum disorders. Thanks to their help we have found a new voice for bringing you a new and trusted source of news, information, education, research, advocacy and resources about the promising and ever changing world of autism spectrum disorders.

Gaining Your Trust

I would like to share my own personal journey with you, and why I believe it explains my sincerity and obligation to bring *Autism Spectrum News* to the community. As many of our readers are parents struggling with children on the spectrum, gaining your trust is of the utmost importance to me and what our organization is all about.

First let me state that I am not the parent of a child on the spectrum, nor am I an expert on ASD's. However, I am a survivor of a devastating illness that has provided me with a unique perspective into what must be a life-changing, overwhelming, and incredibly challenging struggle that parents with children on the spectrum face each and every day. Let me begin by telling you why we stated our first publication, *Mental Health News*.

I grew up in a small town in the northern suburbs of New York City. As a youngster my life was full of happiness, youthful energy and wonder. I enjoyed school and entered college in 1969, where I took a great interest in the study of psychology. I thought about pursuing a career helping people with mental illness. My first job following graduation was caring for patients at a prominent psychiatric hospital located near my hometown. It was an experience of a lifetime and confirmed my desire to further my studies by earning a Masters degree in Social Work at New York University.



Ira Minot, LMSW

Little did I know that 20 years later I would be a patient at that very same hospital, fighting to save myself from being institutionalized in a state psychiatric hospital. I was in my late 30's with a career, family, and a five year old son named David. My mother had just lost a difficult battle with cancer, a loss which affected me deeply. Soon after, I began to develop symptoms of severe anxiety and depression. These early symptoms were a warning sign of what was to become a 10-year life and death plunge into the darkest depths of despair. I had developed a severe form of unresponsive clinical depression. Over the course of my illness, everything I had worked so hard to accomplish in my life was destroyed. My son David grew up in the shadow of my illness and was profoundly affected by it. This compounded my shame and feelings of hopelessness and failure. I had to be brought to the emergency room on a stretcher on several occasions after trying to end my life. In and out of hospitals and programs over the 10 years, my last inpatient stay was at the very hospital where I first worked. Homeless, destitute and still very ill, my doctors gave me one last chance before sending me to a state hospital. I agreed and underwent Electroconvulsive Therapy (ECT). Thankfully for me it was the treatment that finally broke the chains of my relentless illness. Over the next few years, I struggled to rebuild my life and dedicated myself to helping others who struggled with mental illness as I had. I went out into the community and met many of the dedicated leaders of the mental health community to enlist their help in starting a local newsletter called *Mental Health News*. Today, these leaders are our Board of Directors and *Mental Health News* is an award-winning quarterly publication with a readership of over 160,000 from coast to coast.

My son David went on to graduate Ithaca College with honors in Education and Music. He has recently come to work with me as my Associate Director, and brings with him his firsthand experience of how a loved one's illness can disrupt and complicate a young person's world. He understands the need for community education and shares my desire to combat the destructive effects of stigma, champion the cause for increased funding for cutting edge research, and to help others find hope in knowing that they are not alone in their struggle with mental health and autism spectrum disorders.

Our Philosophy

Since it began, *Mental Health News* has embraced a philosophy that provides the community with a trusted and balanced source of information. During this time, the delivery of mental health treatment and services has shifted to a more "evidence-based" scientific framework, designed to bring the best clinical treatment practices to recipients of services. As a survivor of mental illness, I have also followed, supported, and reported on the growing consumer recovery movement—now highly regarded as playing an important role in the recovery process of people with mental illness.

The topic of "alternative therapies" is not new to us. Our approach has been to focus on those that have been proven effective, such as art and music therapy and anxiety reducing relaxation techniques, which have found widespread acceptance as supplemental practices in the treatment of mental illness. To decide what philosophy we would adopt on alternative therapies in *Autism Spectrum News*, we spoke with many people. The more parents and leaders of the autism community we spoke with, the more we realized how many different types of alternative treatment approaches there were, and how confused and desperate parents are in finding trusted and safe therapies for their children. We wanted to distinguish ourselves from the many hundreds of internet sites that may be offering false hope to parents by promoting alternative therapies that have not been proven by sound scientific research. *Autism Spectrum News* will stand apart from these groups by focusing on evidence-based treatments and practices that have been studied in clinical trials by members of the scientific community. We hope that by doing so, we will provide our readers with a safe and trusted source of news and information.

In keeping with this philosophy, we will work with some of the autism community's leading minds in the areas of science, treatment, education and advocacy. They have volunteered to serve on our Editorial Board, and we are deeply grateful for their participation. We introduce you to them beginning on page 26.

The Challenges Ahead

We hope that the autism community will welcome *Autism Spectrum News* as a vital new resource and as an essential educational tool. As a nonprofit organization we will be distributing thousands of free copies of each issue to many organizations in the northeast. As advertising sponsors, these organizations help us deliver *Autism Spectrum News* to you. In addition, we will put each entire quarterly issue of *Autism Spectrum News* on our website: www.mhnews-autism.org. For those readers who want us to mail them their own personal copy, we offer affordable individual and group subscriptions—see page 55 for details.

As a nonprofit organization, our challenge is to be as effective as we can in providing you with a trusted source of news, information, and education about autism spectrum disorders and to continually expand our geographic reach. The only funding we receive comes from our low-cost advertising, an occasional grant, and our new honorary sponsorship program. Our challenge will be to find the financial resources needed for us to continue publishing and to guarantee a secure future for *Autism Spectrum News*.

This premier issue is but a sample of what we can accomplish. We want you to feel that *Autism Spectrum News* is your newspaper—a publication by the community, for the community. Your participation, feedback and support will enable us to make *Autism Spectrum News* a publication the autism community can be proud of. We are calling on all parents, families, adults on the spectrum, treatment professionals, legislators, advocates, members of the scientific community, teachers and members of the educational community, and all organizations that provide programs and services to the autism community to help us accomplish this.

Recently, we began hearing from parents that *Autism Spectrum News* would provide an excellent resource for teachers and administrators at public and private schools, working to meet the special education needs of children on the spectrum. We agree, and encourage teachers and school administrators to contact us about our group subscription discounts.

We would also like to publish stories written by parents and by adults on the spectrum. Having personal accounts of your experiences would be an education and inspiration to others.

We look forward to hearing from you. Please e-mail us at mhnm@aol.com and tell us what issues are important to you, so that we can address them in future issues of *Autism Spectrum News*.

*You Are Not Alone
 Autism Spectrum News Cares About You*

Have a Wonderful Fall Season.

AUTISM SPECTRUM NEWS DESK

The M.I.N.D. Institute Attacks Autism on All Fronts

Staff Writer
Autism Spectrum News

When Leo Kanner described his patients with rare and “fascinating peculiarities” in his seminal 1943 work, “Autistic Disturbances of Affective Contact,” he could never have imagined that one day one in 150 children would carry the diagnosis whose name he coined: autism. Nor could Kanner have imagined the vast arsenal of weapons that researchers would marshal to search for treatments and cures.

At the UC Davis M.I.N.D. Institute (Medical Investigation of Neurodevelopmental Disorders), attacking autism on all fronts already has yielded that there are several different “autisms,” all labeled with one single diagnosis. The M.I.N.D. Institute is developing the largest and most comprehensive biomedical assessment of children with autism that has been attempting to parse out the characteristics of autism’s phenotypes.

Led by M.I.N.D. Institute Research Director David Amaral, the Autism Phenotype Project is a longitudinal study of 1,800 children from multiple sites across the United States that aims to distinguish among different subgroups of autism that might correlate, for example, with regressive autism or autism with particular medical symptoms. Over 52 scientists from eight research areas are taking part in the Autism Phenome Project, using a variety of tools to yield new insights into the genesis of autism, including medical examinations, analysis of environmental exposures, evaluation of behavior and neuropsychology, genomics, brain structure, brain function and immune function. These varied areas of inquiry have started to yield important results.



Robert Hendren, DO

Research by neuroimmunologist Judy Van de Water has found that antibodies in the blood of mothers of children with autism bind to fetal brain cells, potentially interrupting healthy brain development. Van de Water’s study also found that the reaction was most common in mothers of children with the regressive form of autism, which occurs when a period of typical development is followed by loss of social and/or language skills. The finding raises the possibility that the transfer of maternal antibodies during pregnancy is a risk factor for autism and, at some point, that a prenatal test and treatment could prevent the disorder in some children.

The interplay between genes and specific toxins and the roles they may play in the onset and severity of autism is the work of Isaac Pessah, director of the Chil-

dren’s Center for Environmental Health and Disease Prevention. Pessah is the author of a study connecting the mercury-based preservative thimerosal with disruptions in antigen-presenting cells known as dendritic cells obtained from mice. The study provides the first evidence that dendritic cells show unprecedented sensitivity to thimerosal, resulting in fundamental changes in the immune system’s ability to respond to external factors.

Our knowledge of the subtle behavioral markers of autism has grown because of work, led by M.I.N.D. Institute researcher Sally Ozonoff, and has allowed us to identify children with the condition, sometimes as young as 12 months old. While we don’t have any fully effective treatments for children with autism, behavioral and educational interventions, treating associated medical problems and some medications can make significant differences in the lives of children and adults with autism.

Another promising line of research is grounded in the theory that some forms of autism result from the body’s inability to handle environmental stressors. M.I.N.D. Institute Executive Director Dr. Robert Hendren has begun treating patients with methyl B12 which is believed to help the body handle toxins and oxidative stress in the environment. Oxidative stress results in the production of peroxides and free radicals that are toxic to cells, damaging DNA and other cellular components. A preliminary study at Arkansas Children’s Hospital has shown that MB12 supplementation reduced markers of oxidative stress in the blood of children with autism.

Community partnerships are allowing M.I.N.D. Institute clinical and translational researchers to share these insights. In September 2007, 60 children aged 3 and 4 years

enrolled in the Triumph Center for Early Childhood Education, fulfilling a shared dream of neuroscientists, educators and community activists to provide an innovative and affordable preschool for both typically developing children and children with special needs in Sacramento’s socioeconomically depressed Oak Park neighborhood. This partnership will allow the M.I.N.D. Institute to bring intervention strategies to the youngest students, establishing a model early education program that can be used in other school districts throughout the state and nation.

The M.I.N.D. Institute has received funding to expand these efforts even further with the receipt of a grant from the U.S. Department of Health and Human Services to establish a new University Center for Excellence in Developmental Disabilities, Education, Research and Service. Led by M.I.N.D. Institute Education Director Robin Hansen, the grant will increase access for both patients and health-care providers to interdisciplinary training resources and support clinical research that enhances assessment and treatment options for children and adults with developmental disabilities. The new center will serve as a regional, state and national resource for community services and technical assistance to improve the capacity of systems of care to meet the needs of individuals with developmental disabilities.

There is one other partnership that must be acknowledged. The M.I.N.D. Institute came into being through the tireless efforts of the families of children with autism. It is the urgency of their needs for effective treatments, preventions and cures that continues to inspire the M.I.N.D. Institute’s research initiatives and forms the basis for its many advances.

Cold Spring Harbor Laboratory Model for Autism *Suggests Women Carry the Disorder and Explains Age as a Risk Factor*

Staff Writer
Autism Spectrum News

A new model for understanding how autism is acquired has been developed by a team of researchers led by Cold Spring Harbor Laboratory (CSHL) and Albert Einstein College of Medicine. Autism is a developmental disorder, characterized by language impairments, social deficits, and repetitive behaviors. The researchers analyzed data on autism incidence and found a previously unrecognized pattern. The pattern can be explained by assuming that spontaneous germ-line mutation is a significant cause of the disorder. Parents, especially women, who acquire the muta-

tion – but do not exhibit severe symptoms of the disorder – have a 50% chance of passing the mutation on to their children. Sons often show the most severe symptoms.

Spontaneous mutations are changes in a chromosome that alter genes. Germ-line mutations are newly acquired in a germ cell of a parent, and sometimes are transmitted to offspring at conception. Men and women are equally as likely to acquire a spontaneous mutation that can cause autism, but autism is three times more likely in men, making women the more likely carriers of new mutations. “The fact that germ-line mutations increase with age places older parents at a higher risk of having children with autism, explaining a pattern that has been recently observed,” said CSHL co-author of the study Michael Wigler, Ph.D.

The model proposes two prominent risk classes for families affected by autism. Low risk families give rise to sporadic autism, the more common form, by spontaneous germ-line mutation. The children, mostly female, who receive such a mutation, but do not display the disorder, are the source of the high risk families. The data shows that the transmission pattern to boys in high risk families is often of a dominant pattern that may account for a quarter of autism. Although the data does not answer whether there is a gradation of lower risk, the model builds on recent CSHL findings that spontaneous mutation is frequent in sporadic autism and less frequent in children from high risk families.

Wigler suggests that “what we now

know about spontaneous mutations and autism offers an alternative to traditional thinking about genetic disorders as purely heritable from a parent. This has implications for other disorders such as morbid obesity, schizophrenia, and congenital heart disease.”

The research was funded by the Simons Foundation and utilized databases from the Autistic Resource Exchange (AGRE) Consortium, the University of Michigan, and the Interactive Autism Network (IAN). IAN is an on-line national autism registry and database launched in April by the Kennedy Krieger Institute. Families impacted by an Autism Spectrum Disorder can contact IAN at www.ianproject.org.

AUTISM SPECTRUM NEWS DESK

Researchers Present Findings at IMFAR Conference

Staff Writer
Autism Spectrum News

The seventh annual International Meeting for Autism Research (IMFAR) recently concluded in London with over 1,150 researchers from around the world attending and making over 850 presentations. Among the countries represented were Australia, Bangladesh, Brazil, Canada, China, Denmark, Finland, France, Greece, Iceland, India, Ireland, Israel, Mexico, Norway, Portugal, Saudi Arabia, South Africa, South Korea, Spain, Sweden, Taiwan, Uganda, United Kingdom, United States, Venezuela and Vietnam.

The following are brief summaries of some of the IMFAR presentations in the areas of autism etiology, biology, diagnosis and treatment. The record number of attendees and the depth and breadth of the science presented signals that autism research is truly becoming global, with advances being made across the board. But most importantly, the goal of the conference was to help individuals and families who are living with autism by uncovering more effective means to diagnose, treat and determine the causes of autism.

Etiology

Environmental Science: Several presentations focused on the role of the environment as a risk factor for autism. Genetic risk factors may be acted upon by



additional environmental factors to ultimately cause autism. The IMFAR hosted an educational symposium concerning links between the environment and autism. These presentations, led by Craig Newschaffer, Ph.D., were intended to educate the community on ongoing research and current thinking in environmental health science, genetics and epidemiology that is relevant to the investigation of environmental risk factors in autism. This symposium also served to complement other presentations on environmental exposures that are being examined for links to autism, which include such

factors as method of birth induction, ultrasound frequency, as well as chemical exposures found in the home.

Irva Hertz-Picciotto, Ph.D., lead investigator of the CHARGE study at UC Davis, provided an overview of epidemiologic designs to study environmental factors in neurodevelopmental disorders. She focused on epidemiologic approaches, outlining different study designs that each pose a different challenge. She also stressed the importance of connecting epidemiology to neuropathology and neurotoxicology. Her talk emphasized that timing of exposure is critical to develop-

mental outcome, and spoke of the promise of currently ongoing studies that prospectively examine mothers and children in order to assess risk factors and match them with their ultimate outcome.

Tony Persico, M.D. from the University Biomedico in Rome highlighted the importance of a strong pathophysiological foundation to environmental research by discussing how researchers must link particular environmental exposures to the specific disruptions in biological functions that they cause. He presented data from his own lab which examined function of the mitochondrial aspartate/glutamate transporter in brain tissue from individuals affected with autism and also discussed newly published research that pointed to a set of genes that affect immune function which he found may be dysregulated in autism. He concluded that environmental exposures may not be necessary or sufficient in themselves for development of autism, but hypothesized that they may contribute to the apparent abrupt onset of symptoms in a subset of individuals. These groups need to be much more carefully studied.

In two final talks, Brenda Eskenazi, Ph.D. from Berkeley University and Eric Roberts, M.D. from the California Department of Health each presented different approaches to studying risk factors from an epidemiological perspective. Dr. Eskenazi is the lead investigator on an NIEHS/EPA longitudinal birth cohort study called

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NARSAD Researchers Study Neurotransmitter

Overactive Transporters of Serotonin and Sticky Blood Protein Yield Clues to Autism

Staff Writer
Autism Spectrum News

Many children with autism have elevated blood levels of serotonin, a neurotransmitter central in brain processes that regulates mood and anxiety. New research led by a NARSAD investigator suggests that this condition, called "hyperserotonemia," may play a role in the origins of certain autism-associated deficits.

In an article appearing in the March issue of the *Journal of Clinical Investigation*, Ana Carneiro, Ph.D., a 2007 NARSAD Young Investigator, and colleagues at Vanderbilt University Medical Center, report that a well-known protein found in blood platelets called integrin beta3 physically associates with and regulates a protein called the serotonin transporter, or SERT, which controls serotonin availability.

Serotonin has long been suspected to play a role in autism via elevated blood serotonin levels and genetic variations in SERT. Alterations in brain serotonin have also been associated with anxiety, depression and alcoholism. Antidepressants that block SERT, known as SSRIs, or selective serotonin reuptake inhibitors, block the molecule's ability to sweep synapses clean of serotonin.

Looking for Serotonin in Platelets

Working in the lab of NARSAD Scientific Council member Randy Blakely, Ph.D., Dr. Carneiro was searching for proteins that interact with SERT and might contribute to disorders where serotonin signaling is altered. "Levels of SERT in the brain are actually quite low, so we decided to see what progress we could make with peripheral cells that have much higher quantities," said Dr. Blakely, the Allan D. Bass Professor of Pharmacology and director of the Vander-

bilt Center for Molecular Neuroscience at Vanderbilt University Medical Center. "This took us to platelets."

Platelets are the sticky cells that combine to form blood clots. In platelets, SERTs accumulate serotonin that is produced in the gut. Administration of SSRIs or genetic suppression of the SERT protein in animals has been observed to prevent serotonin uptake in platelets. "Prior research had fingered the integrin beta3 gene as a determinant of blood serotonin levels and, independently, as a risk factor for autism," Dr. Blakely said.

Integrin Beta3 Activation Enhances Serotonin Uptake

In the new study, Dr. Carneiro identified a large set of proteins that "stick" to SERT, hypothesizing that they might control SERT activity. One of these turned out to be integrin beta3. Once Drs. Carneiro and Blakely confirmed a physi-

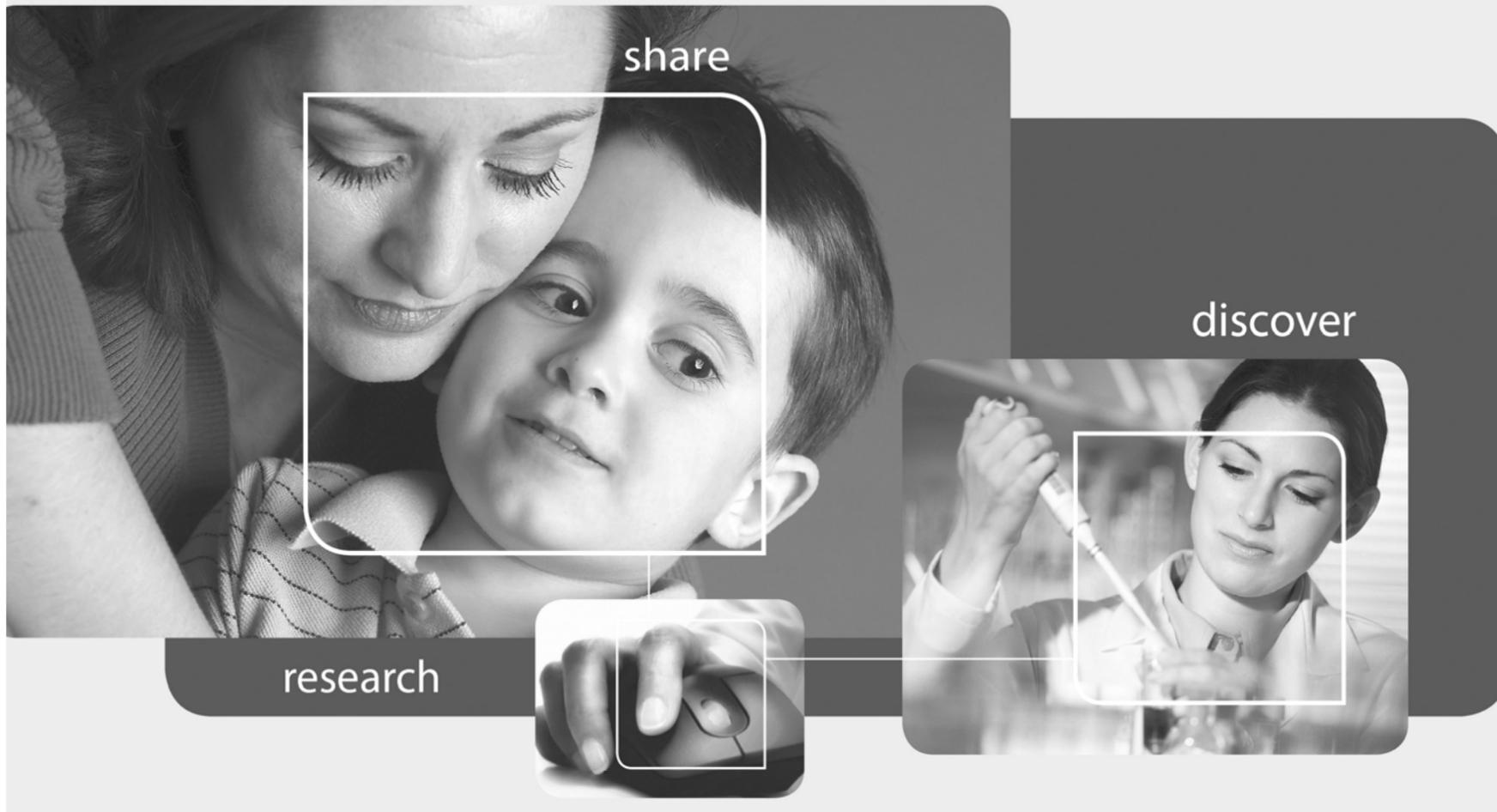
cal relationship between the two proteins, they investigated whether the interaction can change SERT activity. They found that cells lacking integrin beta3 took up less serotonin and that integrin beta3 activation or a human integrin beta3 mutation greatly enhances serotonin uptake.

"We found that integrin beta3 can put the serotonin transporter into high gear," said Dr. Blakely. Notably, Scientific Council member Edwin Cook, M.D., at the University of Illinois at Chicago and a co-author on the study, had previously shown that the same integrin beta3 mutation that elevates SERT activity also predicts elevated blood serotonin.

"Most investigators studying this integrin beta3 mutation have focused on how its high activity state changes platelet clotting and never looked at its impact on serotonin levels or SERT function," explained Dr. Carneiro. "Now they have a reason to."

see NARSAD on page 48

A simple keystroke could help a child with autism



As a parent with a child with autism, imagine your keyboard as a gateway to researchers searching for answers about autism. For the first time, you can share information online with researchers who in return, can share those results with you. You could be helping your child and many others with Autism Spectrum Disorders.



It's a bold new move, but one that can be easily achieved using the internet. What we need is your commitment to sharing the most valuable of all assets... your own personal knowledge and experience.

Share today. And tell others about IAN – so research can flourish, uncovering and unweaving the many mysteries surrounding this puzzling disorder. It's an exciting new way to become part of the solution.

Learn more or participate in the IAN network at www.IANproject.org

Linking autism researchers and families

A Web Project of Kennedy Krieger Institute · Sponsored by Autism Speaks

Volunteer for Research on Autism Spectrum Disorders

IAN, the Interactive Autism Network at the Kennedy Krieger Institute, is looking for volunteers to participate in an online research study. To participate, parents of children with an Autism Spectrum Disorder will answer questions online about themselves, their affected child, and other family members. The study's purpose is to increase knowledge about Autism Spectrum Disorders (ASDs) and help find effective treatments. IAN will also match willing families affected by ASDs with other research studies locally or in the United States.

Who Can Participate?

The following people and their immediate family members can participate in this study – Anyone who is living in the USA and who is less than 18 years of age, who has ever been told by a professional that they have any of the following: Autism Spectrum Disorder (ASD), Autism, Asperger Syndrome, Autistic Disorder, Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CDD). By "immediate family members" we mean biological or adoptive parents and full or half siblings. Step siblings are not included in the IAN Research Database at this point.



Principal Investigator: Paul Law, MD MPH
Contact: ResearchTeam@IANproject.org
JHM IRB#: NA_00002750

Autism Speaks Funds Over \$30 Million in Research

Staff Writer
Autism Spectrum News

It was a momentous year for autism research. In 2007, Autism Speaks funded over \$30 million in research, almost double that of last year. With anticipated annual budget increases of 15 to 25 percent over the next few years, we took the opportunity to clarify and define our research priorities into four distinct areas: etiology (or risk factors), biology, diagnosis and treatment.

What We Fund

Grants and Fellowships: Autism Speaks funds several types of investigator-initiated grants targeting critical areas of autism research. These grants are crucial for allowing investigators to gain enough data to be able to attract even larger, multi-year commitments from the NIH and other traditional medical research funding organizations. Fellowships provide the necessary resources to support and encourage the development of young scientists who benefit from the mentorship of prominent researchers.

Our Research Grants

Augmentation and Opportunity Bridge Awards: In light of a tight federal research budget, these awards are designed to supplement or expand the scope of autism related research projects already funded through the NIH, CDC, or other federal agencies. In 2007, a total of 4 projects were allocated approximately \$450,000.

Basic and Clinical Research Grants: These awards provide enhanced funding to researchers with existing preliminary data from pilot studies. In 2007 Autism Speaks awarded \$11.5 million to 27 projects.

Innovative Technology for Autism Grants: This grant mechanism spurs development of new technology to assist those living with autism. In 2007, five new grants worth approximately \$416,000 were awarded.

Treatment Grants: These grants support research focused on all aspects of treatment, including behavioral, biomedical, and technological interventions. In 2007, over \$2 million in funding was awarded to treatment research.

Pilot Research Grants: These awards support innovative new approaches, funding an investigator's beginning explorations in autism research. In 2007, Autism Speaks committed \$1.7 million to support 15 projects in this category.

Our Research Fellowships

Mentor-Based Fellowships: These fellowships are pre-doctoral and post-



doctoral awards offered to encourage and support the training of young scientists interested in a career in autism research. In 2007, 31 mentor-based fellowships were awarded, totaling \$2.6 million.

Physician/Investigator Beginning Autism Research (PIBAR) Fellowships: These fellowships support medical doctors who wish to spend a year devoted to autism research. In 2007, Autism Speaks awarded \$1.4 million to five such fellowships.

Autism Speaks – Organized Initiatives

As important as individual grants, initiative projects give Autism Speaks a much more proactive role in promoting specific research. Initiatives frequently involve formation of collaborative research consortia, support of targeted research, organization of research meetings, and creation of research resources. We believe initiatives that bring together researchers from varied fields will promote a collaborative approach to help solve the mysteries of this complex disorder as quickly as possible.

Targeted Initiatives

Autism Epidemiology Network: Autism Speaks and the Centers for Disease Control and Prevention (CDC) are co-sponsoring the Autism Epidemiology Network in an international effort to understand the causes of autism, particularly across diverse genetic and cultural settings.

Autism Genome Project (AGP): In 2007, the AGP moved into phase two, in which the coalition of researchers will apply state-of-the-art “gene-chip” technologies to scan the genome for association with newly identified genetic markers, as well as copy number variables along chromosomes in autism.

Brain Development Initiative: This initiative takes its impetus from a confluence of findings on abnormal brain development in autism. This initiative focuses on bridging research disciplines – brain structure, function, chemistry, and genetics—to fund innovative work in understanding why brain development goes awry. In 2007, the Brain Development Initiative funded the second year of the Neuropathology Workgroup, a collaborative effort to understand the cellular and molecular changes in the developing autism brain.

Gene-Environment Interaction Initiative: This interdisciplinary effort began in 2007 and brings together experts in the fields of genetics and environmental health to capitalize on the latest findings in autism genetic and environmental sciences.

High-Risk Baby Siblings Consortium and Toddler Treatment Network: The Consortium's goal is to bring together the major research groups in the field (including the National Institutes of Health [NIH] and scientists worldwide) to discover the earliest behavioral and biomedical markers for ASD and develop treatments appropriate for infants and toddlers.

Innovative Technology for Autism Initiative: This initiative was established to lead in the development of products that provide real-world solutions to issues faced by those with autism, their families, educators, healthcare specialists and researchers.

Resources and Clinical Programs

AGRE - Autism Genetic Resource Exchange: The AGRE collection is the largest private single source of genetic and clinical information for autism research

available to scientists worldwide. In 2007, an \$8.4 million grant from the NIH was awarded to the University of Southern California to establish a Center for Genomic and Phenomic Studies of Autism. Over the next five years, 50 percent of those funds will be allocated to directly support the ongoing data collection efforts of the AGRE program to survey the genetic, physical, and behavioral profiles of children with autism. The NIH funding will double the number of families in the AGRE database (currently at 1700) and expand the data beyond genetic and clinical profiles to include phenomics, the systematic study of the outward physical and behavioral characteristics of autism.

ATN - Autism Treatment Network: The ATN is the nation's first network of hospitals and physicians working together to establish standards of clinical care based on research and shared clinical practice for autism and related disorders. At the end of 2007, Autism Speaks' Board of Directors approved the expansion of the ATN from five to 15 sites nationwide (sidebar), reaffirming Autism Speaks' commitment to evidence-based treatment for autism.

ATP - Autism Tissue Program: The ATP is the only privately funded program dedicated to increasing and enhancing the availability of post-mortem brain tissue for basic research in autism. In 2007, the ATP received support from the NIH for its awareness and recruitment efforts, and hopes to secure additional public and private funding for 2008.

IAN - Interactive Autism Network: IAN, a partnership between the Kennedy Krieger Institute and Autism Speaks, is an innovative web-based project designed to accelerate the pace of autism research by linking researchers with families. In addition, families of children with an ASD can share information in a secure online setting and become part of the nation's largest online research effort. Launched in April 2007, IAN has already registered more than 25,000 people in this program.

CTN - Clinical Trials Network: The CTN is a collaboration of hospitals and medical centers working together on clinical trials. The CTN approach enables sites to enroll children around the country in a single study, allowing sites to reach recruitment goals in a much shorter amount of time, thereby accelerating progress. In 2007, the CTN launched a new study in collaboration with specialty pharmaceutical company Neuropharm Group PLC. The trial, known as SOFIA (study of fluoxetine in autism), will include more than 100 children and adolescents with ASDs to confirm the effectiveness of Neuropharm's custom-designed product.

Autism Speaks is dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention and treatments for autism, and to advocating for the needs of individuals with autism and their families.

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into the
mysteries of*

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We are currently enrolling families to join our important study

Families eligible to participate consist of: only one child with an autism spectrum disorder (ASD), age four or older; one or more siblings without an ASD, age four or older; and unaffected biological parents who are willing to participate. Eligible children with an ASD will receive a behavioral assessment and all family members will donate blood, a source of DNA. A small number of families with no siblings or siblings under the age of four may be eligible to participate in the study. To learn more about this study, please contact:

Simons Foundation, www.simonsfoundation.org/ssc

The Seaver and New York Autism Center of Excellence

Dedicated to Research, Treatment, Education, and Improving Care in the Community

By Eric Hollander, MD, Director
Seaver and New York Autism
Center of Excellence, Mount Sinai
School of Medicine

The Seaver and New York Autism Center of Excellence was launched in 1993 by a grant to Mount Sinai Medical School of Medicine from the Beatrice and Samuel A. Seaver Foundation. The Center is under the direction of Dr. Eric Hollander, the Esther and Joseph Klingenstein Professor of Psychiatry and Chairman of the Department of Psychiatry at Mount Sinai School of Medicine.

In 2003, the Seaver Center was named a Center of Excellence by the National Institute of Health (NIH) as part of the Studies to Advance Autism Research and Treatment (STAART) Centers Program initiative. We have also received funding from several Federal sources, including the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, and the Orphan Products Division of the Food and Drug Administration, in addition to multiple foundations and the pharmaceutical industry.

Our Mission

The Seaver and New York Autism Center of Excellence is dedicated to discovering the biological causes of autism



Eric Hollander, MD

and to developing breakthrough treatments. The Center strives to translate scientific efforts into optimal community care and has alliances with numerous support groups and community agencies, as well as affiliations with the YAI National Institute for People with Disabilities, Federation Employment and Guidance Service (F.E.G.S.), and United Jewish Appeal Federation of New York (UJA).

The Center is also committed to education and provides training opportunities in state of the art assessment, treatment, and research approaches to autism spectrum disorders through funded fellowship programs available to physicians and graduate students.

Clinical Services

Our team consists of clinical/behavioral psychologists, psychiatrists, and neurologists with specialized training and expertise in the diagnosis, assessment, and treatment of autism spectrum disorders (ASD). The clinical team has unique expertise working with children, adolescents, and adults on the autism spectrum who have complex needs and who may be considered difficult to assess and treat.

We offer *Assessment & Evaluation Services*, including diagnostic testing, neuropsychological testing, academic testing, and psychiatric evaluations. In addition, we offer comprehensive *Treatment Services*, including medication management, social skills groups, parent training sessions, cognitive behavior therapy, and a sibling support program. As part of our commitment to education and community care, we also have a *Community Outreach & Training Program* that provides lectures and workshops to parent groups, agencies, and schools. And we also host an annual conference to address current scientific trends and discoveries.

The Center conducts weekly *Social Skills Therapy Groups* for school-age children with ASD. Groups are conducted in 12-week modules targeting deficits in interpretation of social/emotional cues, conversational skills, anxiety-management, and peer interaction/friendship skills. Groups are conducted utilizing cognitive-behavioral models of intervention and include concurrent parent-training sessions to facilitate skills generalization.

Research Program

The Seaver Center research program is a collaborative effort that offers an integrated series of research studies in innovative treatments, genetics, and brain imaging. All services in research studies are provided without charge to eligible participants and include gold standard diagnostic assessments such as the Autism Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview (ADI), and neuropsychological testing.

The *Experimental Therapeutics & Clinical Trials Program* conducts treatment studies for children and adults that target specific symptoms of ASD, including repetitive behaviors, aggression, language delays, motor skills deficits, and social impairment. The Center has a long and successful history of conducting key

see Seaver Center on page 40

The Seaver and New York Autism Center of Excellence— Translating Neuroscience to Breakthrough Treatments in Autism



The Seaver and New York Autism Center of Excellence is dedicated to discovering the biological causes of autism and to developing breakthrough treatments.

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CALL 212-659-8287
VISIT www.mssm.edu/psychiatry/autism



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MEDICINE



Autism Spectrum Disorders

Early Identification Makes a Lifetime of Difference!

Pediatricians should screen all children for ASDs at 18 and 24 months. They should also listen carefully to parents about their child's development. **Remember: Parents are the most reliable sources of information about their children!**

If a child exhibits any of the following tendencies, he or she should see a pediatrician.

- No response to name.
- Lack of or delay in speaking.
- Repetitive and excessive use of words, phrases, mannerisms or gestures.
- Little or no eye contact.
- Persistent fixation on parts of objects

Research has shown that early intervention is critical to maximizing the development of a child with an ASD. Pediatricians and other qualified clinicians can help obtain an early diagnosis and make referrals for appropriate services and interventions.

To learn more about YAI/NIPD Network programs and services for infants, children and adults with autism spectrum disorders, please contact YAI LINK at 1-866-2-YAI-LINK, TDD: 212-290-2787, link@yai.org or visit www.yai.org.



Premier HealthCare and YAI/NIPD are affiliates of The Mount Sinai Hospital and The Seaver and New York Autism Center of Excellence of The Mount Sinai School of Medicine.

Good Health For Life

Meeting the Medical Needs of People with Autism Spectrum Disorders

By Peter DellaBella, MD, Associate Medical Director and Chief of Psychiatry, Premier HealthCare of The YAI/National Institute for People with Disabilities Network

When Devon Kennedy was small, a visit to the dentist could induce an episode of panic. Having a cavity filled, while unpleasant for anyone, was for him, a nightmare.

But his dentist, Chrystalla Orthodoxou, had confidence that Devon, who has an autism spectrum disorder (ASD), could come to terms with a dental checkup — even with having a cavity filled.

As chief of dentistry at Premier HealthCare, a member of the YAI/National Institute for People with Disabilities Network, Dr. Orthodoxou has the training and experience necessary to set patients like Devon at ease. She spent several visits dedicated solely to acclimating Devon to the dental chair and instruments and building a trusting relationship with him.

“For individuals with autism, who may have more difficulty understanding the importance of health care, anxiety can create significant obstacles to physical well-being and overall quality of life,” said David Kaufman, M.D., medical director at Premier HealthCare.



Peter DellaBella, MD

“The staff at Premier HealthCare take the time to understand each patient’s specific situation, help them overcome their fear and successfully complete the necessary clinical procedures,” Dr. Orthodoxou said.

Cathy, Devon’s mother, will never forget the day that Devon was able to calmly have a cavity filled, an event that would have been unthinkable a few months before. “Dr. Orthodoxou called me later that day, saying, ‘I knew he could do it! I knew he could do it!’” she recalls.

For Devon, now 16, trips to the dentist are now easy and, thanks in part to his regular checkups, he has been cavity-free for years.

Overcoming Barriers to Good Health

For many people on the autism spectrum, routine medical checkups and dental visits often have to be administered under general anesthesia and may even result in trips to the emergency room. This often causes families or caregivers to forgo important preventative checkups and exams. Barriers to accessing care are a major issue for this population.

“People with ASDs have the same medical needs as anybody else,” said Stephen E. Freeman, Associate Executive Director of YAI/National Institute for People with Disabilities. “But they also have specific health concerns that need to be addressed. They often require more time and patience to treat than the general population, so it can be very difficult to find doctors, dentists and mental health professionals who have the knowledge and willingness to work with them.”

According to a 2002 report by the U.S. Surgeon General titled “Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation,” children, adolescents and adults with intellectual disabilities — which in-

clude many, but not all, people on the autism spectrum — “experience poorer health and more difficulty in finding, getting to and paying for appropriate health care.”

In fact, a 2002 study conducted by researchers from the Heller School for Social Policy and Management at Brandeis University found that more than a third of children with autism encountered obstacles in obtaining necessary care from medical specialists over a 12-month time span. The reason? An inability to find referrals and providers with appropriate training (Krauss, Gulley, Sciegaj & Wells, 2002).

For decades, this has been a fact of life for many people with ASDs. And while health care services for people with autism have begun to improve, much needs to be accomplished in providing access to services and educating health care professionals about patients with autism spectrum disorders.

A Model for Community-Based Health Care

Premier HealthCare was founded in 1997 to serve people with disabilities, whose needs were simply not being met by the traditional health care system. This person-centered, community-based model

see Good Health on page 47

Early Detection Makes a Lifetime of Difference

By Bernadette Flynn, EdD Director of the New York League for Early Learning, a member of the YAI/National Institute for People with Disabilities Network

At 15 months old, James had not yet begun to speak. His mother, Michelle Lederman, was not particularly worried, but she decided to do the prudent thing and have him evaluated for a speech delay.

When the speech therapist recommended a second, more comprehensive evaluation, “I said, ‘Sure, go ahead!’” Michelle recalls. “Our speech therapist kept saying it was behavioral, but I really wasn’t sure what that meant.”

Months later, James was diagnosed as being on the autism spectrum. Autism is a neurologically based developmental disability that according to the Centers for Disease Control and Prevention affects one in 150 children in the United States.

James was lucky. Because he was diagnosed before the age of 2, he was able to begin receiving crucial early intervention services that, for many children, can change the course of their lives. According to the New York State Department of Health Early Intervention Program, intensive behavioral approaches, when started at an early age, may significantly improve outcomes for children with autism.

In fact, this explains why the American Academy for Pediatrics adopted a new



Bernadette Flynn, EdD

guideline that all children be screened for autism spectrum disorder twice before age two -- once at 18 months and once at 24 months -- as part of well baby checkups. It also recommends that treatment for autism be started when autism spectrum disorder is suspected, rather than when a formal diagnosis is made.

But a diagnosis of an autism spectrum disorder can only occur if parents, caregivers and doctors and other professionals know what to look for.

Like most children on the autism spec-

trum, James has experienced a significant speech delay, which is a prominent indicator for autism. It is also the aspect of the disability that families often have the most difficulty coming to terms with.

“One of the biggest fear for families whose child is more recently diagnosed is: ‘Will my child ever talk?’” said Hilda Chusid, Early Intervention Supervisor of the LifeStart program at the New York League for Early Learning, a member of the YAI/National Institute for People with Disabilities Network. LifeStart offers early intervention services for newborns through age three. “Parents wonder, ‘If my child doesn’t have the words to tell me he’s in pain, how will I know? If my child goes on the school bus and something happens to her, how will I know?’”

For families, speech delays may be the most obvious sign that their children aren’t developing typically. However, parents are also advised to consult a physician if their child exhibits any of the following tendencies:

- No response to name
- Repetitive and excessive use of words, phrases, mannerisms or gestures
- Little or no eye contact
- Lack of interest in making friends
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

When parents call Hilda wondering if their children need evaluations, she tries to be as helpful, and as realistic, as possible.

“Evaluations, the first step in determining a child’s diagnosis, are stressful for parents because of the fear that a professional will tell them that there is something wrong,” Hilda said. “The most difficult part comes when they learn that their fears have been confirmed. Then they have to figure out how they are going to help their child—and how they are going to deal with this.”

Unfortunately, parents sometimes ignore the signs of autism. They may attribute their children’s lack of speech to being a “late bloomer.” Or they may try to rationalize away their children’s developmental delays when they see typically developing children of friends or relatives begin to speak later than usual.

Carol Stein-Schulman, Assistant Director of Education and Training for the New York League for Early Learning, explains that parents sometimes miss crucial indicators for autism because their children appear to be good, easy babies, who play in their cribs without fussing.

“Parents need to see whether their children are understanding language,” Carol said. “You want to make sure that by approximately 12 to 18 months of age, they are interacting with their primary caretaker. If all they want to do is sit in the corner and arrange their cars or play with the

see Early Detection on page 43

The NYU Child Study Center
is pleased to welcome

Catherine Lord, Ph.D.

Interim Director of the
NYU CSC Asperger Institute

Dr. Lord is one of the nation's leading experts on Autism Spectrum Disorders. She is currently on sabbatical from the University of Michigan where she is Director of the Autism and Communication Disorders Center, and Professor of Psychology, Psychiatry, and Pediatrics. While at NYU CSC, she will be furthering her ground-breaking research on the early diagnosis and treatment of toddlers and pre-schoolers on the autism spectrum. Interested families can contact her through the Center's intake number at 212.263.8919.

The NYU CSC **Asperger Institute** is dedicated to diagnosing, providing treatment and support, developing clinical and educational models for children and adults with Asperger Syndrome, and advancing the knowledge to create a better understanding of the condition.



NEW YORK UNIVERSITY
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Langone Medical Center

Social Skills Groups: What Does the Research Tell Us?

By Lynda Geller, PhD
Clinical Director, Asperger Institute
NYU Child Study Center

Social skills deficits are considered to be one of the critical diagnostic impairments that define autism and Asperger Syndrome, so it is perhaps not surprising that both school personnel and clinicians in the community frequently recommend that a child or adolescent on the autism spectrum should be enrolled in social skills groups. The intention of such groups is to improve the development of these skills that often are so compromised. Yet just how much research evidence exists supporting the effectiveness of social skills groups as they are currently being delivered? The goals of this review are to summarize what the research tells us regarding efficacy of group social skills development models and to suggest to families what they should require from those delivering this kind of service.

Social skills are critical to successful adult outcome, from having rewarding personal relationships to academic and vocational accomplishment to overall mental health and quality of life. When considering these issues for the individual with an autism spectrum disorder we must be cognizant of the developmental nature of these conditions. Individuals on the autism spectrum have underlying brain differences that affect how they experience the world. In turn, experiences in life have direct consequences on ongoing brain development. So the outcome of any child's development is the sum total of underlying assets and deficits and the life experiences that continuously shape all of us and directly impact brain development. That is why early intervention is such a powerful tool. It actually shapes brain development during critical periods and individual outcome can be profoundly affected by having or not having these kinds of experiences.

Those of us who work intensively with children with autism continually witness how autism unfolds and how the lack of certain experiences contributes to the ultimate outcome of each one of them. For example, it is not uncommon for parents to tell us that their child has never had a friend. While this is painful in and of itself, the developmental ramifications are significant. Peer interactions are necessary to develop the skills for maintaining conversation, taking perspective, playing appropriately, controlling emotional expression, negotiating conflict, and experiencing intimacy. Without these experiences in childhood, establishing a positive adulthood is very difficult. So, the child with the developmental differences of autism suffers the additional burden of limited experience in critical areas, resulting in what we so often see in young adults as inability to establish relationships or maintain a job and personal independence. Therefore it is no wonder that so many clinicians and educational professionals try to provide development in the area of social skills. We all know it is critical for successful adulthood. But is what is being typically provided in



Lynda Geller, PhD

schools and clinics effective in improving essential social skills?

Very recently, four significant reviews of social skills interventions have been published (White et al., 2007; Rao et al., 2008; Matson et al., 2007; Bellini et al., 2007.) They provide guidelines for assessing social skills groups as they have been implemented and give us important standards for assessing whether critical qualities exist in what is being currently offered.

White, Keonig & Scahill describe their concern with social skills development as being based on findings that social skills deficits do not remit but become more devastating with age as the social milieu becomes more complex; that children in inclusive settings are often more rejected and isolated, yet are not given the skills to succeed; and that social skills deficits contribute to academic and occupational underachievement and later mood and anxiety problems. Given these outcomes, high quality social skills interventions are crucial. Fourteen studies were identified that addressed group intervention for children and adolescents identified as having an autism spectrum disorder (ASD.) All studies had very small sample sizes (ten or less.) Only two studies utilized a manualized approach specifically developed for individuals with an ASD while others used techniques developed for other populations. Others simply described their approaches in greater or lesser detail. Only five studies included a comparison group and none used randomized assignment to treatment group. None of the studies could be considered an effectiveness study, that is, one that examines the generalizability of gains to other settings. White et al. concluded that the state of research about social skills groups is still in its infancy. However, they identified some promising strategies, based on what was demonstrated in the studies, that should be considered in future program development. These include stimulating social motivation, rewarding social initiation, reinforcing appropriate social responding, treating interfering behaviors,

and providing opportunities for skill generalization. Their strongest recommendation was that we need to develop and validate manualized social skills curricula to be utilized in schools and community-based groups.

Rao, Beidel & Murray reviewed papers evaluating social skills training programs for youth with Asperger Syndrome or high functioning autism to assess their efficacy and make recommendations for future research directions. They examined ten studies of high functioning children on the autism spectrum as such students are more likely to be in inclusion settings where the social demands are more intense. They found that current research is lacking in the following areas: establishing a common definition of what comprises social skills; conducting research that includes having control groups to compare outcomes and having blind observers to evaluate results; generalizing techniques to other settings; and conducting long term follow-up to determine if an intervention had any effects on eventual outcome. They recommended that future studies utilize manualized treatments specific to particular social deficits (e.g. simple interaction versus relationship development,) that more rigorous research designs be employed to assess effectiveness, and that generalization beyond the office be specifically implemented and measured. As in the previous review, these authors noted that the feasibility of improving social development through group instruction has been demonstrated, but the specific methods need further research.

Matson, Matson & Rivet examined a wide range of social skills interventions for children with ASDs of all functioning levels. In their review of seventy-nine treatment studies, they generated specific recommendations of what is required for the field to move forward toward more validated and specific social skills treatments. They suggest:

- Parent training models to improve generalization and to make intervention available for younger children
- Programs that address interfering behaviors or co-morbid disorders (such as severe anxiety)
- Interventions for children under six years of age whose brains have greater plasticity and who should be developing skills they can practice throughout elementary school
- Need-specific programs that can differentiate between those who need very basic versus more advanced skill development
 - Consistent use of measurements in existing school and community social skills programs to assess if participants are meeting their specified goals

Bellini, Peters, Benner & Hope reviewed social skills interventions being delivered in school settings. As social skills development is almost universally stated as a goal for special education students with ASDs, this is a particularly

critical area to examine. A meta-analysis of fifty-five single-subject design studies was conducted to formulate some generalizations about treatment effectiveness of programs as they are currently being delivered in schools and to specify what approaches seem to offer the best potential. Bellini et al. reiterate that there is only minimal evidence that social skills training programs are effective for children in general, let alone for those for whom social deficit is the defining attribute.

The most important conclusions of this review were that social skills interventions in schools, as they are being reported in the literature, have low to questionable treatment and generalization effects and moderate maintenance effects. That implies that most treatments were not particularly effective in changing social behavior or affecting any changes that generalize across settings, but that any changes that occurred were somewhat maintained. The studies were then assessed by approach with the general findings that interventions need to be more intensively implemented, that they should occur in context rather than in an office, that the strategy should match the specific skill deficit, and that validated treatments should be implemented by clinicians trained in the specific intervention to insure effectiveness. The findings of this analysis were discouraging and implied that much of what is now being done for students with ASDs in schools may be rather ineffective.

Given the limited research evidence for the effectiveness of group social skills interventions, what are responsible recommendations? For community-based interventions, parents should ask the following questions:

- Is there a manualized, evidence-based curriculum or a well-designed, explicit program with specific goals?
- Do the proposed group members have similar needs that are being addressed specifically?
- Do the target behaviors being addressed make sense for each member?
- Is generalization to real-life settings being designed as an integral part of the program?

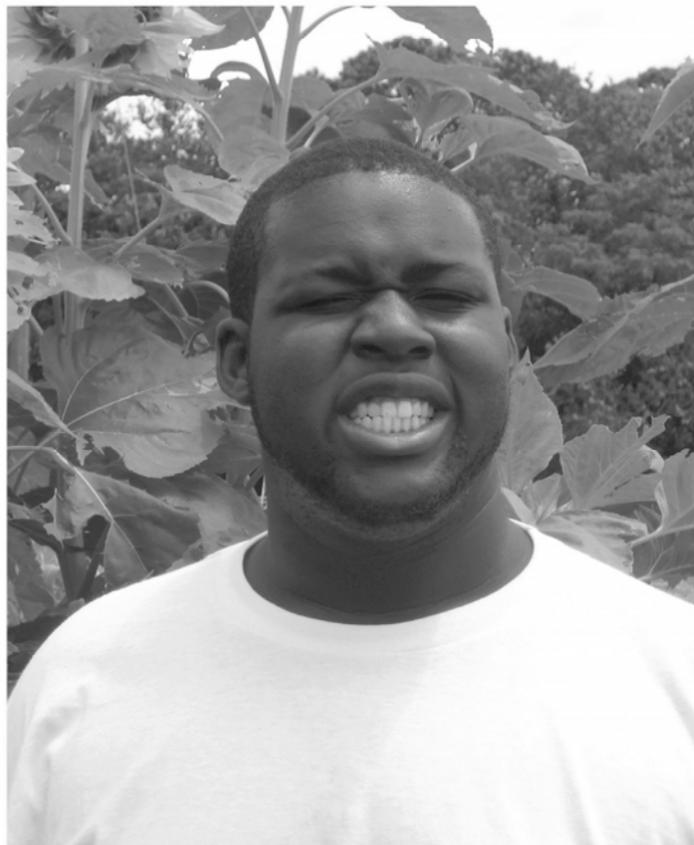
As children with ASDs typically lack good generalization skills, it is necessary to provide more specific opportunities for practice in realistic settings. This can be implemented through parent involvement with each session's lesson, rehearsal and reinforcement homework for members, and prescribed member interaction between sessions. Interventions can also take place in actual life locations. Of importance, as well, is the therapist's orientation to achieving measurable goals. Does the group leader:

- Assess each member's needs before inclusion in the group?
- Have plans for assessing effectiveness?

see *Social Skills Groups* on page 45

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Evidence-Based Practices for Educating Children with ASD

By Cindy Alterson, PhD, BCBA
Principal and Program Director
Devereux Millwood Learning Center

The use of interventions derived from principles of applied behavior analysis (ABA) has a decades-long history in providing effective methods of ameliorating some of the symptoms of autism spectrum disorders. As a notable example, functional communication training (FCT) (Durand, 1990) has been shown to be an effective way to decrease behaviors that interfere with learning, including behaviors that can be significantly or severely harmful. Briefly, FCT assumes that all challenging behaviors have communicative intent, and FCT decreases those challenging behaviors by providing an individual with alternate, more appropriate ways to communicate that intent. So a child who throws himself on the floor when asked to do a difficult task, may be provided with a way to communicate "I need help."

Based on the example provided, one may wonder whether to consider functional communication training in a clinical or educational intervention. The elimination or decreasing of challenging behaviors has traditionally been under the purview of the medical, psychiatric or psychological fields and thus may be seen as a clinical intervention. Helping an individual learn to state "I need help" has traditionally been under the purview of



Cindy Alterson, PhD, BCBA

speech pathology, and can also be considered a clinical intervention. Clinical fields like medicine and psychology can demonstrate, through a history of research, that providing this intervention can result in certain improved outcomes. These interventions may be defined as evidence-based and it is the expectation of insurance companies that an intervention prove its ability to reach certain outcomes before it will be paid for by them.

However, schools are required by fed-

eral law (IDEA) to complete a functional behavioral assessment for an individual on any behavior that interferes with learning. The determination that a challenging behavior functions to help a child escape from difficult tasks, and then the development of a program to help that child communicate "I need help" may in some circumstances, be completed by licensed clinical staff, such as a psychologist and a speech pathologist. For this intervention to be truly effective, it must be implemented as well by teachers, aides, other classroom support staff and parents so that the new behavior of requesting a break is demonstrated across all settings. And in all likelihood, it is probably the teacher, aide, support staff and parents who complete the FBA and develop FCT as an intervention in most schools anyway. That FCT is now thankfully provided by educational teams, has resulted in more students with autism included in less restrictive settings and tremendous advancements for individual students to have better behavioral and social outcomes.

However, it also may have contributed to the current debates over whether insurance companies will cover ABA as an intervention with autism. Any good intervention plan using ABA as a model will include increasing skills. It is usually a school's responsibility to teach new skills. Why would a medical insurance company take on the task of education? To the best of my knowledge, only six states have a law in place requiring private insurance companies

to cover ABA as a service for individuals with autism (Arizona, Florida, Indiana, Minnesota, South Carolina, and Texas). Over 20 states have no such laws, and no bills on the horizon to address this issue.

It is important for autism intervention that educational and related service providers become more attuned to the need for empirical evaluation of teaching strategies. As a field, education is rife with "fad" instructional practices (Jacobson, Foxx, & Mulick, 2005); special education less so than general education, as the development of strategies for students who struggle to learn in traditional ways has required research analysis to some extent. For autism in particular, the type of strategies that are needed to ameliorate symptoms can be so complex and varied and can need contributions from medical, psychiatric, behavioral, speech, occupational and physical therapies, that true analysis of what is effective for each individual should be a required component of the child's educational plan.

It would greatly benefit autism services if all providers were required to learn how to conduct and consume research in single-case design. When a medical intervention is tested, it is demonstrated effective if the *average* amount of change in all individuals combined pre-to post-treatment is greater for the sample who received the intervention than those who didn't. This may be acceptable in

see *Educating Children* on page 43

What Parents Should Consider When Evaluating School Programs for their Child with Autism

By Todd Harris, PhD
and Karen Neifer, MEd
Devereux CARES

One of the greatest challenges that parents of children with disabilities face is finding the most appropriate educational program. When looking for a school for a child with autism, the parents' task often is complex and difficult, but understanding instructional and social variables will help in making the right decision.

Instructional Considerations

First and foremost, parents need to determine if the instructional strategies used by a school and its philosophy are consistent with what they feel will be effective for their child. Ensuring this "goodness of fit" is critical and can be assessed by not only asking questions of a school administrator, but also by touring a program and observing classrooms in action.

While observing a classroom, parents should note the engagement levels of students. For learning to occur, a student must be frequently and appropriately engaged with materials, as well as staff and other children. During an observation, select several students to watch and determine if they are watching the instructor

(and/or appear to be listening), following instructions, actively completing work, and/or appropriately engaged with recreational materials (such as toys, a computer, a book, etc.). Ideally, students should be engaged at least 80% of the time.

Parents should also carefully note the number of learning opportunities for communication and social skill instruction that are presented. Good programs will systematically arrange their learning environments so students will need to frequently communicate. For example, at snack time, students are encouraged to ask for their snack rather than having the teacher simply present it to them.

There should also be obvious chances to learn and practice social skills. These types of skills can range from something as simple as looking at a speaker, greeting others and taking turns, to more complex skills such as saying "please" and "thank you," engaging in conversations and giving compliments. Using snack time as an example, students can be taught to take turns pouring their own juice, passing napkins to other students and saying "thank you" when receiving food.

It will also be important that independence and generalization areas are targeted. Families should look for evidence that students are taught not only academics (or functional academics), but also self-care, motor skills, recreational/play, and do-

mestic and vocational skills. Parents should also ask about the level and intensity of a school's community-based instruction program. For optimal progress, most students should receive frequent instruction in community locations, such as the grocery store, at least weekly. This type of instruction should also be supported by instruction that takes place outside of the classroom in other locations within the school (such as the office, library, lunchroom and/or kitchen, etc.).

When observing structured teaching, parents should look for evidence that there is a motivational system in place (such as a token or point card system), fun materials and visual supports to enhance understanding (such as a visual schedule, pictorial reward cards, word/picture prompt cards and social stories). Families should also ask how staff are trained to implement different strategies, as well as what systems are in place to ensure that programs are consistently implemented across time and staff (i.e., how often are administrators or supervisors in the classrooms observing staff). Parents should also determine if the teaching methods and other types of interventions used by a school are supported by scientific research.

A parent should ask about the school's philosophy regarding reducing unwanted behaviors. Are functional behavior assessments used for program planning?

Are these plans proactive and designed to teach appropriate alternatives to replace challenging behaviors versus plans that emphasize reactive strategies and what to do when the behaviors occur? Another consideration is how staff responds to unwanted behavior. Are staff members calm when addressing challenging behaviors, or do they get upset and/or show their frustration?

Social Considerations

While it's crucial to consider the instructional aspects of a school, the social climate should be thought of as equally important. In particular, parents should pay close attention to the frequency and quality of staff-to-student interactions.

Not only do staff members need to be highly supportive with students, but they also need to deliver high rates of verbal praise. This praise should be varied and offered in an enthusiastic and animated manner. Families should also take note of the frequency of corrective feedback and how it's delivered (i.e., in a kind way as opposed to using a harsh and disapproving tone). If instruction is designed carefully, error rates will be low and the use of corrective feedback can be minimized. Most experts agree that for every instance

see *The Right School* on page 54



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Identifying Émigré Children with Special Needs in Mainstream Preschools

The Brooklyn Autism Spectrum Disorder Initiative

By Bruce A. Grellong, PhD
and Fern Fisher, MA, MS, LCSW
Jewish Board of Family and Children's
Services (JBFCFS)

Irina was puzzling to her teachers in the day care center. For a 3 ½ year old, she spoke very little, sometimes mixing English and Russian words or phrases. She seemed to like being nearby the other children but did not initiate interaction or seem to follow the sequence of activities going on around her. She used only a few materials in the room and always in the same way and sometimes resisted changing activities. Her family had been in the U.S. about 2 years, so maybe she was unfamiliar with the language or the routines of a busy New York day care center. Irina's teachers needed some guidance to better understand her development and what Irina needed. They worried about how they would communicate their questions and concerns to Irina's parents. Our project was developed specifically to help early child care settings that serve émigré families become better able to meet such special needs as emerged with Irina and her family. We accomplished this through a teacher training program on autism spectrum disorders and ongoing early childhood consultation.

Nowadays there are more children diagnosed with Autism Spectrum Disorders (ASD) than ever before. Yet teachers trained to work with young children in mainstream early childhood programs are not routinely taught about spectrum disorders. Because of the proven value of early intervention, and the need for teachers to have information about ASD, a course was designed to provide early childhood educators with information to help them become aware of children who may be on the spectrum and to understand and better serve these children in their classrooms. The community-based sites that participated in this program each served émigré families (primarily, but not exclusively Russian) so it was important that our program be bicultural-bilingual in order to address the unique needs of families unfamiliar with both the language and culture of the dominant community served by the day care centers.

The funding for this course was made possible by a partnership grant from the UJA-Federation of New York, Butler Foundation and New York Community Trust. The course became a part of a larger program that was designed to support community-based organizations in early identification of children who may be on the spectrum, support efforts by schools and parents to provide these children with the services they require and integrate the children into the community.

The funding organizations conducted a twenty month needs assessment and were convinced that early childhood teacher education would be crucial in helping to identify ASD children and helping their families. Parents with children on the spectrum often become more conscious of their children's difficulties when preschool begins. The funders believed



Bruce A. Grellong, PhD

strongly that knowledgeable early childhood educators could help these parents by offering support and information and by instilling the confidence to find therapeutic services when necessary.

The funders sought expertise from The Jewish Board of Family and Children's Services both for well-informed teachers to work with the four chosen sites in Brooklyn and for experienced early childhood consultants to provide consultation services to settings that didn't already have it.

Course Design

The teaching portion of this grant was designed to cover normative development, atypical development, communication and interactions with parents, classroom management and problem-solving. The four session course included supplemental readings, information about important websites, discussion, a listing of community resources and videos. The program covered four distinct areas:

Typical Development, Infancy to Age 5: Temperament, Personality, Age & Stage

Knowledge of child development governs the principles of practice for early childhood education. This session covered physical, cognitive, social, emotional and linguistic development and explored how growth, maturation and certain behaviors, beginning in infancy, follow a well-defined sequence in typically developing children.

Atypical Development, Infancy to Age 5: Red Flag Behaviors

Participants were questioned about their familiarity with ASD in an effort to look at their previous knowledge and experiences with children who displayed a variety of behaviors that were either hard to understand or difficult to manage.

We used a 'First Signs' video aimed at improving observational skills and showing the routine screening that is designed to identify children at risk for ASD and other developmental disorders. The video



Fern Fisher, MA, MS, LCSW

clearly showed the sometimes extreme behaviors associated with ASD. It highlighted children from infancy to age five and included children from many backgrounds.

Participants also read and assessed descriptive anecdotes that involved children who had subtle signs of ASD, but still exhibited behaviors that should cause concern. The ability to understand these anecdotes was based on understanding of development from the previous class.

Working Closely with Parents

Changes in the field, in family life, in identification and remediation for developmental problems have all increased the responsibilities of teaching staff to interact with parents in helpful ways. The course covered both daily parent/teacher interactions and then the very complicated and difficult meetings that take place when a child is in difficulty and needs to be evaluated by outside professionals.

Just as early childhood education for teachers doesn't include ASD awareness, teacher training for early childhood educators rarely includes the complicated work they sometimes do with parents. Work with parents is always central to practice, but when parents begin to realize that their child isn't managing in preschool, they experience indescribable anxiety and pain.

Training can help professionals become more empathic toward parents, respecting both their feelings and culture. Teachers can develop knowledge of the way in which to approach parents and be able to make appropriate suggestions when help is needed. Teachers can also become familiar with the services available in their community and can be ready to lend a hand to parents when it is necessary for them to negotiate the public education entitlement system.

Classroom Management: Problem Solving Together

This class explored the day to day experiences that teachers have with the chil-

dren and with the specialists who visit their classrooms. We explained who the specialists are: Occupational Therapist (OT), Physical Therapist (PT), Special Education Itinerant Teacher (SEIT) and/or Play Therapist, and what their area of practice tries to accomplish.

The reality of specialists in early childhood classrooms and what having other practitioners in your classroom means to classroom teachers is another topic not addressed in most pre-service or in-service teacher training. This was a class where discussion was central to the goal of relationship building in the service of enhancing the sense of community in the classroom.

Participant teachers were very interested in knowing how they could work more effectively with specialists. Moreover, they wanted to acquaint themselves with helpful classroom strategies and interventions to address the problems of children when the specialists were not on-site. These included how to help specific children with language acquisition, social skills, self-regulation and managing their anger and aggression. Teachers contributed a lot of anecdotal information and were pleased to receive individual and specific as well as more general recommendations.

Consultation

A series of teacher training workshops such as those described above are not sufficient to sustain the teacher's learning or support teachers as they take on the difficult tasks of including youngsters with special needs in their classroom and being able to work collaboratively and empathically with the parents of these children. For that reason, this project also placed early childhood consultants in each participating site. These consultants had experience and training in work with special needs children and autism spectrum disorders in particular. Moreover, the consultants were all sensitive to the cultural issues of the émigré families in the centers and in most cases the consultants were also bilingual. The consultants enabled the teachers to feel better prepared to include children with a range of developmental challenges in their classrooms.

Moreover, the consultants were there to work with the directors and the parents themselves in order to put into motion the efforts necessary to have these children evaluated and become eligible for all the therapeutic interventions needed to address their challenges. We have found that for émigré parents in particular, the process of understanding and accepting their child's developmental differences and then negotiating a complex system of evaluation, intervention services, and entitlements is daunting and confusing. Accomplishing this outcome became a central role for the consultants.

Participating teachers became open to new ideas and new ways of working with children as they became informed about special needs children and working with their parents. The support of the consultants each week also helped further inspire

see Émigré Children on page 45

Attention Deficit Hyperactivity

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Vital Services Available at Long Island Psychiatric

By James B. Snyder, MD
Long Island Psychiatric, PLLC

Since our inception in 2001, Long Island Psychiatric has provided expert comprehensive treatment for children and adults afflicted with Autism, Asperger Syndrome and comorbid mental health disorders. Our highly regarded, private outpatient treatment center provides distinguished service to countless families and children and is acknowledged as one of the most well-established centers of excellence for Autism and Asperger Syndrome in our community.

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James B. Snyder, MD

help to children and adolescents who are having difficulty with peer relationships and self-esteem issues. Children who are socially isolated or have problems with teasing and bullying learn to recognize social clues and how to respond appropri-

ately to them. Our groups are led by experienced consultants with knowledge in child development and the treatment of children with Learning Disabilities, Asperger Syndrome, Autistic Spectrum Disorders and other related childhood disorders. Our behavioral team works closely with schools and vocational programs to establish a fully integrated, individualized treatment plan.

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View From the Spectrum Matching Best Practice to Children's Needs

By Stephen M. Shore, EdD
Executive Director
Autism Spectrum Disorder Consulting

Boom! The "Autism Bomb" explodes. Like many children with regressive autism I lost functional communication, had tantrums, engaged in self-stimulatory and abusive behaviors beginning at 18 months. Others are affected earlier and mothers may report that their child was "different" even before birth. Life was never the same again from me, nor for others supporting me.

It was the mid 1960's and there was very little information about this seemingly psychiatric condition that affected only 1 in 10,000 people and was tantamount to a life sentence of dependency. Possibly, with luck and much effort, adulthood in a group home and employment in a sheltered workshop could become reality. My parents were told to put their "sick" child in an institution and to get on with their lives.

Fortunately, my parents advocated on my behalf, and implemented what would today be best described as a home-based intensive early intervention program emphasizing music, movement, sensory integration, narration, and imitation. Done at a time when the term "early intervention" hadn't even been developed, their work closely aligned with developmental-cognitive or affective approaches such as the Miller Method or DIR. Does that dis-



Stephen M. Shore, EdD

count the behaviorally oriented or other approaches for children with autism? No. It just means that my parents were able to provide for my needs and did what was best for me at that time.

Grade school, especially at the elementary level, was very difficult. However, I did graduate. In fact, I made it through higher education and have recently completed my doctoral dissertation on matching best practice to the needs of children on the autism spectrum. I have been married for 18 years and live a fulfilling, productive, and interdependent life. Not an independent life, because only hermits live without appropriately depending on others for their needs.

Different Strokes for Different Folks

When I was diagnosed in 1964 the amount of material written about autism could fit in a single bookshelf and was restricted to "highly qualified" medical professionals. There was no alphabet soup of ABA, DIR, DLT, MM, RDI, or SCERTS, which makes up just a small piece of what there is available today. A recent search for "autism" on Google.com now brings 24,600,000 hits. The challenge now is to sort out appropriate information that best matches the needs of the person with autism you are supporting.

More than ever there are myriad intervention, approaches, and techniques for working with people on the autism spectrum. Stephen Edelson, Executive Director of the Autism Research Institute (www.autism.com) suggests that children with autism need treatment in three main areas of interventions, including: educational/behavioral/developmental, biomedical, and sensory integration. Then there are other supporting techniques such as Powercards, Picture Exchange Systems, assistive communication devices, etc., not to mention all the bio-medical interventions that are available.

Matching Best Practice to Individual Needs

One of my special or focused interests (termed "restricted" by the DSM IV) is comparing educational/behavioral/developmental approaches for working

with children on the autism spectrum. As I began my literature search on different methods I found there to be no such research, possibly due to a combination of practical and political reasons.

Practically, finding matched groups of children with autism to accommodate a study spanning several approaches, as well as finding the needed control groups is problematic at best. Even if several dozen matched children could be located there would be the challenge of controlling for variables such as therapist experience and efficacy, home life, exposure to previous interventions, and biomedical issues. Additionally, there are ethical or moral concerns concerning withholding intervention from a population in desperate need of support.

The second reason is that I have found that many practitioners of certain approaches get locked into their methodologies to the exclusion of others and to the detriment of people on the autism spectrum. The diverse nature of the autism spectrum indicates that different people will have different needs in terms of intervention. It is not a one size fits all situation. No one person or approach has all the answers.

Since I was unable to find work done in this area, I felt that the best way to open the line of research into comparative approaches was to gather more information by finding out how leading theorists and developers of today's promising approaches

see Best Practice on page 45



SPECIAL NEEDS

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KULAM: TOGETHER

Children, Family and Community

Kulam is a Sunday program for children with special needs and their families. Classes include art, music therapy, photography, cooking, theater, fitness, Jewish culture with MATAN, SibFun and more. Classes are designed for children on the high-functioning end of the autism spectrum and those with varied communication and learning differences.

Funding provided by grants from UJA-Federation of New York and the Gruss Lipper Family Foundation.

TRANSITIONS

Transitions is a social program for 16-21-year-olds with a variety of special needs, including those on the high functioning end of the autism spectrum and those with varied communication and learning differences. On Sundays during the academic year, young people meet to participate in fun and social activities that help build friendships while emphasizing independence and the acquisition of life skills.

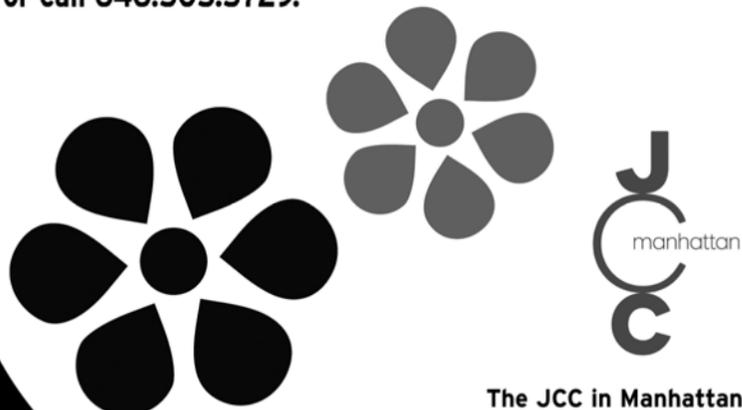
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The Path Forward: Brain Stimulation in Autism

By Alexandra L. Sporn, MD
Assistant Professor of Clinical Psychiatry
Columbia University College
of Physicians and Surgeons

Autism and Autism Spectrum Disorders (ASD), while once considered extremely rare, are now recognized as relatively common. At Columbia University Medical Center, we are using the cutting edge technology to develop an innovative approach to studying and treating the symptoms of autism.

What Do We Know of Brain Functioning in ASD?

According to the DSM-IV, there are three core symptom clusters in autism and ASD: social deficits, speech/communication deficits and repetitive behaviors.

Converging evidence suggests that autism involves abnormalities in brain volume, (Courchesne 2004) neurotransmitter systems and neuronal growth. (Courchesne and Pierce 2005) In addition, evidence links autism with abnormalities in the cerebellum, the medial temporal lobe, and the frontal lobe. (Penn 2006) Neurochemical findings suggest involvement of multiple neurotransmitter systems (serotonergic, GABA-ergic and cholinergic as the primary ones. (McDougle, Erickson et al. 2005)



Alexandra L. Sporn, MD Sitting in a Trial TMS Treatment

Why Is It Difficult to Study Autism?

Present methods of studying brain functioning mostly include structural MRI, functional MRI (fMRI) and Positron Emission Tomography (PET). However, fMRI, though very safe, usually requires

performing a certain task while in the scanner, paying attention, pressing a button in response to a stimulus, which is hard for children or low-functioning patients. PET is invasive, and uses radioactive substances that have to be injected into the bloodstream.

Here at Columbia, we are developing a new approach to study brain functioning in autism. We are bridging the fields of fMRI and noninvasive brain stimulation techniques, such as Transcranial Magnetic Stimulation and transcranial Direct Current Stimulation (tDCS).

What is Transcranial Magnetic Stimulation (TMS)?

TMS is a noninvasive tool that induces focal electrical currents in the brain by creating a magnetic field. It has been applied to map attention, memory, movement, and speech. (George, Nahas et al. 2003) There are three types of TMS: single-pulse TMS, paired-pulse TMS, and repetitive TMS (rTMS). In single- and paired-pulse TMS, pulses are given to the motor cortex to measure various aspects of motor cortex excitability. In rTMS, trains of pulses at various frequencies are given to acutely probe functioning of cognitive systems, or to treat disorders such as depression, OCD, or schizophrenia. (George, Nahas et al. 2003).

Our Protocols

Our main protocol "Neurocircuitry of Autism" is designed to use fMRI and TMS to study the neurocircuitry of autism symptoms. Using single and double pulse TMS we compare excitability of motor

see *Brain Stimulation* on page 50

Efforts in Autism Research at Columbia University Medical Center

By Bradley Peterson, MD, Chairman,
Division of Child and Adolescent
Psychiatry, Columbia University College
of Physicians and Surgeons and
New York State Psychiatric Institute

The autism spectrum disorders or autisms (including the DSM diagnoses Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified) are a set of developmental disorders involving problems with social behavior, communication, and repetitive behavior or interests (we will use the term "autism" to refer to the set of these disorders). Autism is among the most debilitating of all childhood neuropsychiatric disorders and has the potential to derail cognitive, emotional, and behavioral development.

Over the past several years a growing appreciation for the number of individuals affected by these disorders and the impact they have on individuals, families, and society at large has led researchers at Columbia University to study autism, its causes, and its potential treatments from a wide range of perspectives. Our research program is dedicated to identifying the causes of autism and to developing more effective approaches to diagnosis, treatment, and cure. This dedicated research team, spread throughout the Columbia campus, is joining forces to help us learn more about



Bradley Peterson, MD

this disorder and how we can help the people affected by it and their families.

As an infant develops, his or her genetic material, or DNA, controls the growth of the cells which become the brain, which in turn governs his or her behavior. The causes of autism can be traced to a complex interaction of many elements adversely affecting the links of this chain. The yet unknown genetic and environmental factors that influence the

molecular and cellular processes within the developing brain are presumed to disturb (a) the formation of connections, or *synapses*, between cells, (b) the proper integration of those cells and synapses into local circuits, and (c) the organization of those local circuits into large neural systems that process and transmit information across the brain. These disturbances in circuit formation disrupt the brain functions that support socialization, attachment, and relatedness to other human beings, disturbances considered to be the "core" or defining symptoms common to all of the disorders included in the term autism.

Fortunately, the advent of powerful new research techniques, many of them developed and used at Columbia University, has brought us to a new era in which we can legitimately hope to identify and understand the genetic and environmental causes of autism. These discoveries are bringing us closer to designing truly effective treatments that will address the core symptoms of these disorders. Columbia University is covering the gamut in autism research, with studies investigating each link in this developmental chain: from genes, to cells, to brain, to behavior.

Our program for research brings together basic and clinical neuroscientists to focus their attention and formidable skills on identifying the disturbances in brain development that cause autism, and then to use that knowledge to develop new and

improved treatments for these conditions. We are building the knowledge, technology, and collaborative ties necessary for making discoveries that were unimaginable even a few years ago. We believe that ultimately this course will lead to identifying the causes of autism and to developing more effective approaches to their treatment and cure.

Genes and Cells

Many previous genetic studies of autism have been "multiplex" studies, involving families who have more than one member affected. In these studies, researchers seek to identify *inherited* genetic patterns. A "simplex" study, a study of families with only one member affected by autism, seeks to examine the *de novo*, or brand new genetic mutations that contribute to the development of autism. The Simons Simplex Collection (SSC) is a core project and resource of the Simons Foundation Autism Research Initiative (SFARI). At Columbia, the SSC team, headed by Dr. Bradley Peterson, is one of thirteen research teams across North America who have joined together to gather genetic samples from 2000 simplex families. The family of each affected individual will also undergo a detailed set of interviews and neuropsychological tests in

see *Research at Columbia* on page 44

Genetic Abnormalities in Older Fathers: Implications for Autism

By **Jeremy M. Silverman, PhD**
Lauren J. Donnelly, BA
 and **Lauren J. Brickman, BS**
 Mount Sinai School of Medicine

The Mount Sinai School of Medicine's Family Studies Research Center has initiated a new study investigating the possibility of new genetic changes in autism and related disorders in the sperm of fathers of children with autism. More specifically, this study will directly examine whether there are elevated levels of *de novo* copy number variants (CNVs) in autism spectrum disorders (ASD).

This new study follows from an exciting and potentially very important new line of research in autism. In 2006, researchers from the Mount Sinai School of Medicine's Family Studies Research Center contributed to a study investigating the relationship between paternal and maternal age and autism (Reichenberg et al., *Arch Gen Psychiatry*, 2006). Within an Israeli population, offspring of men 40 years and older were about 6 times more likely to have ASD than offspring of men



Jeremy M. Silverman, PhD

younger than 30 years old. Maternal age showed no association with ASD. These

results have since been replicated in several other populations including those in the United States.

In that same year, Wyrobek et al. (*PNAS*, 2006) suggested that genetic mutations, other genetic abnormalities, and genomic anomalies in sperm increase in frequency as men age.

Finally, Sebat et al. (*Science*, 2007) studied *de novo* CNVs in simplex families (one ASD child), multiplex families (multiple siblings with ASD), and controls. A CNV is micro-deletion or insertion on a chromosome – a tiny segment of a chromosome that is missing or duplicated. A CNV is considered *de novo* when these genomic anomalies are present in an individual but not in their respective parents. Sebat et al.'s study identified 14 out of 195 ASD children with CNVs (12 out of 118 simplex; 2 out of 77 multiplex) and 2 out of 196 control children with CNVs. This suggests there is a greater frequency of *de novo* CNVs (7.2%) in the autism sample in comparison to controls (1.0%). Similarly, Marshall et al. (*The American Journal of Human Genetics*, 2008) suggested *de novo* CNVs were more common in simplex

families (~7%) as compared to multiplex families (~2%).

Given the work on paternal age as a risk factor for autism, CNVs in autism, and the evidence that CNVs may be increasingly common in sperm as men age, the Family Studies Research Center's will now directly examine CNVs in the sperm cells of fathers of autistic children and fathers of normal controls. The group has begun collecting sperm samples in order to determine whether there is an increased frequency of *de novo* CNVs in the sperm of fathers of children with ASD in comparison to the sperm of fathers with typically developing children.

More information regarding this study can be obtained by calling Lauren Donnelly or Lauren Brickman at 212-659-5654 or 212-659-5655 or e-mailing us at Lauren.Donnelly@mssm.edu or Lauren.Brickman@mssm.edu.

Jeremy M. Silverman, PhD is a Professor, Lauren J. Donnelly, BA is a Clinical Research Coordinator and Lauren J. Brickman, BS, is a Clinical Research Coordinator at the Family Studies Research Center at the Mount Sinai School of Medicine.

The Cody Center at Stony Brook University Medical Center

Excellence in Research, Clinical Services and Family Support

By **John C. Pomeroy, MD**
Founding Director, The Matt & Debra
Cody Center for Autism and
Developmental Disabilities at Stony
Brook University Medical Center

We, at the Cody Center, are pleased to join Ira and David Minot's initiative to "address the need to provide information, education, advocacy, and resources to the Autism community." Over 25 years ago, when I was both studying and serving individuals with disorders that have come to be known as the Autism Spectrum, it was a relatively easy task to keep up to date with the small amount of literature that was published that related to Autism and associated disorders. With the increased awareness of these disorders has come a virtual epidemic of publications, theories of cause and treatment, support services and advocacy, as well as much controversy. It is not possible any more to feel comfortable with one's own ability to adequately review all the exciting things that are happening in the field of Autism Spectrum Disorders (ASD). There is tremendous potential for this publication to assist in disseminating information and become a major resource for all involved with these disorders – personally and professionally.

As implied, research in the field of Autism has never been so promising and yet so tantalizing. Scientists from so many fields of basic and clinical science have been enticed into this area of study due partly to increased funding, but also because of the realization that Autism is



John C. Pomeroy, MD

such a complex neurobiological disorder (or, as generally agreed, group of disorders) that our understanding of Autism will require integration of data from diverse fields of study. These include neuroanatomy, neurophysiology, neuroimaging, genetics, cognitive neuroscience, developmental neurobiology, behavioral psychology, education, clinical and medical sciences, as well as developing areas of study such as proteomics (essentially the study of specific actions of genes) and the utilization of neuroimaging technology to understand regional brain function, active metabolic processes, brain pathways and connections, and stem cell activity in the brain throughout the lifetime. Given all the information available, it is apparent that we all need to be able to sift through

the research data to identify what is most relevant requiring us to be somewhat conversant with a complex range of disciplinary skills.

In that sifting there will be a necessity to place priorities on aspects of available research data that are most important for the individual situation or specific professional. No area of research really has prominence and reporting on a successful form of intervention for some clinical aspect of individuals with Autism may be of more immediate importance for those individuals, and others like them, than the isolation of one gene that in the future will lead to greater understanding and, perhaps, treatment for these disorders. Scientists from these various disciplines must work collaboratively and set common goals for their focus of study. Unfortunately the scientific process is rarely rapid and frustration with the pace of research and difficulty in foreseeing the potential rewards of more basic science discoveries has led to considerable disappointment with the mainstream academic research approach, for some. This has been accompanied by the ready availability in the community of presently unproven treatments often based on theories that have also not had the necessary scientific review. Unfortunately this has led to divisiveness within the Autism community that we can hope will be addressed by publications like *Autism Spectrum News* and centers like our own.

Matt & Debra Cody are the parents of three children, all of whom have received a diagnosis of Autism. Their experience with their own family, education and service systems, and communication with

other parents made them realize that there was a great need for a central source of information and support for families on Long Island who were affected by ASD. In 1988 they funded a resource center located in Stony Brook University's Division of Developmental Disabilities. Over 700 families used the center in the first year and it became apparent that a center with a broader mission was necessary. With their financial support the Matt and Debra Cody Center for Autism and Developmental Disabilities at Stony Brook University was founded in 2001. Its mission is to promote excellence in clinical treatment, research, community service, and education for those with Autism and related developmental disabilities. The Cody Center has been formally designated by the New York State legislature as a State University of New York Center for Autism and Developmental Disabilities.

In creating the center there was a conscious effort to systematically develop in a balanced fashion the three major components of clinical service, education and community outreach, and multidisciplinary research. The Cody Center provides a variety of clinical, educational and family support services to individuals on Long Island affected by Autism and related developmental disabilities as well as having a research consortium of world-class scientists who collaborate in the Cody Center Research Consortium. They are engaged in clinical, basic and translational research on the Stony Brook University campus, as well as at Brookhaven National Laboratory and at Cold Spring Harbor Laboratory.

see The Cody Center on page 44

Doctor Thomas Insel Speaks with Autism Spectrum News

Staff Writer
Autism Spectrum News

Autism Spectrum News had the unique opportunity to interview Thomas R. Insel, MD. Dr. Insel is the Director of the National Institute of Mental Health and the National Institutes of Health. We are delighted to present Dr. Insel and his candid discussion on the subject of autism.

Q: Dr. Insel, where are we currently in our understanding of autism?

A: In many ways we are still in the early days of autism research. But it is an active research area and many promising efforts are underway led by top scientists. We think of autism as a developmental brain disorder, but we do not know when, where, or how it develops. Most scientists consider autism to be the result of genetic risk as well as environmental exposures, but we have very few specific genes and even fewer specific environmental factors that have been empirically validated. We now recognize that autism is a heterogeneous group of disorders (Autism Spectrum Disorder, ASD). Indeed, we should probably become accustomed to speaking of "autisms" rather than "autism." This heterogeneity is found not only in the clinical features, but almost certainly in the biological bases of ASD. We need much more information to understand the various autisms. What are the specific risk factors for each? And what are the best interventions for a given individual on the autism spectrum?

Q: What areas of research is NIMH exploring that might hold a key to unlocking the mysteries of the cause and treatment of autism?



Thomas R. Insel, MD

A: NIMH is only one of several government and private sources of ASD research funding, including other institutes within the NIH, CDC, Dept of Defense, Autism Speaks, and the Simons Foundation. NIMH supports a broad range of research including basic molecular studies, clinical trials, and services research which measures the effectiveness and costs of services in different settings. In virtually every area of biomedical research, genetics is transforming our understanding of human diseases. This is just beginning to happen with ASD with more than 10% of people with autism having a known genetic lesion. While we have yet to identify a genetic "cause" in the other 90%, common variations may confer risk for developing autism after exposure to environmental factors. In many areas of medicine, genetics has led to the development of novel targeted treatments or prevention strategies. Autism genetic research has yet to yield this type of treatment or pre-

vention but it is beginning to identify subtypes of the disorder and already it is clear that many different mutations can lead to ASD. NIMH also supports research on the efficacy and safety of various treatments, from behavioral interventions to specific diets to medications. Ongoing clinical trials are investigating the value of a range of medications, including anti-inflammatories and antidepressants. One of the most exciting areas of research has been the study of infants at high risk of developing ASD. These "baby sib" studies have demonstrated that 50% of infants who will develop autism can be identified by their first birthday. Early detection and early intervention is one of the most promising areas for ensuring the best outcome for children at risk.

Q: What do parents and members of the treatment community need to know about early detection and treatment of autism?

A: One of the biggest shifts in medicine in the past two decades has been the emphasis on early detection and early treatment. In cancer and heart disease, this approach has led to profound improvements in outcomes. We can expect the same effects with autism. Most scientists believe that the earlier ASD can be detected and treated, the better the outcome for most children. Ideally, we would like to identify the disorder or risk for the disorder with a biomarker, long before any behavioral signs develop. We are not there now, but this needs to be a goal for the future. Today, parents need to know the importance of early detection based on behavioral signs. The CDC and Autism Speaks have sponsored campaigns to increase awareness and information on early red flags that help parents distinguish between typical and delayed development. The American Academy of Pediatrics now recommends screening all children at 18 months and again at 24 months ([http://](http://www.aap.org/healthtopics/autism.cfm)

www.aap.org/healthtopics/autism.cfm). Nevertheless, too many parents find that their concerns are dismissed or when a referral for evaluation is recommended, precious months may be lost waiting for an appointment. Awareness is necessary but not sufficient if resources for diagnosis and treatment are not available. Fortunately, with increasing access to information on the Internet and growing awareness of the needs of parents with autistic children, resources are becoming easier to find in many parts of the country.

Q: What are your hopes for the future of autism education, treatment and research?

A: Recently I have been reading about the polio epidemic of the 1950's. This was a time of broad public concern and confusion, dominated by a range of theories and therapies, all advocated passionately in the absence of scientific data. Fifty years later, none of this matters because polio is largely a history lesson and not a threat. I would like my grandchildren to read a book about autism as a history lesson because every child at risk for autism has grown up to enjoy a full and productive life.

Q: How can *Autism Spectrum News* best serve the needs of the family, treatment, and scientific community?

A: I am pleased to see the initiation of *Autism Spectrum News*, and to be a part of this inaugural issue, as this publication and others like it play a critical role in ensuring the communication of research findings and evidence-based treatment options to clinicians and families. The dissemination of information is a vital component of public health. I hope that *Autism Spectrum News* will help individuals with ASD and their families receive the best information so they can make the best choices.

A Path Into the World

Passion for Football Brings a Boy With Autism Out of His Shell

By Robin Morris
Patient Advocate

The NFL draft is a machine, hardly designed for the faint of stamina. Fans line up at the doors of such landmarks as Madison Square Garden, or Radio City Music Hall this year, on a first-come, first-served basis and hope to hear the name of their choice player scooped up by their favorite team. It is a day of promise for young talent and fodder for the fans; another vehicle that creates heroes.

What's interesting about the coveted results of the NFL draft is that ultimately it is simply a list. Lists are food for individuals with autism. Lists provide comfort and stability. Lists are a constant; once announced, they do not change. Lists have been the fruit of our child's steadiness in a world of uncertainty. A devout sports fan, our son Paul, 15, thrives on athletic minu-



Robin Morris

tiae with precise notation.

One dreary Saturday in spring 2003 marked an event that diehard football fans might appreciate, but it is the families of

autism who will truly comprehend. It was raining - a cold and bitter kind of weather that chills your bones. The doors had closed, denying entry to the hundreds of hopefuls who wanted to witness football history. Disappointment prevailed as the mob began to disperse. Paul, plagued by the rigidity of autism, could not reconcile his frustration. So there he wailed in the rain, right at the door of Madison Square Garden, heartbroken. How could we explain to the gawking crowd that autism vandalizes the social and neurological systems of those who suffer from it? How could we explain what drives a child tormented with such behaviors? It is foreign to those who navigate the social world within customary guidelines. The disappointment for Paul was so tangible that his body was visibly shaken. The only way that he could articulate his pain was to repeat a mantra that he hadn't "been good enough to go to the draft."

Words failed us. We who love this boy

beyond words could not alleviate his agony. But we vowed to help him learn flexibility, a daunting challenge for those on the autism spectrum.

Time and intervention were our partners. It is an arduous task to usher children with autism into the typical social world. Every nuance must be taught to a child with autism. There is no natural progression for understanding idiom or banter. Words are meaningless without comprehension. We made Herculean efforts with little response, fully aware that hard work does not necessarily glean success. That explains the complexity and mystery of autism.

A year later, Paul again began to fixate on the NFL draft. Perhaps it was simple fear of the inevitable or a last-effort idea, but we encouraged Paul to write a letter to Jeff Lurie, owner of the Philadelphia Eagles, whose brother suffers from autism.

see *A Path* on page 42

Introducing the Editorial Board of Autism Spectrum News

Cindy Alterson, PhD, BCBA
Principal and Program Director
Devereux Millwood Learning Center

Dr. Cindy Alterson received her BA in Psychology from Binghamton University- State University of New York in 1993 and her Ph.D. in Clinical Psychology from State University of New York- University at Albany in 1999. Her pre-doctoral internship was completed at the renowned Neurobehavioral Unit of the Kennedy-Krieger Institute- Johns Hopkins University School of Medicine. Dr. Alterson is a licensed psychologist, Board Certified Behavior Analyst, and a NYS School District Administrator.

Dr. Alterson is currently the Principal and Program Director of the Devereux Millwood Learning Center (DMLC). DMLC is a non-public school utilizing principles of applied behavior analysis serving 48 children on the autism spectrum from age five to 21 in Westchester County, NY. Dr. Alterson provides administrative and clinical expertise to the school towards skill acquisition and reduction of behaviors that interfere with learning and consultation to part- and full-time inclusion programs in less restrictive settings. She started a pre-vocational program which has since grown to include 24 students at more than ten job sites in the local community.



Cindy Alterson, PhD, BCBA

Dr. Alterson is an adjunct faculty member of Manhattanville College and teaches courses in applied behavior analysis, functional behavior assessment and functional analysis in the Department of Special Education. She participates on the New York State Child-specific Exceptions Panel, and is a frequent presenter at local, state and national conferences in the areas of positive behavior support and instruction of students with autism spectrum disorders.

Lynda Geller, PhD
Clinical Director of the Asperger Institute
NYU Child Study Center

Dr. Geller is one of the nation's foremost experts on Asperger Syndrome and Autism Spectrum Disorders. She is a Clinical Associate Professor of Child and Adolescent Psychiatry at the NYU School of Medicine and the Clinical Director of the NYU Child Study Center's Asperger Institute, where she is responsible for the development of innovative clinical services, the supervision of therapeutic care for individuals with Asperger Syndrome and related conditions, and the training of young professionals planning a career in autism.

Dr. Geller is a frequent speaker for professional and family audiences on evidence-based treatment and support services and consults to a wide variety of schools, community agencies, and universities regarding Asperger Syndrome across the lifespan. She also developed a training DVD for families whose children with Asperger Syndrome are planning for the college experience.

Dr. Geller earned her Ph.D. in Counseling Psychology from the University of Miami and her M.A. in School Psychology from the University of Illinois. She completed an externship and an internship in Developmental Disabilities and Pediatric Psychology at Mailman Center for Child



Lynda Geller, PhD

Development at the University of Miami and Georgetown University Child Development Center. Dr. Geller serves on the professional advisory boards of the Asperger Syndrome and Higher-Functioning Autism Association and the YAI/ National Institute for People with Disabilities Network's Center for Autism.

Eric Hollander, MD, Director
Seaver and New York
Autism Center of Excellence
Mount Sinai School of Medicine

Dr. Hollander is the Esther and Joseph Klingenstein Professor and Chair of Psychiatry at the Mount Sinai School of Medicine in New York City. He is also Director of the Seaver and Greater New York Autism Center of Excellence, also at the Mount Sinai School of Medicine.

Dr. Hollander received his B.A. from Brandeis University (1978), and his M.D. from SUNY Downstate Medical College, Brooklyn (1982). He completed his internship in Internal Medicine at Mt. Sinai Hospital (1983), residency and chief resident in psychiatry at Mt Sinai School of Medicine (1986), and his NIMH research fellowship at Columbia University College of Physicians and Surgeons (1988). He was appointed Associate Professor of Psychiatry at Columbia University College of Physicians and Surgeons in 1992. He joined the faculty of Mount Sinai School of Medicine as an Associate Professor of Psychiatry in 1993, and rose through the academic ranks at MSSM and was appointed Professor in 1996.

Dr. Hollander is the principal investigator for a number of current federal grants, including the NIH Greater New York Autism Center of Excellence, the NIMH Research Training Grant in Psychopharmacology and Outcomes Research, and an FDA funded multicenter



Eric Hollander, MD

treatment trial of pediatric body dysmorphic disorder. He is the principal investigator of the autism Clinical Trials Network, and Chair of the eight center NIH STAART Autism Steering Committee. He is involved in research on the neuropharmacology, neuropsychiatry, functional imaging, and treatment of obsessive-compulsive disorder, impulsive/aggressive personality disorders,

see Dr. Hollander on page 50

Ami Klin, PhD, Director
Autism Program
Yale Child Study Center

Dr. Klin is the Harris Associate Professor of Child Psychology and Psychiatry at the Yale Child Study Center, Yale University School of Medicine, in New Haven, Connecticut. He obtained his Ph.D. from the University of London, and completed clinical and research post-doctoral fellowships at the Yale Child Study Center. He directs the Autism Program at Yale, which is one of the National Institutes of Health Autism Centers of Excellence. This program includes a broad range of diagnostic and treatment services, and an interdisciplinary program of research that includes behavioral, brain, and genetics investigations. The program also provides training in a broad range of disciplines, and is strongly committed to advocacy at the local, national and international levels, with collaborations in several countries in Europe, Israel, and Latin America. Dr. Klin's primary research activities focus on the social mind and the social brain, and on aspects of autism from infancy through adulthood. These studies include novel techniques such as the eye-tracking laboratory that allows researchers to see the world through the eyes of individuals with autism. These techniques are now being applied in the screening of babies at risk for autism. He is the author of over 150 publications in the field of autism and



Ami Klin, PhD

related conditions. He is also the co-editor of a textbook on *Asperger Syndrome* published by Guilford Press (soon to be released in its second edition), the third edition of the *Handbook of Autism and Pervasive Developmental Disorders* published by Wiley, and several special issues of professional journals focused on autism and related disorders.

Dr. Klin's primary research interests are in fundamental mechanisms of socialization and their disruption in autism

see Dr. Klin on page 40

Introducing the Editorial Board of Autism Spectrum News

Harold S. Koplewicz, MD
Founder and Director
NYU Child Study Center



Harold S. Koplewicz, MD

Harold S. Koplewicz, MD is the Director of the NYU Child Study Center; Arnold and Debbie Simon Professor and Chair, Department of Child and Adolescent Psychiatry; Sr. Vice President and Vice Dean for External Affairs, NYU Medical Center; Professor of Pediatrics, NYU School of Medicine; Director, Division of Child and Adolescent Psychiatry, Bellevue Hospital Center; Director, Nathan Kline Institute for Psychiatric Research

In May of 2006, Governor George Pataki and Sharon Carpinello, R.N., Ph.D., Commissioner of the New York State Office of Mental Health, appointed Dr. Koplewicz the Executive Director of the Nathan S. Kline Institute for Psychiatric Research (NKI), making him the third person in that position since its 1952 founding. NKI is one of only two New York State-funded research institutions and is nationally and internationally known for its pioneering contributions to psychiatric research in the study of the etiology, treatment, prevention and rehabilitation of severe and persistent mental illnesses.

In October of 2006, the NYU School of Medicine established the Department of Child and Adolescent Psychiatry, cre-

ating only the second independent department of a major university in the United States. Dr. Koplewicz was named chairman of this new department.

The NYU Child Study Center is dedicated to increasing the awareness of child mental health issues, expanding scientific knowledge, and improving the treatment

see Dr. Koplewicz on page 51

Cecelia M. McCarton, MD
Founder and CEO
The McCarton Foundation



Cecelia M. McCarton, MD

With over 30 years of experience as a pediatrician, researcher, and lecturer, Cecelia McCarton, M.D., is among the nation's leading experts in diagnosing and treating children with developmental disorders.

In 1998, Dr. McCarton founded The McCarton Center for Developmental Pediatrics, a diagnostic and treatment center dedicated to childhood developmental disorders. The Center provides assessments and therapeutic interventions for a wide range of developmental disorders in children from birth to 14 years of age. She is also the founder and executive director of The McCarton School, serving children with autism and autistic spectrum disorders, which opened in September, 2002. It offers a dynamic and broad-based approach integrating scientifically supported best practices from a number of disciplines in the treatment of autism.

Early in her medical career, Dr. McCarton developed an affinity for children who displayed special needs. After completing her residency in Pediatrics at the Bronx Municipal Hospital Center, where she also served as chief resident, she received two prestigious post-doctoral research fellowships from the Department of Psychiatry at the Albert Einstein College of Medicine and the Rose F.

Kennedy Center for Research in Mental Retardation and Human Development at the Albert Einstein College of Medicine.

After finishing her formal training, she has served as Director of the Clinical Research Unit at the Rose F. Kennedy Center. Her research experience includes national studies on developmental complications in infants with low birth weight, infant health and development, and the prevention of mental retardation. Dr. McCarton has also taught pediatrics for over 30 years and is currently Clinical Professor of Pediatrics at the Albert Einstein College of Medicine. She received numerous grants and has published over 50 book chapters and has peer-reviewed articles in medical journals.

Judith Omidvaran
Parent Advocate
Westchester County, New York



Judith Omidvaran

My name is Judith Omidvaran and I reside in Westchester County, a northern suburb of New York City. My journey into the world of autism began in 1981 when my 2-year old son, Sina was diagnosed with autism. From that point in time, I immersed myself in any type of information I could find to best serve Sina's needs. My objective was to do whatever I could to "normalize" him as much as possible so that he could eventually survive in the world without his parents.

One of my first goals was to find a school that would help Sina develop his language and social behavior skills, which in turn, would gradually improve his intellect and interaction with his peers and other persons. I consulted with many psychiatrists and psychologists in order to decrease Sina's serious emotional and behavioral disorders that were induced by his severe anxieties, fears, and rigid thought processes. He also had sensory problems such as his dislike of being touched by anyone, his acute hearing which made him very nervous when hearing certain sounds, and his other sensory disorders. Sina developed Epilepsy as a teenager and on June 9, 2007 his life suddenly ended when he succumbed to a seizure, in spite of the medication he took to control his Epilepsy.

Throughout Sina's life I immersed

myself in the world of autism. I found the need to learn everything I could about coping with his emotional difficulties. In searching to locate support services I journeyed into the world of psychiatry, psychology, the social services system and support services systems of Westchester County and the New York Metropolitan area. I learned how to network with other parents about resources and joined various support groups. I also joined organizations that advocate for people with autism, other types of

see Judith Omidvaran on page 42

Theresa Pirraglia
Co-Founder and Board Member
The Foundation for Educating
Children with Autism



Theresa Pirraglia

Theresa Pirraglia is the parent of a son with autism and has been actively involved in the field of autism since 1990. She is a board member and co-founder of the Foundation for Educating Children with Autism (FECA). FECA is a non-profit organization dedicated to providing the appropriate educational opportunities for children with autism based on applied behavior analysis (ABA), through the development of schools, inclusion and vocational programs, consumer advocacy and community outreach.

FECA was founded in 1994 by a concerned group of eight families who knew the most appropriate method to educate their children was through applied behavior analysis (ABA). This therapy provides an extremely structured learning environment for children with autism. At the time, there were no schools in the lower Hudson Valley of New York offering this method of teaching, and the only way to provide this intervention was to create and administer an ABA program in the individual's home.

This changed in 1996, when FECA celebrated the opening of the Devereux Millwood Learning Center (DMLC). Theresa was a co-founder of

DMLC, the first and only school in the Lower Hudson Valley offering this method of teaching children with autism. Since its creation, DMLC has become a model program for educating children with autism, and has been used as a blueprint for other schools in Pennsylvania and California. She has been actively involved in the planning of the foundation's annual conference since 1995.

Theresa was recently awarded the Martha Fitzpatrick Citizen Advocate Award by the New York State Rehabilitation Association. Theresa has served on the New York Autism Network, (NYAN) and is presently a member of the newly formed Autism Advisory Committee of the Westchester County Department of Community Mental Health.

Introducing the Editorial Board of Autism Spectrum News

Pat Schissel, LMSW, President Asperger Syndrome and High Functioning Autism Association

Pat Schissel, LMSW, is the President of the Asperger Syndrome and Higher-Functioning Autism Association (AHA), a support and education group with close to 1000 parent and professional members across Long Island and New York City. She facilitates three of their ten support groups, manages their Website and e-list, and is the coordinator of their two yearly conferences. She served as a Board of Education Trustee for close to twenty years. She is an adjunct associate professor at Adelphi's Ammon School of Education teaching a course on the autism spectrum to graduate and undergraduate students. Previously at Long Island University, CW Post Campus in the School of Education she taught a course titled, "Contemporary Issues in Autism Spectrum Disorders" to graduate students who had a focus in autism. She is a frequent lecturer.

Ms. Schissel holds a BFA from Boston University and an MSW from Adelphi University. She has published an article, College Planning - What You Need to Know, for The Source, A Publication of ASPEN of America (Summer

Fred Volkmar, MD Director Yale Child Study Center

Fred R. Volkmar, M.D. is the Irving B. Harris Professor of Child Psychiatry, Pediatrics, and Psychology and Director of the Yale University Child Study Center, Yale University School of Medicine. He is also the Chief of Child Psychiatry at Yale-New Haven Hospital, New Haven, Connecticut.

A graduate of the University of Illinois where he received in undergraduate degree in psychology in 1972 and of Stanford University where he received his MD and a master's degree in psychology in 1976. Dr. Volkmar was the primary author of the American Psychiatric Association's DSM-IV autism and pervasive developmental disorders section. He is the author of several hundred scientific papers and chapters as well as a number of books including *Asperger's Syndrome* (Guilford Press), *Health Care for Children on the Autism Spectrum* (Woodbine Publishing), and the *Handbook of Autism* (Wiley Publishing). He has served as an Associate Editor of the Journal of Autism and Developmental Disabilities, the Journal of Child Psychology and Psychiatry, and the American Journal of Psychiatry and now serves as Editor of the Journal of Autism and Developmental Disabilities starting in January of 2008. He has served as co-chairperson of the autism/intellectual disabilities committee



Pat Schissel, LMSW

(1999) and co-authored a manual, *Orienting New School Board Members*, The Roslyn Public Schools, 1998. Ms. Schissel is the mother of two; one an adult on the autism spectrum who was diagnosed with Asperger's Syndrome in his 20's and the other an attorney who works in public interest law.



Fred R. Volkmar, MD

of the American Academy of Child and Adolescent Psychiatry. In addition to directing the internationally known autism clinic he also serves as director of autism research at Yale. Dr. Volkmar is the principal investigator of three program project grants including a CPEA (Collaborative Program of Excellence in Autism) grant from the National Institute of Child Health and Human Development and a STAART (Studies to Advance Autism Research and Treatment) Autism Center Grant from the National Institute of Mental Health.

Alison Tepper Singer Executive Vice President Autism Speaks

Alison Tepper Singer is Executive Vice President for Autism Speaks. Singer has been with the foundation since its launch in February, 2005 and is a staff member of the Board of Directors. She served as Interim CEO of the organization from February through July 2005. Currently, she supervises all of the foundation's autism awareness initiatives, including its award-winning public service campaign, produced in conjunction with the Ad Council and the Centers for Disease Control (CDC). She is also the Executive in Charge of Production of Autism Speaks' documentary "Autism Every Day" which premiered at the Sundance Film Festival in 2007 and is used in schools across the country as a tool to teach educators about autism spectrum disorder. In addition, she oversees all of Autism Speaks' media relations activities and serves as a spokesperson for the organization, appearing on *Oprah*, *The Apprentice*, *NBC Nightly News*, *Good Morning America*, *CBS Early Show* and many other news programs. Singer also played a critical role in the passage of the Combating Autism Act of 2006, which authorizes the doubling of current federal funding for autism research.

Prior to joining Autism Speaks, Alison spent 14 years at NBC and CNBC, in a variety of positions. From 1994-1999 she served as Vice President of Programming in NBC's Cable and Business Development division, where she launched NBC Desktop Video and oversaw long-term planning for both CNBC.com and MSNBC.com. Prior to that she served as Producer of several top-rated CNBC programs, including *The MoneyWheel*, *MarketWrap*, *Capital Report*, *Power Lunch*, *Wall Street Journal Editorial Board* and *Wall Street Week with Louis Rukeyser*. In 2005, she produced the award-winning CNBC series *Autism: Paying the Price*.

Singer graduated magna cum laude from Yale University with a B.A. in Economics and has an MBA from Harvard Business School.

Singer brings unequivocal leadership, vision and creativity to the senior management of Autism Speaks. As the



Alison Tepper Singer

mother of a child with autism and legal guardian of her adult brother with autism, she is a natural advocate. In 2007, Singer was appointed by Health and Human Services Secretary Michael Leavitt to serve as one of six public members of the Federal Interagency Autism Coordinating Committee (IACC). She also serves on the National Institute of Mental Health's *Alliance for Research Progress*. In past years she served on the IACC subcommittee for *Autism Research Matrix Review* and on the Institute of Medicine planning committee for the *Autism and the Environment* conference. For the past four years Singer has served as the co-chair of the Westchester/Fairfield "Walk Now for Autism Research", and as co-captain of Team Scarsdale CHILD, the highest fundraising team in the nation. Singer also currently serves on the Executive Board of the Yale Child Study Center Associates Committee and the Westchester County Autism Council. From 2003-2006 she served as Co-Chair of Scarsdale CHILD (Children Having Individual Learning Differences) in Scarsdale, New York.

Alison is married to Dan Singer, a director in the media practice at McKinsey & Company. They live in Scarsdale NY with their two daughters, Jodie (10) and Lauren (8).

*Autism Spectrum News
Wishes to Thank All the Members
Of our Editorial Board
For Their Support and Participation*

*At the time of printing this issue
we had not received the biographies of
Joel Bregman, MD, Steve Freeman, John C. Pomeroy, MD,
Douglas K. Stern, Esq., Richard Swierat, and Carey Zuckerman.*

We will introduce you to them in our next issue.

Autism and Inclusion in the Classroom: The Social Challenge

By Diana Friedlander
Doctoral Student and Special
Education Inclusion Teacher

Autism is, for the most part, a social disability. The very derivation of the word autism reflects a preference for isolation. One of the most challenging tasks set before parents and educators integrating students with autism into the general education classroom is overcoming social obstacles. By the time typical children enter kindergarten they have developed skills and strategies which enable them to navigate the social aspects of the classroom. Children with autism often do not possess these strategies.

A Rare Insight

Temple Grandin is a professor at Colorado State University who has autism. In her book, *Emergence, Labeled Autistic*, she writes about her experience in the elementary school classroom and describes herself as a visitor from another planet who had to learn the strange ways of the aliens (Grandin, 1986). She further shares the difficulties and successes she encountered in her quest to gain social understanding giving readers a rare insight into a child struggling with the social uncertainties of autism. Often these overwhelming uncertainties manifest themselves in behaviors that can become barriers for inclusion. A child struggling to understand the active environment of the elementary school classroom has little ability to appropriately interact with others. Schools must provide supported and authentic opportunities for students with autism to gain the necessary skills of social interaction.



Diana Friedlander

Inclusive Practice

Classrooms are micro societies designed to facilitate learning in a routine manner. Teachers strive to maintain order and achieve curriculum benchmarks, while attempting to meet the social and emotional needs of each and every child. The needs of children with autism are so diverse and individual and they can be quite difficult to meet in this setting. We have learned through practice and legislation that inclusive environments are generally preferred placements for children with autism. It is here they have access to the general education curriculum and opportunities to observe the day-to-day social and behavioral models of typical children doing what children will do.

Unfortunately, this is the most difficult environment for children who have difficulty understanding and interacting with their peers. Inclusion for the autistic child

can be a deadly sentence if those responsible for overseeing the process are not properly prepared. It is imperative that educators receive instruction and training on the methods and strategies necessary to insure success. Too often students with autism are left to their own sparse devices for unstructured times of the day such as lunch and recess. These activities, although loosely organized by adults, are highly social and peppered with unspoken childhood rules.

A child with autism has little or no understanding of these rules unless they are specifically taught, explained and practiced under the guidance of a knowledgeable adult. Typical children quickly comprehend what it means for a peer to turn their back on them, children with autism can be observed talking to the back of a peer's head well into the elementary grades and beyond.

How Can We Help?

Since inclusion is preferred, how can we improve the practice? Children with autism must be taught to recognize those subtle cues, identify an implied intent and formulate a plan of action in response. Although typical children learn to read this blueprint usually beginning in infancy through constant observation, this is not the case for children with autism. They often do not possess the tools needed for making these social, emotional and behavioral adjustments. Perhaps more important than math or reading, teachers must teach students with autism how to navigate this complex world. They must learn to see the world through "autistic eyes" and recognize the potential pitfalls their students encounter throughout a school day. Taking a close diagnostic look at their students with autism and appreciating their confusion

is a responsible starting place. Understanding how overwhelming school can be we should ask ourselves, "Why is he/she acting this way? What is it about this classroom that makes it so difficult or even unbearable for this student?" An environmental inventory which considers all aspects of the classroom, noise level, lighting, space definition, peers, seating, smells, temperature, etc. will increase the teacher's awareness of classroom surroundings previously unnoticed. Observing how children relate and the intensity, speed and duration of these interactions can provide guidelines for creating a less challenging and more understanding classroom environment, allowing greater success for all students.

Social Scripting

Carol Gray developed a method of teaching children with autism to literally read these social situations (Gray, 2000). With careful planning, adults target particular social situations which have been troublesome in the past resulting in a lack of appropriate classroom behaviors, such as lining up to go to the lunchroom. They then compile a booklet using simple drawings and descriptive sentences to explain the procedure. Using words like "I will, or "You can", help children understand social expectations. A positive conclusion might contain phrases such as "Your friends will be proud of you" to reinforce behaviors and underscore opportunities for social connectedness. Social stories can be used in a variety of settings and can be designed to address simple or complex social situations. Their design is unique to a particular social encounter which is misunderstood or even incomprehensible for the student with autism.

see *Inclusion* on page 48

Autism Speaks Reaches Out To Latino Community

Website, Information Kit, and Walk Now for Autism Materials Now Available in Spanish

Staff Writer
Autism Spectrum News

In an effort to better convey important information about autism to Spanish speakers, Autism Speaks -- the nation's largest autism advocacy organization -- today announced that it has begun to make key pages on its web site available in Spanish. The organization is also releasing a new Spanish-language version of its 100 Day Kit this summer for newly diagnosed families and has created Walk Now for Autism materials in Spanish.

The Autism Speaks web site www.autismspeaks.org now features several key pages of essential information about autism in Spanish (www.autismspeaks.org/espanol/), including What Is Autism?, Facts, FAQ, Learn the Signs, and Diagnosis.

In addition to offering the 100 Day Kit in Spanish, Autism Speaks will add bi-lingual



staff to its Autism Response Team to answer phone calls and emails from Spanish-speaking families who have requested the kit and are seeking additional information about support services in their region.

Those interested in receiving Spanish-language Walk Now for Autism brochures and other printed materials, including fundraising guides and a one-sheet explanation of autism, should contact their local walk office. Contact information for each office is available at www.walknowforautism.org.

"Our goal is to reach as many families as possible with key information about autism, including the importance of recognizing the early warning signs and ways to get help," said Mark Roithmayr, president of Autism Speaks. "This initiative is an important step toward making it easier for Spanish-speaking families across the country to access this critical information so that they can make informed decisions and get the services they need."

Autism Spectrum News Asked Readers

What are the Needs and Challenges Facing the Autism Community?



Stephen M. Shore, EdD

The potential for people with autism to lead fulfilling and productive lives is unlimited. It is our challenge to find a way to empower those on the spectrum to reach success to the best of their ability. One of the primary keys will be continued research on matching best practices to the needs of people on the autism spectrum. We have only some of the answers. Furthering our efforts will empower us to reach this goal.

Stephen M. Shore, EdD,
Executive Director
Autism Spectrum Disorder Consulting



Valerie Paradiz, PhD

As a designer of educational programs, a parent of a teenager with ASD, and an individual diagnosed with Asperger's syndrome, I feel one of the most urgent needs we have in schools and organizations is to train staff and support people in how they can assist people with autism and Asperger's syndrome to become better, more effective self advocates.

Valerie Paradiz, PhD
Co-Founder of the Open Center for Autism



Regina Brandow & Deborah Berger

We believe that the challenge faced by parents of children with autism is to get appropriate services for their children from birth through age 21. In Long Island, New York, children with autism tend to get research based models of therapy through early intervention and preschool and then services change when the children reach school age. Unfortunately the case law that we see in New York State allows school districts to use eclectic type methodologies based on what we believe to be limited proof that these eclectic methodologies work. We thought the use of eclectic methodologies would change given the changes made to the IDEA in 2004.

There are also limited programs available for children with autism in Long Island. The private programs have waiting lists and the good programs in school districts are filled by the district's own residents. We believe that all children with autism are entitled to a free appropriate public education using research based methodologies. There is still a great need for advocacy to change legislation to require school districts to use research based methodologies that have been proven to work with children with autism. We need universities and colleges to provide teacher training to all teachers in working with autistic children so that we can see more mainstreaming of children to regular education settings. We need more programs in our public schools so that all children, regardless of income, receive what should be the best education not the 'floor of opportunity' that is now allowed. To do this we need to again change laws and make it clear that children with autism and children with disabilities need to be educated by trained teachers and staff, that our children are entitled to have education that is based on methodologies that we know work, and that rather than the 'floor of opportunity' our children receive an education that allows them to reach their full potential.

Deborah Berger & Regina Brandow, Esqs.
Berger & Brandow, LLP



Patricia J. Slager, MA, SSS, LDT/C

Clearly as an advocate for children on the Autism spectrum, I feel that school districts are often short changing our children. Districts are being near-sighted with regard to cost factors and they often are not looking at the long term prognosis for learning challenged children. By putting resources at the front end of the educational process, research is clear that certain educational methods can effectuate life altering changes. As a learning consultant and an advocate in New Jersey, I want to make sure the rights of our students and parents are safeguarded.

Patricia J. Slager, M.A., SSS, LDT/C
Learning Disabilities Specialist and
Founder of Educational Resources, Inc.



Richard H. McCarthy, MD, CM, PhD

While I am a "true believer" in the usefulness and power of medication to bring about significant change, the essence of the Doctor-Patient interaction relies on a relationship. I worry that in our enthusiasm for biological approaches to treatment, we will overlook the need requirement to meet our patients as people.

Richard H. McCarthy, MD, CM, PhD
Research Psychiatrist and Member
of the Consult Service, NYSOMH



Stephanie McCaskill, MS

Research in the effectiveness of various intervention methods will have the most impact on educational services for people with Autism. As educators are provided with additional research on how each intervention method is proven effective with different profiles on the Autism Spectrum, options for students in various school settings will increase.

I see the largest challenges for the Autism community as access to gainful employment, and availability of college-based programs. As the number of young adults diagnosed on the spectrum increases, gaining assistance in seeking meaningful employment and identifying employers who are knowledgeable about the needs of a person with Autism will continue to be a challenge. In addition, access to college-based programs for young adults and support services on campus will be a focus for change. The college campus offers many opportunities for peer-mentoring models, social skill programming, job opportunities and academic focus. The challenge ahead is the establishment of support services on the college campus to address scheduling, time management and choice making skills specific to the needs of a person with Autism.

Stephanie McCaskill, MS
Director, Office of Autism
NYC Department of Education District 75



As a parent of autistic twins, I have followed the directions of numerous professionals and doctors. My sons are now eleven years old and they continue to make progress. I have seen also various professionals in the school system work tirelessly to help these boys and I have also seen some people torpedo those efforts by overwhelming the children and the pointing out that these guys cannot

see *As a Parent* on page 48

Autism Spectrum News Asked Readers

What are the Needs and Challenges Facing the Autism Community?



Debra Machado, LCSW

As a Mental Health professional and a parent of children with neurological disorders, I am painfully aware of the lack of emphasis on the emotional well-being of family members - parents and siblings, of those with Autism Spectrum Disorders. Families suffering intense, and chronic emotional stress from all of the ramifications of having a family member with ASD contribute to the difficulties of helping the ASD member themselves.

Taking care of marriages, single parents and siblings needs much more attention in the treatment of ASD, than is currently offered or stressed in the field. The burnout rate is extremely high and family members need their own, professional, supportive therapy services in order to maintain the ability to handle the normal situations and experiences that occur with having an ASD family member.

Debra Machado, LCSW



Theresa Pirraglia

One of the greatest challenges affecting the autism community is the wave of individuals who are just entering the adult service system. Unfortunately, federal and state governments as well as local service providers are ill prepared to face this new demographic tsunami.

Theresa Pirraglia
Parent/Advocate



Megann Czekalski, MA, BCABA

A research based approach to the treatment of autism is essential to ensure measurable progress utilizing best practices. Consumers are bombarded with "fad" treatments that lack validated procedures and outcomes, but promise to "cure" autism. Through evaluation of literature containing scientifically validated interventions the individual receiving services will be more likely to make progress and be treated ethically. Now and in the future the Autism Community will be faced with the challenge of accessing research based services in the natural environment to ensure the generalization of skills learned and to develop meaningful interpersonal relationships that will endure through adulthood.

Megann Czekalski, MA, BCABA
Director of Interactive Kids



Danielle M. Torre, MS

As a psychologist working with adolescent males with a diagnosis of Autism in a residential setting, I am fortunate to be a part of a wonderful team of professionals who work tirelessly to assist in maximizing their functioning and independence. It has been a pleasure to work directly with these residents and their

see As a Psychologist on page 48



Jill Harris, PhD

This is a very exciting time for the world of autism! There is widespread focus on autism and the search for causes and most effective treatments. We are learning more and more about the role of genetics and possible role of environmental factors. Of course, with autism being a spectrum disorder, there may be multiple causes and multiple effective treatments for various forms or aspects of autism.

With excitement comes confusion and frustration as well. Although more funding and attention are being allocated, it feels as though it is never enough. Also, there are many "treatments" being publicized but not enough careful studies about whether these treatments work. What might appear to be a fun and attractive intervention might actually do nothing to improve functional skills. Thus, families may need direction so they don't waste their time and money with ineffective interventions.

Who will provide that direction? Currently, there are various agencies, programs, and websites that deal with autism. Rather than more agencies or websites, we need central clearing houses that can provide the linkages that both families and professionals need to work together to finally solve the puzzle of autism.

Jill Harris, PhD
Director of Psychology
Coordinator of Autism Center of Excellence
Children's Specialized Hospital

As a society in which we tend to compartmentalize, we must continually strive to serve each individual with autism in a holistic manner. Inherently the arts invite us to address the needs of people with autism in a way that acknowledges and integrates the seemingly disparate aspects of the individual. Our everyday challenge in the arts is to find the pathways through which each person will not only connect with his creativity but will actualize his capacity for self-expression and interaction. Approaches to arts involvement must uphold the integrity of each discipline while making participation

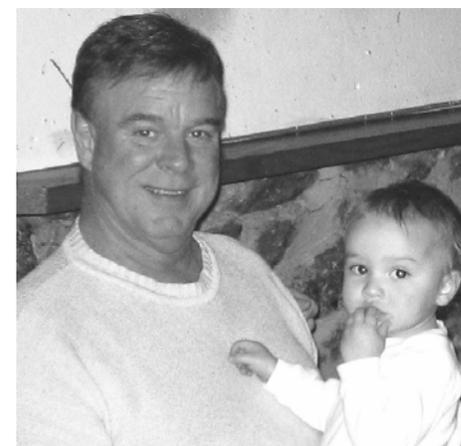
see As a Society on page 48



Stephanie Hamarman, MD

It is important for parents to have their children vaccinated. We have recently had an outbreak of measles in Brooklyn. Vaccinations will help prevent such outbreaks, which can have terrible consequences.

Stephanie Hamarman, MD
American Psychiatric Association Committee
on Autism & Developmental Disabilities
Clinical Asst Professor of Psychiatry,
Chief of Psychopharmacology, NNCA



David L. Holmes

The concern of most parents and professionals, advocating for appropriate educational services and educational benefit for children with autism, is that many special educators and administrators feel that exposure to an education or containment during the educational day satisfies the standard for an appropriate education. The simple presence in any educational setting, be it regular education or special education, without educational benefit for the child is a waste of the child's time and potential in life.

What must occur for our children with autism is an education that confers benefit; an education that challenges them to acquire adaptive skills that will serve them well during the adult years. Anything less is a waste of their time and their lives.

Dr. David L. Holmes
Chairman/CEO
Lifespan Services, LLC

What are the Needs and Challenges Facing the Autism Community?

I am a clinical psychologist who has served adults on the autism spectrum for 15 years. As I look ahead I have hopes for more research and program development funds being steered toward adult needs. I would like to see work done to increase supports and interventions that will allow adults to enhance their *quality of life*. This means different things to different people, but most have goals to improve their satisfaction with their work lives, relationships and sense of emotional balance. Many want to play a more active role in making their own choices about their lives, exercising more *self-determination*, instead of having others speak for them as they make plans for the future. The professional community must develop more programs and interventions to meet their needs, and all such endeavors need to be backed by data from well-controlled outcome research. Even if this ideal were to be met, professionally designed efforts will have limited success if adults on the spectrum are not included in the planning process. Adults in the autism community need to continually look for ways to voice their perspectives, educate pro-



Valerie Gaus, PhD

professionals about their goals and desires, and in some cases, design and run their own programs and supports.

Valerie Gaus, PhD
Clinical Psychologist

Not so many years ago, our knowledge of Autism was in the dark ages. Parents were blamed and we knew little about how to help the children. Now, we know that Autism is a genetically-based disorder and that early intensive therapies can produce dramatic improvements in a child's ability to communicate and to relate.

As a medical student, I was taught that Autism occurred in 5-6 out of 10,000 children. Now, through a broader understanding of a spectrum of Autism, we know that number was at least 10 times higher all along. Later in medical school I trained in an evidence-based treatment - Applied Behavioral Analysis (ABA) and worked with a child who blossomed from a silent world of her own to a fully fluent, very interactive little girl. I saw the power of a properly delivered, intensive, evidence-based treatment.

Now researchers are honing in on the chromosomes involved in causing Autism and testing which environmental, immune-mediated or other factors may be involved in turning on those genes. We already know that earlier intervention is more effective. At the NYU Child Study Center, we are focusing on making the diagnosis as early as possible, before a child's second birthday. The next challenge will be to provide sufficient therapists, pro-



Melissa Nishawala, MD

grams and services to all of the children who could benefit so immensely."

Melissa Nishawala, MD
Assistant Professor of Child and Adolescent Psychiatry, Director, Tisch Young Adult Program, and Clinical Director, Autism Spectrum Disorders Service, NYU Child Study Center

Statewide Autism Initiative Evolves From Regional Center in Albany, New York

By Kristin V. Christodulu, PhD
SUNY Albany

The Center for Autism and Related Disabilities at the University at Albany (CARD Albany) is a *regional resource center* that brings research and practice together in community settings. Since 2002, CARD Albany has been providing evidence-based training and support to families and professionals and, through ongoing research, has been contributing knowledge to the field of autism spectrum disorders (ASD).

CARD Albany currently provides education/training in the area of autism and related disabilities as well as technical assistance/consultation to parents, educators, and community professionals. CARD Albany's highly successful "train-the-trainer" model targets skill development in school professionals and capacity building to empower districts to share information and resources. Data indicate that our center has had broad and significant impact on increasing knowledge of ASD and evidence-based practices across all stakeholder groups. Our research activities in the areas of peer modeling, teacher and parent training, and sibling support, continuously inform our practice and the broader autism community through our various dissemination efforts.

In 2007, CARD Albany formed partnerships with six university-affiliated programs across New York State to establish and operate additional *Regional Centers for Autism Spectrum Disorders* (RCASD). The overarching goal of the seven centers is to identify, disseminate, and assist in the implementation of evidence-based practices to build capacity to improve services and outcomes for children and youth with ASD. CARD Albany currently serves as the headquarters for this statewide network, with partners at the University of Rochester, the University at Buffalo/Summit Educational Resources, Inc., SUNY Binghamton, Hunter College-CUNY, Queens College-CUNY, and New York Medical College/Westchester Institute for Human Development (WIHD). Using the regional model approach, an approach demonstrated to be a successful paradigm around the nation, resources are now available to families and professional in areas of NYS that have not had access to cost-effective services in the past. Each of



Kristin V. Christodulu, PhD

the seven centers provides high quality, cost-effective community education and technical assistance to families, schools, and community providers specific to ASD. Activities vary across the centers allowing for region specific capacity building that is sustainable. For example, the Rochester center leverages its research and treatment resources to engage in community-based cross-systems collaborations to provide a seamless system of support for individuals with ASD, their families and community providers, across the lifespan. The center at Hunter is developing a new ASD kindergarten model for the NYC public schools. The center in Westchester provides training on empirically-validated interventions to its well-established network of school districts and parent groups. The Binghamton center is providing a range of school support services. The Queens center is providing support to families of children with autism who also display challenging behavior, and the center in Buffalo is conducting workshops on topics specific to autism for school personnel and parents.

For more information on the NYS Regional Centers for Autism Spectrum Disorders, visit us at www.albany.edu/psy/autism.

Kristin V. Christodulu, PhD, is with SUNY Albany. Additional contributors to this article include: Caroline I. Magyar, PhD, the University of Rochester, Shirley Cohen, PhD, Hunter College, David Kuhn, PhD, the Westchester Institute for Human Development, and Raymond Romanczyk, PhD, SUNY Binghamton.

**For Our Upcoming
Themes and Deadline Calendar
See Page 3**

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AHA Provides Essential Services to the Autism Community

By Patricia R. Schissel, LMSW
 President of the AHA Association
 Adjunct Professor, Ammon School of
 Education, Adelphi University



Patricia R. Schissel, LMSW

Asperger Syndrome and High Functioning Autism Association (AHA), Inc. began in the spring of 1988 under the auspices of the Department of Child Psychiatry at Stony Brook University. The Association has changed names multiple times as the classifications and diagnoses of autism have evolved. After 20 years of volunteers working in bedrooms and basements, AHA has now, in the last two years, set up their first offices at The Fay J. Lindner Center for Autism in Bethpage where all of our volunteers and our small part-time staff work together on our many projects.

Each year our fall conference is held at Eastern Suffolk BOCES in Holbrook, Long Island. Now in its 18th year, it was among the first conferences anywhere designed to educate educators about high functioning autism, pervasive developmental disorder, Asperger Syndrome and related conditions. This year, on Monday and Tuesday, October 27 and 28, it will feature speakers on behavior strategies for the classroom, understanding language and communication of students with higher functioning autism and Asperger

Syndrome and a teen panel of 'experts'. The speakers will include Brenda Smith Myles, Ph.D., Michelle Garcia Winner, SLP-CCC, and Barry Grossman, Ph.D. and Ruth Aspy, Ph.D. of the Ziggurat Group.

Our annual spring conference held at Adelphi University in Garden City, NY, focuses on assisting older teens and adults

on the autism spectrum to become more independent. Considered unique among conferences, it is attended by families, individuals on the spectrum and professionals, and features a keynote speaker, panels, and workshops with lectures on varied topics such as 'coping with anxiety', 'understanding sensory issues', 'communication strategies', and many more. In the words of one of the people attending, "So many conferences I go to are characterized by people wandering around in isolation between presentations . . . failing to make those connections with other attendees that seem to characterize this type of event. You have found the formula - you should bottle it and sell it!"

In 2009, the Keynote speaker for the annual spring conference to be held on May 9, 2009 will be Temple Grandin.

Some of the Services AHA Offers:

- AHA now has 10 support groups from Montauk to Manhattan. Two of them, a teen group and a group for adults, are for individuals on the spectrum.
- AHA's two conferences have attained national attention with foremost speakers in the field conducting workshops and making presentations.
- AHA's information telephone sup-

port line answers upwards of 2500 calls per year.

- AHA offers free seminars and workshops for member families.
- AHA's newsletter, *On The Spectrum*, keeps people informed and connected to the high functioning autism community.
- Special events like AHA's annual picnic and bowling programs fill a need for appropriate social and recreational activities.
- AHA's website is a valuable source of reliable scientific information and is visited by thousands who have an interest in Asperger's Syndrome, High Functioning Autism and related conditions.
- AHA's e-list provides the most current news in the field of autism, with special attention to up-to-date research.

Join the AHA e-list by going to the main page of the website www.ahaNY.org and clicking "JOIN E-LIST" at the top. You will receive news articles, research abstracts and timely information on autism and the association in your email mailbox every day. You can email us at info@ahanY.org or call us anytime at (516) 470-0360 for assistance.



Do you know a child, teen, or adult who...

- Is socially awkward or isolated?
- Has difficulty making or maintaining friendships?
- Has difficulty with changes in routine?
- Has a problem with give and take in conversation?
- Shows "odd" behaviors and mannerisms?

Looking for information and support?

AHA Association can help!

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 Bi-annual conferences for professionals, family, and individuals on the autism spectrum
 Email listserv and member newsletter

(516) 470-0360

Asperger Syndrome and High Functioning Autism Association (AHA) Inc.
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Putnam County ARC Launches Autism Website

Staff Writer
Autism Spectrum News

With a legacy of 54 years providing exceptional services and extensive programs which offer new and exciting initiatives to participants and family members, PARC is pleased to announce to development and launch of the region's first, comprehensive website dedicated to Autism.

Putnam County ARC has a new website, www.AutismResourceCenter.info, a one-stop clearinghouse of information related to Autism Spectrum Disorders (ASDs), including autism, pervasive developmental disabilities (PDD), and Asperger's Syndrome. The autism spectrum disorders are developmental disabilities that cause significant impairments in social interaction and communication. The ability of individuals with ASDs to think and learn ranges from gifted to severely challenged. And rates for those affected by autism are changing rapidly. Autism now affects 1 in 150 children, and 1 in 100 male children.

"PARC has always been at the forefront of advocacy and services for people with all developmental disabilities," said Susan Limongello, PARC's Executive

Director. "With the numbers of children being diagnosed with autism and thousands of people living with autism in New York State alone, we knew it was time to have a centralized place for information, assistance and hope for families and people with Autism."

AutismResourceCenter.info went live on March 1, 2008 and now offers more than 80 pages of information about diagnosing autism, warning signs, information for parents and educators, where to find help, treatments and intervention, regional and national resources, and much more.

The website is just the first component of the PARC-sponsored Regional Autism Resource Center located at the Mahopac Public Library in Mahopac, New York. The library, which is easily accessible to residents of Westchester, Putnam and Dutchess counties and has an extensive inter-library loan system, will be working with PARC to increase the size of its autism collection, including materials and books for parents, as well as children and people living with autism. In the coming months, center staff will work to create support groups for parents and caregivers, and an annual, regional conference related to Autism care, advancements, research, information, and more.

For more information about the Autism Resource Center, call 845-278-PARC.

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Provides Excellence in Working with Adults on the Autism Spectrum

By Lee Rambeau,
Senior Vice President of Disabilities
and Special Needs Services
F·E·G·S Health and Human
Services System

The explosive growth in the incidence of autism now affects one in every 150 children and gives new impetus to reexamine and improve the services provided to adults with Autism Spectrum Disorder to help them achieve their highest possible quality of life.

Autism is a complex neurobiological developmental disorder that starts in childhood and is characterized by abnormalities in social interactions and communication, severely restricted interests, and highly repetitive behavior. It is pervasive in that it affects all aspects of an individual's life and is a life-long condition. Persons with diagnoses on the Autism Spectrum Disorder (ASD) continuum – unlike individuals diagnosed with other intellectual deficits – often have very uneven needs in areas such as communication, behavior, socialization, and sensory integration.

Inevitably, students with ASD “age out” of the educational system. Many are successful graduates but all too often their families face new challenges, barriers and obstacles in the world of adult services. As interventions for children with ASD change with advances in research and practice, it is incumbent that related changes be studied and implemented in the provision of services to adults with ASD. New interventions are part of our goal to maximize each per-



son's independence at work, at home and in the community.

F·E·G·S Health and Human Services System is a not-for-profit organization that serves adults with a wide range of emotional, developmental and physical disabilities. Of approximately 2000 individuals and families that the F·E·G·S Developmental Disabilities Division reaches annually throughout the Greater New York area, 100 adults diagnosed with ASD are engaged in day, residential, clinical, and family support programs. In order to make the necessary improvements in service delivery, F·E·G·S believes that services to adults with ASD must be more specifically tailored to reflect a person-centered approach. To

achieve this goal, two areas require more focus: applied research and staff training.

The Mount Sinai School of Medicine (MSSM) Seaver and New York Autism Center of Excellence and many other research bodies have conducted well-documented clinical trials and scientific research on individuals on the spectrum, including the understudied and underserved population of adults with ASDs. F·E·G·S believes that partnerships between providers of service and the university and research community will lead to more meaningful and targeted advances in effective assessment and treatment approaches for adults on the spectrum. In 2006, F·E·G·S partnered with the MSSM Seaver and New York Autism Center of

Excellence to establish a direct link between the latest research findings on assessment and treatment with “Best Practices” in the field.

One current project involves a formal joint fellowship training program, in which a fellow is trained two days a week at the Seaver Center and works at F·E·G·S for the rest of the week. At the Seaver Center, the fellow is trained in assessment procedures in ASD and is involved in ongoing research. While working at F·E·G·S, the fellow uses her training to provide diagnostic and neurocognitive assessments, develop and implement evidence-based interventions to increase independent living in adults with ASD, and run autism-specific seminars for selected F·E·G·S professionals. The fellow also trains and supervises clinical staff and works to identify best practices and research programs that align the needs of the Agency and the expertise of the Medical Center.

The partnership between F·E·G·S and the Seaver Center provides opportunities for integrated research approaches and facilitates the translation of research into state-of-the-art clinical practices. One example is the implementation of visual-support structures (e.g. picture-based classroom schedules and leisure schedules) into classrooms for adults with ASD – a clinical practice with wide support in the literature and which maximizes on the strengths of many ASD individuals in visual learning/processing. Visual supports such as picture activity schedules have been shown to improve independence and decrease problem behaviors in

see Partnership on page 48

Filling the Gaps: Developing Programs for the Lifespan

By Kristen Macaluso, MS
and Patricia Grossman, LCSW
Westchester Jewish Community Services

The number of children being diagnosed with autism spectrum disorders (ASD) has, without a doubt, been increasing rapidly over the past 20 years. The increase can be attributed to several factors, a few of which make it clear that many children with autism spectrum disorders went undiagnosed in the past. *Why is this? Where are these individuals now? What can we do to fill gaps in services to meet the needs of this older population of individuals? What do we need to have available to meet the future needs of children being diagnosed today with an autism spectrum disorder?*

There are many reasons why more children today are being diagnosed with autism compared to the number identified previously. One factor that has contributed significantly to the increase is that our knowledge base of signs and symptoms of autism spectrum disorders has

increased. One only needs to do an internet search on “autism” and find an endless number of websites filled with information. Not only are families more savvy in terms of awareness of differences in their child, but professionals are more knowledgeable as well. The result is two-fold: more parents today demand assessments of their child at an earlier age and more professionals are adept at recognizing and diagnosing the condition. The DSM-IV classification of autism has broadened as well, offering the ability to diagnose autism as part of a continuum of severity or “spectrum”. By broadening the definition, more individuals fit the diagnosis. Additionally, psychologists and medical doctors have become more aware of the signs and symptoms of an autistic spectrum disorder, therefore more readily recognizing and diagnosing the condition.

While this addresses the needs of children today, there remain large numbers of adults living and working in the community who were misdiagnosed or undiagnosed as children. We face questions regarding the reality of these individuals who are now adults. Could it be that they

were given another type of diagnosis such as mental retardation, attention deficit disorder, depression, impulse control disorder or an anxiety disorder? Who are these adults? Are they the students who are able to do well academically but are completely overwhelmed when trying to navigate the unfamiliar new social world of college? Are they the individuals who were able to graduate from a university but do not have the social aptitude to get past an interview and obtain appropriate employment? Can we find them in our judicial system or our jails? Do we find them unable to access state services for people with disabilities? Are they at home being supported by their parents, who themselves have not been given adequate resources to help their children?

We are facing a complex problem of finding ways to support families as they face the challenges of having a child on the autism spectrum and address the needs of adults who may have been overlooked as being on the spectrum as youngsters. There are many questions but the most important one to ask is what can we do to help this older population of individuals

who, if they were children today, would be diagnosed with an autism spectrum disorder. First and foremost, information and education are key. We must continue to educate school personnel, therapists, physicians, first responders and employers on signs, symptoms and unique characteristics of individuals with autism spectrum disorders. We must recognize and put into place supportive programs that will provide the necessary anchors for those with autism spectrum disorders throughout the lifespan. Supportive programs need to be developed that begin during school and continue throughout a student's transition beyond high school. Social service agencies and schools need to recognize the importance of providing comfortable, structured, social outlets for these individuals to both meet others who share in their experiences and learn the social skills necessary for successful integration into the community.

Westchester Jewish Community Services (WJCS) opened an Autism Family Center (AFC) in December 2006 with

see Lifespan on page 42

Addressing the Needs and Challenges of Latino Children with Autism

By Carmen Inoa Vazquez, PhD, ABPP
Clinical Professor
New York University School of Medicine

Autism spectrum disorders cause a great deal of pain to families, individuals with this syndrome and society. However, in the past, research studies focusing on understanding autism were scarce due to a misunderstanding that autism was rare (Moldin, S.O., Rubenstein, J. L. R. (2006). This has changed within the last two decades due to the many studies focusing on autism spectrum disorders (ASDs) contributing to a better understanding of this syndrome. Most recently, research efforts have focused on providing answers and resolving the controversies surrounding environmental contributors such as the mumps-measles-rubella (MMR) vaccine (Phillips M. 2003) as possible causes of autism. Other environmental causes that have been associated with autism such as heavy metals, including lead and mercury, have prompted epidemiological surveys in a number of countries. There are no specific answers and there are many different opinions and controversies.

There have been specific controversies among those who reject and those who accept the proposition indicating that, at the moment, there is not enough evidence to accept a direct connection between



Carmen Inoa Vazquez, PhD, ABPP

exposure to heavy metals or vaccines and autism. The reality is that there is a need to conduct more studies that can help to provide the professionals and parents of children with autism with clear and useful information for the treatment of autism and related disorders since approximately one in 150 children is diagnosed with

autism, making it more common than pediatric cancer, diabetes, and AIDS combined. There is still a lot to learn as there are many unanswered questions in terms of whether culture and language are important components in the diagnosis and treatment of these children.

Autism spectrum disorders become evident in the first three years of life, manifesting a pattern of problems in social interactions, communication, and repetitive behaviors. The disorders of the autism spectrum are defined in different categories. The different definitions listed in the Diagnostic and Statistical Manual-IV (DSM-IV) can add confusion and can add to the difficulties experienced by many parents and professionals. There are five different disorders under the term pervasive developmental disorders (PDDs) which include different levels of difficulties in functioning. The categories of Asperger's disorder, pervasive developmental disorder not otherwise specified (PDDNOS), Rett syndrome, and childhood disintegrative disorder (CDD) all fall under the umbrella of PDDs and create a great deal of ambiguity in the definitions of the different types of ASD. These different types of ASD's could also include Asperger's syndrome, atypical autism, and high functioning autism (Rutter, 2005; Wing, 2005; Klin, Sparrow, Maramba, Carter, & Volkmar, 2000). Many clinicians for example do not regularly

follow the decision-making steps proposed by the DSM-IV (Tryon et al., 2006). However, most studies use the definition that includes several impairments in communication and language, social interaction, play style and behavior providing at least a certain level of consistency when referring to autism.

In terms of language, most children with autism have delays in the acquisition of both receptive and expressive language. These specific language delays can at times be misunderstood in Latino children living in the United States, when their parents or the professionals assessing them assume that what appears as language delays are only difficulties related to the simultaneous exposure to Spanish and English with uneven reinforcement in the teaching of the two languages. On the other hand, the opposite is also true when a language acquisition delay that relates to autism is minimized and erroneously seen as the result of the simultaneous and unevenly reinforced exposure to two languages. Needless to say, exposure to two languages is not detrimental to a child. On the contrary, it provides an added cognitive component. But as stated, when a child's exposure to two different languages in the home and in the school is not equally reinforced, then the end result can often be a delay in both languages.

see *Latino Children* on page 46

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Adulthood: It's Closer Than You Think

By Theresa Pirraglia
Co-Founder and Board Member
The Foundation for Educating
Children with Autism (FECA)

It is difficult to think about the future; when you are just trying to make it through each day. In the early 1990's when my son, Matthew was first diagnosed with autism and for many years later I consistently pushed any thoughts about his future away. Inevitably, the passage of time and the new realities that accompany it have an unrelenting way of forcing their way into the present. So, eight years ago as my son turned twelve, I literally forced myself to begin thinking about his adulthood.

Where to Begin

It is important to realize that all the educational and support services that your child has received during his or her school years have been funded by a federal mandate. This mandate is a direct result of the Individuals with Disabilities Education Act (IDEA). Unfortunately, this entitlement and the funding that accompanies it terminates when your child's eligibility for special education ends. That is either when he graduates from high school with a regular diploma or until the child reaches the age of eligibility for a free appropriate education under state law. In most states ineligibility expires at the end of the school year in which your child turns 21; but be sure to check with your



Theresa Pirraglia

state's department of education because some states have increased the age limit.

Adult services for individuals with autism are funded under the Medicaid system. Medicaid provides only a fraction of the funding that was allocated to your child under IDEA. So it is vital that you secure all the educational/vocational and transition services your child is entitled to while they are still in school.

At any time during your child's schooling but especially as he or she approaches adolescence it is a wise to step back and review your child's educational program. Remember the "IDEA" clock is ticking. Ask yourself: How does my child learn? How long does it take him to learn a new concept or skill? How functional will the things he is learning today be to him when he graduates? Will it enable

him to be employed? Will it help him enjoy life as an active member of his community? Will these skills help him lead as independent a life as possible?

You may be proud that your child can do long division, but if he can't independently take care of all his own "self help" needs by the time he graduates what have you really accomplished?

The Process

Transition is a process that will span several years and must begin under federal law by the time your child turns sixteen. The general consensus is that it should begin by the age of fourteen.

Transition is not a spectator sport. It is a team sport, and guess who the captain is? Yes, it's you. If done correctly it will require you and, if possible, your child's active participation. More than likely you will be the one informing your school district of their transition obligations as per IDEA. Do not be surprised if you will also have to do a lot of the leg work when it comes to finding and securing the necessary resources for this process.

In my son's case I located, requested and obtained from my school district the services of an outside transition consultant from our local independent living center to help guide me and my son through the process. Over several years, the consultant, I and a school district representative met twice a year to work on the transition component of his Individual Education Plan, (IEP). During these meetings we discussed his educational, prevocational,

behavioral, community integration and independent living needs. (*note: Remember to request that transition assessments be conducted for your child.*) In addition, she helped me navigate the myriad of transition "to do's," such as: applying for Social Security/Medicaid benefits, registering for the draft, (No exceptions), registering to vote, getting a non-driver identification, and enrolling in our state's adult developmental disability and vocational rehabilitation systems. She also advised me to address the issues of guardianship and estate planning and what to look for in adult agency for Matthew. Her knowledge of the adult service system was priceless.

There are well over 500 Independent Living Centers in the United States. In addition, some adult service providers have begun to provide the service. One caveat, if you work with a transition consultant from an adult service provider make sure that they are advocating for the interest of your child, and not as recruiter for their agency's services.

IDEA and Transition

The reauthorization of IDEA in 2004 modified and strengthened the provisions for transition services. Below is a brief overview of the provisions of the act, IDEA and Transition Services 300.320(b):

Transition services. Beginning not later than the first IEP to be in effect when the

see Adulthood on page 46

Westchester County Convenes Autism Advisory Committee

By Christine Reinhard, MA, MS
Deputy Commissioner
Westchester County Department
of Community Mental Health

We have all heard the statistics—1 in 150 children born in the US will be diagnosed with Autism. But it wasn't until Westchester County Executive Andrew Spano heard the stories from families with children of every age on the Autism Spectrum that he realized the impact it was having on the citizens of Westchester County. The stories ranged from struggling with getting the right diagnosis to finding the best therapy or therapist to difficulties with the criminal justice system for families with adult children on the Spectrum. In response to these stories and the fact that Autism is the fastest growing developmental disability in the United States, County Executive Spano charged the Westchester County Department of Community Mental Health to convene Westchester's first Autism Advisory Committee. The Committee, comprised of parents and advocates, professionals and educators knowledgeable and active in the field of Autism, will assist the Department of Community Mental Health in identifying research, services,



Andrew Spano

resources and funding mechanisms that would expand and enhance the opportunities for children and adults in Westchester County on the Autism Spectrum and their families. They will also assess the existing services available to individuals and families in Westchester County and determine, based upon current trends, research

and resources, where gaps exist in the current service delivery system and the types of services needed to fill those gaps.

The Committee will make recommendations to Dr. Grant Mitchell, Commissioner of the Westchester County Department of Community Mental Health, who will report these recommendations to the County Executive. The Advisory Committee was announced during the Westchester County State of the County Address on April 10, 2008. In the address the County Executive said, "Parents of Autistic Children spend a lifetime of energy and effort, not counting the huge emotional and financial toll, trying to find the right programs, guidance and support to help their youngster to be educated and their older child to be independent. Autism affects not only families, but the community at large. There must be public understanding and acceptance."

The goals of the Advisory Committee include identifying initiatives that could be acted upon locally and would benefit those individuals and families in Westchester County. Some of the areas they hope to address include an Autism Information Center to serve as a clearinghouse to provide information and resources to families throughout their child's lifespan, education and training on Autism to law enforcement and other first responders

and a "bracelet" tracking system to assist families whose children wander. The Department of Community Mental Health is also revising and expanding their Autism Website which can be accessed through the department's main website at www.westchestergov.com/mentalhealth. Based on national statistics, it is estimated that between 2000 and 6000 children and adults in Westchester County have a diagnosis on the Autism Spectrum. Currently over 800 children in Westchester County public schools (aged 5 to 21) have a diagnosis on the Spectrum.

The Autism Advisory Committee has been meeting on a monthly basis since April. The Committee was one of several initiatives by the Department of Community Mental Health in recognition of April as Autism Awareness Month. Other initiatives included a half-day workshop on April 10th by Dr. John Pomeroy, a nationally known psychiatrist and founder of the Cody Center for Autism and Developmental Disabilities at Stony Brook University Medical Center, attended by 200 family member, providers and educators. On April 6th DCMH co-sponsored the Second Annual Autism Information Fair with Navigating the Spectrum, a parent advocacy and information organization.

see Westchester County on page 45

Teaching Social Skills Through Video Modeling

By Jennifer Jacobs, MS, CCC-SLP
Social Skill Builder

Some children with Autism Spectrum Disorders have to cope with considerable deficits in social and communication skills. They may have difficulty understanding the expectations of them in certain social situations resulting in inappropriate behaviors. One intervention method that targets social skills and is often under-utilized is video modeling – observing appropriate behaviors on a monitor and, through repetition, learning to model those behaviors in day-to-day, real-life situations.

The science behind the effectiveness of video modeling is strong. In numerous studies, comprising decades of scientific research, video modeling has been shown to be the most effective method for teaching social skills and target behaviors to children with autism.

Target Behaviors and Skills

Research on children with autism has shown that video modeling can be very effective in improving the following skills and target behaviors: social interaction behaviors, academic and functional skills, communication skills, daily living skills, play skills, social initiations, perception of emotion, spontaneous requesting and perspective taking.



Jennifer Jacobs, MS, CCC-SLP

Video modeling can teach target behaviors very quickly compared to other methods, and the behavior is said to be "generalized" (i.e., the child is able to exhibit the behavior in real-life situations that are similar to the research scenario). In fact, a 2000 study comparing video modeling with in vivo modeling for teaching children with autism (Charlop-Christy, et al.) suggested that that video

modeling led to faster acquisition of tasks than in vivo modeling and was effective in promoting generalization.

Video modeling also has been proven to decrease certain problem behaviors, including aggression, tantrums and other off-task activities.

Why Does Video Modeling Work?

There are several key characteristics of children with autism that favor the use of video modeling over other learning techniques. A study entitled "Video Modeling: Why Does It Work for Children with Autism?" (Corbett & Abdullah, 2005) lists these key characteristics:

- Over-selective attention (making them very prone to distraction)
- Restricted field of focus
- Preference for visual stimuli and visually cued instruction
- Avoidance of face-to-face interactions ability to process visual information more readily than verbal information

Because they can be replayed over and over as needed without additional cost, videos have been in use as a teaching tool almost since the advent of motion picture

technology. The same entertainment appeal that videos hold for mainstream children applies also to autistic children – only much more so. Since children with autism respond more readily to visual cues, videos and television have a more powerful effect on them. Videos are more motivating and provide more positive reinforcement to autistic children.

Video Modeling at Work

Christopher was 18 months old when his mother, Noreen, noticed that he wasn't paying attention and following directions like the other kids. Rather, he seemed lost.

At Christopher's two-year checkup, the pediatrician said that he was developmentally-delayed, but Noreen's motherly intuition told her that something didn't add up. Christopher could effortlessly recite the alphabet and count to 20. Unlike other developmentally-delayed children, by age two-and-a-half he could put words together, but didn't seem to understand what they meant. Thus began a year-and-a-half long odyssey to uncover the true cause of Christopher's communication problems. With the help of a private therapist, they found the answer: Semantic-Pragmatic Disorder (SPD), a little-known syndrome on the high-functioning end of the Autism Spectrum.

See *Video Modeling* on page 43

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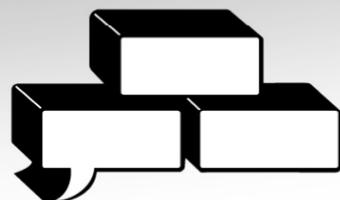
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Dimensions of Quality: Best For Educating Students with ASD

By Mary Jane Weiss, PhD
Cecelia McCarton, MD
Ivy Feldman, PhD
and Jackie Hickey, MS
The McCarton Foundation

Learners with autism spectrum disorders have diverse and unique needs. They struggle with attention, communication, cognitive delays, and behavioral control. Their learning and behavioral challenges are highly idiosyncratic, and each learner requires a fully individualized intensive and comprehensive educational program.

The most effective intervention for learners with ASD's is Applied Behavior Analysis, which has been documented to be extremely effective in building a wide variety of skills. ABA intervention uses empirically validated instructional strategies, develops precise educational goals, and uses ongoing collection of data to monitor student progress and make data-based decisions. ABA intervention has been criticized as teaching students in a robotic fashion, but it is actually a dynamic and flexible educational programming approach, enabling the practitioner to not only develop carefully constructed incremental programs for skill acquisition, but also to assess the functions of challenging behaviors and develop behavior intervention plans matched to function, analyze and program the generalization of skills to the natural environment.

A combination of discrete trial instruction and naturalistic instructional approaches is used to build skills across all curricular areas. There is generally a strong focus on providing reinforcement to build behaviors, on prompting to facilitate skill acquisition, and on assessing the transfer of skills. Quality ABA programs focus on providing a high number of learning opportunities and on capitalizing on naturally occurring opportunities for instruction.

Many programs that utilize ABA also incorporate interventions from other disciplines, such as speech and occupational therapy to address communication and sensory issues. ABA can be used in combination with these approaches to assist practitioners first in gaining behavioral control so they can institute their interventions more effectively. ABA can also be helpful in refining interventions by developing operationally defined targets, in standardizing some interventions within these approaches to assist in tracking progress, and in evaluating the impact of these methods for particular learners.

Outcome of ABA

As mentioned above, there is a substantial data base on outcome with behavior analytic intervention. Lovaas (1987) compared a group of children under age 4 who received 40 hours of intervention per week for 2 or more years with groups of children who received fewer hours of intervention. Almost half of the children in the intensive intervention group were able to be placed unassisted in regular education classes and achieved IQ's in the average range. Other researchers have replicated that early intensive behavioral intervention results in significant gains for some children (e.g., Green,

Brennan, & Fein, 2002; Smith, 1999). From a clinical perspective, it is important to note that more research is still needed to completely understand the effective elements of instruction. Furthermore, outcome remains highly variable, and reliable predictors of outcome have not been clearly identified.

Quality Indicators

One of the central issues for both parents and professionals is the identification of quality indicators of programs serving individuals with autism. Parents seek information on this as they seek to locate appropriate programs that will maximize their child's skills. Professionals seek to identify these variables to develop, refine, and improve their educational services.

Most programs utilizing ABA focus on using a combination of formal and naturalistic strategies. Discrete trial instruction has been effective in teaching a wide variety of core skills in a structured, formalized context. Elements of its effective use include errorless learning procedures (e.g., Etzel & LeBlanc, 1979; Lancioni & Smeets, 1986; Terrace, 1963; Touchette & Howard, 1984) and task variation and interspersal (e.g., Dunlap, 1984; Mace, Hock, Lalli, West, Belfiore, Pinter, & Brown, 1988; Winterling, Dunlap, & O'Neill, 1987; Zarcone, Iwata, Hughes, & Vollmer, 1993). In addition, discrete trial teaching is much more effective if utilized with strategies for effective generalization to the natural environment (Smith, McAdam, & Napolitano, 2007; Stokes & Baer, 1977). Strategies that facilitate transfer to the natural environment include the use of varied phrases in instruction and the use of a naturalistic tone of voice in delivering instructions.

Other elements of effective instruction within formal discrete trials include attention to pacing of instruction and to the provision of frequent and motivating rewards. In pacing, the goal is to maximize the number of opportunities there are for the student to learn in an instructional session. Fast-paced instruction increases learning opportunities, increases access to reinforcers, ensures high rates of engagement, and prevents inappropriate and off-task behaviors. Even when formal instruction is delivered in groups, it is important to attend to the pace of instruction, as faster pace facilitates attention, engagement, and appropriate behavior.

Programs utilizing ABA are committed to taking data, not just for accountability, but for quality control and for decision-making purposes. From a quality control perspective, the collection of data provides information on the integrity of treatment (i.e., is treatment being implemented as designed?) For decision-making, data is collected and reviewed and analyzed on a daily basis to provide information on rate of acquisition, error patterns, the need for additional prompts, and recommendations to alterations in treatment.

Data were collected across a wide variety of learners and teachers in our school (15 learners, 12 staff members). The data allow for the evaluation of treatment integrity along some critical dimensions (e.g., are there at least 5 instructions delivered per minute in intensive individualized instruction? ; are at least 4 reinforcers delivered per minute in intensive individualized instruc-

tion?; are there at least 4 instructions delivered per minute in group instruction?) Results of the analyses indicated that instructors delivered 6.5 instructions per minute in individual instruction, and 4.8 times per minute in group instruction. Reinforcers were delivered 4.5 times per minute in individual instruction, and 3.1 times per minute in group instruction. All of these numbers fall within the indicators of high quality instruction, and reflect intensive programming and high rates of student engagement.

Other indicators of quality programs involve aspects of program organization, environmental set-up, or classroom management. These variables include ensuring staff readiness for instruction and involving the learner in decisions about the sequence or types of activities selected. Data were collected on several aspects of these antecedent/preventive strategies to assess whether the environment was maximally conducive to learning. Data were collected in 16 observations, across 8 learners and 10 staff members, and indicated that staff members were maximally prepared for instruction 97% of the time, and that choices were provided to students in 96% of potential opportunities. These data indicate good use of strategies associated with lower levels of challenging behaviors.

In addition to maximizing formal instruction and ensuring an optimal environment, there is also a need for naturalistic instruction. While the formality of discrete trial

instruction builds responsivity, naturalistic strategies build initiation. Initiation skills are critically important for navigating environments independently, and for reducing the need for instructors to anticipate the learner's needs. One naturalistic approach is incidental teaching, in which the learner initiates a request or a conversation about a particular item or topic. The teacher prompts an elaboration of that initiation, and the learner's more elaborate communication results in immediate access to the desired item (Fenske, Krantz, & McClannahan, 2001). One of the most important aspects is that the learner is leading the teaching interaction, as his or her interests create the opportunity for the instruction (Fenske, Krantz, & McClannahan, 2001). Incidental teaching is an excellent way to increase initiation and spontaneity.

Other naturalistic methodologies within ABA have also emphasized the themes of initiation and learner interests. Pivotal Response Training (PRT) and Natural Language Paradigm (NLP) emphasize using high interest and motivating materials, teaching in natural situations, and capitalizing on the child's interests to target deficits in language (Koegel & Koegel, 2005; Koegel, Koegel, & Surrat, 1992; Koegel, O'Dell, & Koegel, 1987; Laski, Charlop, & Schreibman, 1988). Natural Environment Training (NET; Sundberg & Partington, 1998), like NLP and PRT, focuses on the use of

see *Dimensions* on page 50



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Seaver Center from page 11

clinical trials in psychopharmacological interventions as part of the NIH STAART Centers Program, including trials of fluoxetine and citalopram. We have created the Clinical Trials Network (CTN) funded by Autism Speaks with the mission of bridging the gap between new discoveries at the basic science level and large clinical trials. Our efforts have led to an Orphan Indication/Investigational New Drug application for the production of fluoxetine to treat repetitive behaviors, now being studied by the CTN. Other studies at the Center also suggest that divalproex sodium may be well tolerated and effective for the treatment of core symptom domains in autism (Hollander et al, 2005). We remain extremely committed to investigating best practices in the treatment of autism, and are currently participating in several national, multi-center clinical trials of medications, including fluoxetine, in addition to exploring the use of memantine, a novel glutamatergic agent, to treat language, attention, motor planning, and memory in ASD.

Most recently, our efforts have grown to focus on a novel and innovative agent, oxytocin. Oxytocin is a nine-amino-acid peptide which is synthesized in the hypothalamus and released into the bloodstream from the posterior pituitary. In addition to its release in systemic circulation, oxytocin is widely distributed throughout the central nervous system. It is well known for its peripheral effects on facilitating uterine contractions during parturition and milk let-down. However, oxytocin also plays an important role in social attachment and affiliative behaviors, including sexual behavior, mother-infant and adult-adult pair-bond formation, and separation distress. Moreover, oxytocin plays a role in repetitive behaviors and stress reactivity. Investigators in our Center have found that synthetic oxytocin administered via intravenous infusion to adults with ASD produced significant reductions in repetitive behaviors and facilitated social cognition/memory (Hollander et al, 2003). We are currently conducting an important study examining the effect of intranasal oxytocin on repetitive behaviors and social functioning in adults with ASD.

Another exciting direction of research involves the association between autism and immune dysfunction. There is a significant body of literature linking central nervous system dysfunction in autism to neuroinflammation and several studies report increased levels of proinflammatory cytokines in individuals with ASD. The study of Helminth worms for the treatment of autoimmune disorders emerged in part from the observation that reduced exposure to infectious agents in industrialized countries has led to the rise in allergic and autoimmune diseases. Stimulation of the immune system by microbes may therefore be protective against the development of inflammatory diseases. As a result, porcine whipworm *Trichuris Suis Ova* (TSO) has been studied extensively as a potential treatment for Crohn's disease and ulcerative colitis, among other autoimmune diseases. TSO regulates immune function by inducing the host to selectively produce Th2 cytokines while blocking Th1 cytokine proinflammatory responses and inducing regu-

latory T cells. Recent results of clinical trials with TSO show extremely positive results in patients with inflammatory bowel disease and several anecdotal reports describe dramatic responses in individuals with ASD. Our group remains eager to explore the potential of TSO to ameliorate behavioral symptoms of autism.

For more information about any of our treatment studies, please contact Jessica Kiarashi (jessica.kiarashi@mssm.edu) at 212-241-7098.

The Laboratory of Molecular Neuropsychiatry is under the direction of Dr. Joseph Buxbaum who has been studying the genetics of ASD, including autism, Asperger syndrome, PDD-NOS, and Rett syndrome, for over 10 years. Currently, the laboratory carries out genetic analyses, identifying known and novel genetic causes for ASD in patient samples, and also makes use of mouse model systems to evaluate the mechanisms by which genetic variants can cause ASD as well as to evaluate potential therapies.

The rationale for genetic analyses in ASD is several-fold. First, there is compelling evidence for a large, albeit complex, contribution of genetics to ASD. Second, in some cases, by identifying genetic causes for ASD, there can be immediate benefits to the families, including awareness of recurrence risk and potential medical conditions to be aware of. In very rare instances, experimental therapeutics are available to individuals with specific genetic causes of ASD. Third, knowing genetic causes can lead to functional studies in experimental systems, including animal models, which can be used to develop and evaluate therapeutics.

The Laboratory of Molecular Neuropsychiatry has taken advantage of the evolving methods of genetic analyses to look at genes that increase risk for ASD (susceptibility genes) as well as gene mutations and chromosomal abnormalities that are causal for ASD. We have identified causes of ASD in individuals, including mutations that are causal for ASD (e.g., mutations in the PTEN gene), and chromosomal abnormalities that are causal for ASD (e.g., duplications in 15q11-13 and 22q11). We have also identified risk factors for ASD, including single nucleotide polymorphisms that increase risk (e.g., the SLC25A12 and STK39 genes) and chromosomal changes that increase risk, including duplications in the regions of the X-chromosome.

With these various causal and susceptibility loci for ASD, we are now able to create mouse model systems that have alterations in these loci and these mice can be studied for their neurodevelopment and behavior. We have implemented a large battery of behavioral and neuroanatomical tests and the mice we have characterized to date show deficits in social communication, social memory, and learning, as well as other deficits. Ultimately these mice will represent important model systems to evaluate therapeutics.

For more information about genetic studies, please contact Danielle Zurawiecki (danielle.zurawiecki@mssm.edu) at 212-659-8767.

The Family Studies Research Program is under the direction of Dr. Jeremy Silverman and conducts a wide range of

see Seaver Center on page 47

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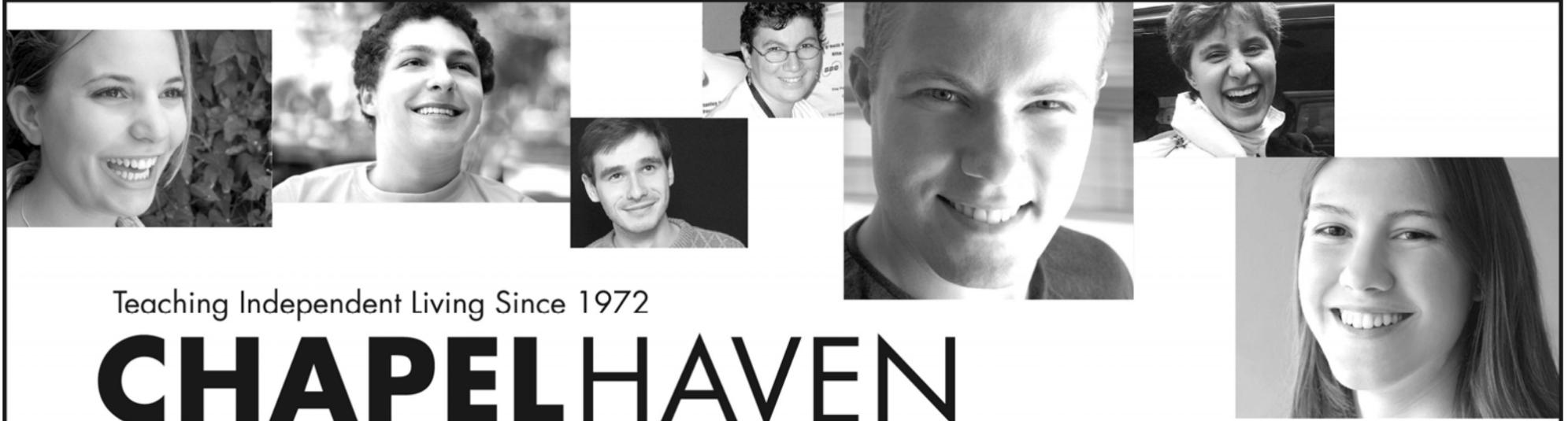
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Dr. Klin from page 26

spectrum disorders. These include studies of looking at and thinking about others. In the past few years, this line of research has focused on the use of eye-tracking technology to visualize and quantify visual engagement with the social world. Research paradigms include free-viewing of dynamic, spontaneous social stimuli such as complex social interactions or infant-directed approaches of caregivers. Novel data analytic techniques were developed to quantify visual fixation patterns of groups of viewers, and to statistically compare the patterns of individuals or groups of viewers relative to normative visual scanning data obtained for typi-

cal samples. This work began with studies of adolescents and adults with autism, and it now involves toddlers and school-age children with autism. These techniques are also being used to study the development of social visual engagement in infants followed prospectively from birth. The goal of this line of research is to devise techniques for the detection of vulnerabilities for autism in the first months of life. Other lines of research include the co-registration of eye-tracking and functional magnetic resonance imaging data and of eye-tracking and electrophysiological data, and the utility of eye-tracking measures of social engagement as outcome measures for psychopharmacological and other treatment studies.



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Commissioner

see *Lifespan* on page 35

funding from UJA-Federation of New York. The AFC is a community of families (parents, grandparents, extended family, spouses and siblings) living with or affected by an individual(s) with an autism spectrum disorder who join together on a formal and informal basis to build emotional and social supports as they face the challenges of autism. Additionally the AFC serves as a centralized information and referral resource. Through our work of compiling information about resources available in Westchester County for individuals with autism, it became apparent that gaps in services existed, particularly for adults. As a result of identifying a lack of services for adults with Asperger's or high functioning autism, two programs were developed.

The Breakfast and Supper Clubs, funded by the Daniel Jordan Fiddle Foundation and the Elaine Gorbach Levine Charitable Foundation, offer adults a welcoming environment where they can meet

others who share their difficulties with initiating conversations, understanding social cues, maintaining employment and ultimately socializing. These individuals now have the opportunity, which they did not have in the past, to enjoy breakfast or dinner while connecting with others and developing social skills.

Both of these newly developed groups filled up quickly after local schools, agencies, therapists, and families were informed about the program. The Breakfast Club meets monthly and is made up of older adults with Asperger's. Group members struggle with building friendships, forming romantic relationships and finding appropriate employment. The participants also want to learn more about what it means to have Asperger's syndrome. The young adult Supper Club meets monthly as well, whose members experience many difficulties transitioning into college or employment. Like the older adults, they also long for the intimate relationships in which typical peers their age are involved.

A Path from page 25

Slowly and deliberately, he typed a short note on the computer. This was equivalent to volumes in our eyes. One day Paul received a call from Lurie's office asking how many tickets he would like to attend the 2004 draft. What generosity of spirit and thoughtful consideration! Jeff Lurie simply knows.

And so, on that Saturday, Paul, accompanied by his father and brother, walked down the bleachers at Madison Square Garden, and sat surrounded by broadcaster Chris Berman and Bob Shoop, then football coach of Columbia University. The exhilaration for Paul was electrifying, and we silently planned to tackle new vistas. That day, our boy transcended the pitfalls of autism. He socialized, fraternized, verbalized and clearly triumphed in the day. That Saturday cemented another kind of hero: Paul.

Time provides a unique perspective in separating the forest from the trees. Sometimes, when we live in a world of chaos, we are totally immersed in the now, rather

than the look where we've been. Autism is so consuming, for parents, children, family and friends. It does not matter how significant the impairment; our personal pain is not measured by degrees.

Our struggle with autism continues, but Paul has employed his enthusiasm for the NFL draft and used that skill to converse with others. Following the 2004 draft, he e-mailed Shoop at Columbia and forwarded statistics about one of our high school players. The senior was then called for an interview. Go figure!

Most compelling for his family is that Paul has learned that he can be flexible. In subsequent years, he has watched the NFL draft on TV and been able to report to us his passion with the usual gusto. That is Paul's plan for Saturday. For parents, how sweet that is!

Robin H. Morris is a patient advocate for Revolution Health at revolutionhealth.com/advocacy/robin-morris. E-mail her at RHAdvocateRobin@revolutionhealth.com. Please visit Robin's blog at www.revolutionhealth.com/blogs/resilientmom, and the Revolution Health

For many of the groups' members, this is the first time they have connected with someone else who is "like them." They can share feelings with someone who understands and meet others with the same diagnosis. It is the first time they are talking about what it is like to feel as if you are an outsider wanting to be let in. They share stories about being the target of many jokes growing up or feeling like their parents always viewed them as failures. They discuss the "what ifs." "What if my parents found out sooner? Maybe I would be better off." "Maybe if my parents knew more about Asperger's they would've understood why things were so hard for me." Because of the Breakfast and Supper Clubs, they are no longer alone in their thoughts and in their worlds. Friendships have begun to form and, at a minimum, they each know that once every month they have a place to come where they are not an outsider and are always free to be themselves.

support group and resource center at revolutionhealth.com/advocacy/robin-morris. Her article was reprinted with permission from the Philadelphia Inquirer.

Robin H. Morris Biography

Robin H. Morris received her BS degree in Secondary Education from Boston University. She majored in English, with a minor in theater. She taught on the high school level for two years, but followed the 'roar of the greasepaint' to pursue her passion for theatre and performing arts. She appeared in various television commercials and daytime soap operas, while performing in Off Broadway productions.

Mrs. Morris's greatest production occurred in 1987 when she and her husband became proud parents of quadruplets, three boys and one girl. The demands of premature infants paled in comparison to the shock and devastation that one of the boys was diagnosed as autistic.

Her son's treatment was viewed as

Recognizing that there are many adults today who went undiagnosed and untreated, WJCS' Autism Family Center offers original programs to help adults with autism spectrum disorders build upon their strengths, improve communication and develop connections with others. Just as programs are being developed for children diagnosed with an autism spectrum disorder, attention needs to be given to forming opportunities for adults diagnosed with the disorder who have had very little support in their formative years. The WJCS Autism Family Center recognizes this gap and is working with the community to create more programs, like the Breakfast and Supper Clubs that meet the needs of this unique and underserved population. There is much work to be done.

Kristen Macaluso, MS is Program Coordinator of the WJCS Autism Family Center, and Patricia Grossman, LCSW is the Program Director of the WJCS Out Patient Services for the Developmentally Disabled.

'pioneering', as therapists utilized behavioral interventions nearly twenty years ago. Robin's expertise as a mother living a life with autism, has incurred a plethora of phone calls with quests for information about her choices for treatment and intervention.

Robin's efforts to elevate awareness and discover scientific information in the field of autism, prompted her to join NAAR (National Alliance for Autism Research) in 2002. Her son's team "Paulie's Promise" raised several thousand dollars for the premier Walk Far for NAAR in her area. NAAR merged with AUTISM SPEAKS in 2006 in efforts to galvanize the global efforts to cure autism, while raising consciousness about the debilitating effects of this disease.

Mrs. Morris credits the power of her 'survivor skills' fueled by the support of her husband Daniel, and all of her children, as the family tackles autism as a formidable adversary. She continues to attend seminars and lectures given by prominent specialists in the arena of autism research.

Advertise in Autism Spectrum News - See Page 55 for Details

Judith Omidvaran from page 27

developmental disabilities, and mental illness. Since autism is comprised of a complex of various types of disorders, I studied about many other types of disorders which either share core symptoms of autism or are disorders that can have autistic traits. A few of these psychiatric and developmental disorders are Fragile X Syndrome, Obsessive Compulsive disorders, Anxiety disorders, Attention Deficit Disorders, Impulse Disorders, Schizophrenia, Bi-Polar disorders and many others. Some of the organizations I became affiliated with advocate for individuals with autism, developmental disabilities, mental health disorders and social services They include: NAAR and CAN (which merged with Autism Speaks), the National Alliance for the Dually Diagnosed (NADD), the Asperger's Association of New England (AANE), ASPEN, the Autism Society

of America (ASA), the Attention Deficit Hyperactivity Disorder Association, NARSAD, NYSACRA, LADDERS, the Cody Autism Center and many others too numerous to list. I also gained a great deal of knowledge by reading *Mental Health News*, from the same organization now bringing you *Autism Spectrum News*.

My dear friend Bonnie Kaplan and I established a support group to address the needs of families with adult children with Asperger's Syndrome and High Functioning Autism. Ours is the only group in the Hudson Valley, NY region assisting families, to assist families in learning about services related to employment, supported living, socialization/recreation, special needs estate planning, guardianship, medical treatments, medical research, behavior modification, etc. We do this to empower caregivers to better cope with the myriad of problems in caring for an

adult living at home or away from home with Aspergers/HFA, and to begin planning to provide a secure future for their autistic adult child. We invite a variety of speakers to our monthly meetings, many of whom are professionals with expertise in subjects that address the concerns of our group members.

I currently serve on the Westchester County Department of Mental Health's Advisory Committee on Autism and also on the department's MR/DD Subcommittee. I also serve as a Science Ambassador for the Autism Tissue Program (ATP) an initiative of Autism Speaks. In this capacity, I will be promoting organ and tissue donation to increase scientific projects related to autism research in order to find the causes and treatments for this devastating disorder.

My most important challenge now is to advocate for services for adults with autism. After an autistic individual leaves school (usually around the age of 21)

there are no mandated services to serve them. Because of this, most autistic adults and their families have an extremely difficult time due to the severe lack of services specifically designed for adults with autism. These autistic adults need a service delivery system that meets their special needs in the areas of Employment, Mental Health, Housing, Recreation, Social Services and the Criminal Justice System which often encounters individuals with Asperger's Syndrome/High Functioning Autism and treats them harshly and unjustly due to their lack of understanding adults with autism.

I am deeply honored that Ira and David Minot have invited me to serve on the Editorial Board of *Autism Spectrum News*, and want to thank them for their tireless efforts in bringing *Autism Spectrum News* to the community. It is a unique and beneficial publication which I hope has continued growth and success in the years to come.

Educating Children from page 17

general education, where the intention is to treat as many students as possible with the same instruction, and get the largest number of those students graduating. The drawbacks of large group research designs (in general and for autism in particular), is that you cannot predict how any one individual will respond to treatment when you are looking at averages.

To make this a concrete example, let's say we have five individuals who score a "20" on some test pre-treatment. The average pre-test score would then be $(20+20+20+20+20)/5 * 100 = 20$. Let's then say that post-treatment, that four of the individuals increase their score to a 30, and one individual decreases their score to a 5, making the post-treatment average $(30+30+30+30+5)/5 * 100 = 25$. There are more complex statistical analyses for this, but for sake of argument, since an average score of 25 post-treatment is higher than an average score of 20 pre-treatment, a group research design would determine this was an effective intervention. How would you feel though, if you were the individual whose score decreased to five? This is not an intervention that you would want, as you

Video Modeling from page 38

According to the National Autistic Society, features of SPD include delayed language development, learning to talk by memorizing phrases instead of putting words together freely, problems understanding questions, and difficulty following conversations. Children with this disorder have trouble comprehending the meaning of what other people say and cannot use speech appropriately themselves.

Now that Noreen had pinpointed the issue, Christopher's parents and grandparents got to work helping Christopher where he needed it most – socialization and appropriate communication. When Christopher was about to receive a gift,

Early Detection from page 13

string on the rug, it might be a red flag."

Carol advises parents to watch for certain behaviors that can vary with each child's development: By about six months, babies should have big smiles and be able to express warmth and joy; by around nine months, they should be able to engage in reciprocity of sounds, smiles and other facial expressions; by approximately 12 months, they should be babbling; and by about 16-18 months, they should be able to form at least some words.

And anytime there is a loss of speech or social skills, parents are advised to consult a pediatrician or developmental pediatrician for an evaluation.

"The good news is that early intervention is here," Carol said. "We didn't have it 30 years ago. If there's a delay it gives the child a good start on the right path to learning how to communicate and interact appropriately."

Cultural factors and language barriers can also hinder early identification of an autism spectrum disorder. The shame that some cultures still associate with disability and a lack of information and services in non-English languages often create further barriers for first-generation Americans

got worse with it than without. Group designs to empirically-validate a treatment do not give you information about how any one individual will respond.

Single-case design research, however, does provide a methodology for evaluating instructional practices, behavior interventions, or other medical or environmental modifications that may impact on the education and outcome of a student with autism. These research designs allow the evaluation of the effectiveness of an intervention for one specific individual, and some common ones are described briefly below (Barlow, Hayes & Nelson, 1984):

- **Reversal design:** This research design involves taking data while systematically providing and withdrawing an intervention, to see if the rate of behavior changes as a function of the intervention.
- **Alternating treatments:** This research design allows you to compare two (or more) interventions provided in alternating sessions within the same time period.
- **Multiple baseline:** This research design allows you to evaluate effects of

Noreen would whisper in his ear, "Put on your happy face." And when he was angry with her but didn't know how to express it, she'd coach, "now it's time for your mad face."

Christopher's therapist also recommended video modeling and pointed them towards a CD-ROM from Social Skill Builder (www.socialskillbuilder.com), a company that provides interactive learning tools for teaching social skills to children affected by Autism Spectrum Disorders and other language/learning difficulties. Video modeling is the basis for their instructional, yet child-friendly, programs.

The CD-ROM, *Preschool Playtime*, was a good fit for Christopher. It offers five levels of role-playing exercises in which real-

on the autism spectrum and their families.

According to the Centers for Disease Control and Prevention:

Developmental Milestones for a Typically Developing Three-month-old

- Smiling at caretakers and loved ones.
- Lifting his or her head when lying on the belly.
- Gazing intently at faces.
- Smiling at the sound of familiar voices.

Developmental Milestones for a Typically Developing Seven-month-old

- Enjoying social play.
- Transferring objects from hand to hand.
- The ability to follow moving objects with his or her eyes.
- Responding to his or her name.
- Finding partially hidden objects. *Developmental milestones for a typically developing one-year-old*
- Enjoy initiating play with peers and family members.

an intervention across individuals, across settings, or across different behaviors.

With decades of single-case design research behind it, components of ABA (like FCT mentioned above) have emerged as the only empirically-validated interventions for individuals with autism. As such, insurance companies are increasingly required to take ABA services seriously as interventions to address communication, social, and behavioral deficits in autism. Schools that support students with autism, whether public or self-contained, should be required to demonstrate that services provided are resulting in improved outcomes. These students already have individualized education plans that list services to be provided and goals to be addressed. Measures of the empirical basis of a service and accountability for outcomes should be standard practice. ABA provides a methodology to do this, even for interventions that are not based on those same principles.

As an example, students with autism routinely receive occupational therapy as a service on their individual education plans in New York. These services can include "sensory integration" activi-

ties, which is par-for-the-course in occupational therapy, but does not have research support as an effective intervention for autism (NYSDOH, 1999). I have conducted single-case research designs with individuals in the school for whom sensory activities are recommended by an occupational therapist to improve reduce impulsivity and distraction. I have been able to demonstrate for a few individuals, that these sensory activities can be provided contingently as effective reinforcers to increase attention to task.

Again, it would benefit autism services if there was a greater emphasis placed on the use of evidence-based practices in education. First, we could truly determine those strategies that will help an individual reach their goals and improve their lives in the community. Second, it would add some accountability to education that is not based on inappropriate standardized tests or teacher-created portfolios of student work. Third, it would assist in legitimizing services that are provided in schools as necessary for some students with autism and would allow a mechanism for families to obtain those services when the school can or does not provide it.

life children are presented in real-life situations – in the park, in a play group, at preschool and on an outing. Playing the game, Christopher was asked to identify correct behavior related to social interactions such as taking turns, sharing, apologizing, cooperating, maintaining personal space and listening.

"Greetings, and how to act when playing traditional games like Duck-Duck-Goose, do not come naturally to Christopher, but he doesn't like me to explain these things to him," says Noreen. "Using Preschool Playtime, we're able to take advantage of the fact that he's a really visual child. When he watches a child in the program stop over at a friend's house to say hi, or a group playing Ring-Around

-The-Rosie, he's able to imitate the situation with other kids later on."

Since starting therapy, Christopher has made incredible progress. "It's like night and day," says Noreen.

Jennifer Jacobs, M.S. CCC-SLP, is co-founder of Social Skill Builder (www.SocialSkillBuilder.com), a company launched in 1999 to provide computer-based tools for teaching social skills to children affected by Autism Spectrum Disorder (ASD). Jennifer, along with her sister and co-founder Laurie, developed the software line when she recognized a deficit in quality products for children and adolescents with social competence issues. Contact Jennifer at Jennifer@socialskillbuilder.com.

- Sit up by themselves.
- Bang objects together.
- Respond to simple verbal requests.

Marni Goltsman and her husband say that they "weren't super concerned" when their 18-month-old son Shafer still wasn't talking or playing with other children. A pediatric neurologist evaluated Shafer and diagnosed him with a pervasive developmental disorder. "We didn't even know what pervasive developmental disorder was," Marni recalled.

The doctor recommended 20-25 hours a week of early intervention services, including speech, occupational and physical therapies.

"A part of me was comforted that we were finally going to get some help," she said.

Today, Shafer is 5 and doing extremely well, thanks in part to the intensive early intervention he began receiving before he was 2.

"My advice to parents is to get their children evaluated," Marni said. "There's no downside. If it's nothing, it's nothing; but if it's something, it makes tremendous difference to get help early."

"Don't wait," adds Michelle Lederman. "Do not wait. It does not take anything away from you to have your child evaluated immediately. The sooner your child begins receiving services, the better."

Today, Michelle is thrilled to see James developing language skills. "He now has more words than I can count and he just started putting two words together," she said.

But she can't help but wonder what progress James might have made if he had received intensive therapies sooner.

"I'm now at a place where I balance reality with optimism. The reality is this is not a six-month or one-year thing; he'll need years of therapy and support, but that won't prevent him from having a full and happy life."

Bernadette Flynn, EdD, is Director of the New York League for Early Learning, a member of the YAI/National Institute for People with Disabilities Network. For more information on evaluations and services for children and adults with autism spectrum disorders, please contact YAI LINK at 1-866-2-YAI-LINK; TDD: 212-290-2787, link@tyai.org or visit www.yai.org.

The Cody Center from page 24**Clinical Services**

In the last 12 months, the Center has served over 1400 individuals or families and provided over 4500 clinic visits. 30 percent of clients are adults. Approximately 75 percent have ASD and 25 percent have other developmental disabilities. The Center provides comprehensive multi-disciplinary diagnostic evaluations for children and adults; psychiatric treatment, including medication management; individual, family and group psychotherapy; neuropsychological testing; educational assessments; and specialty consultations in genetics, developmental pediatrics, and child neurology. The center also runs a State sponsored sex education and family planning program for adolescents and adults with a developmental disability.

Education and Community Resources

Family Support Services include a Resource Center for information and referrals, parent and grandparent support groups, social skills training, and Sib-Shops sibling groups. In 2007, the Resource Center provided over 25 family

workshops and community lectures in topics related to special education services, behavioral programs, guardianship, autism research and other topics. The Center also specializes in services for young persons transitioning to adulthood including short-term care coordination, assistance with applications for OMRDD and other adult services, and providing workshops for parents in transition planning.

Two programs address college based education and training programs. The first is a summer orientation program within a local community college to prepare more able high school students with ASD for the expectations of college education. The second program will start this year and will provide support services for individuals with ASD or developmental disability to attend college based vocational training programs provided in a local community college. This will also be linked with a job search program and training peer mentors on the worksite to provide job support.

The Cody Center provides educational consultation services to 20 Long Island school districts as well as continuing education workshops for general and special education teachers, psychologists, guidance counselors, social workers and other professionals. The Center also offers

graduate courses for special education teachers and other professionals in Autism, behavioral methods, and other topics as part of the MALS (Master of Arts in Liberal Studies). The masters level coursework series leading to the credential of Board Certified Behavior Analyst (BCBA) is also offered by the Cody Center. The Cody Center offers internships and residency rotations for health sciences and other graduate students.

Research

The consortium is engaged in multidisciplinary clinical, basic and translational research currently focused on the genetics of autism, MRI mapping and MRSpectroscopy of the brain, brain cell biological studies, and studies of psychiatric conditions that co-occur with autism spectrum disorders. Among the resources available to researchers is a clinical database of more than 2000 cases of patients with ASD seen at the center.

Important contributions have been made by the consortium and include the identification of 2 candidate genes for ASD (Dr. Eli Hatchwell), the identification of stem cell growth and development in specific regions of the brain when

treated with anti-depressant therapies (Dr. Grigori Enikolopov), the study of additional psychiatric disorders in ASD with preliminary findings suggesting that biologic genetic markers might confirm true comorbidity (Dr. Ken Gadow), and measurement of brain metabolic profiles that may differentiate between ASD clinical subtypes and can provide a non-invasive measure to study stem cells in the brain (Dr. Mirjana Savatic). More details and consideration of research issues at the center could be a feature of future issues of this publication.

The Cody Center is a division of the Department of Pediatrics at Stony Brook University Medical Center and is the only multi-disciplinary Center of Excellence for Autism and Developmental Disabilities on Long Island that is a component of a tertiary care, university based, medical center. It is staffed by psychiatrists, psychologists, primary care and specialist physicians, social workers, special education teachers, and behavioral consultants. Further information can be found on our web-site – www.codycenter.org

The Cody Center congratulates all who have developed this first issue and looks forward to seeing great success for *Autism Spectrum News*.

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Research at Columbia from page 23

order to precisely characterize the nature of their difficulties and strengths (termed the "phenotype"). The genetic samples and phenotypes collected will be made available to research scientists all over the world. This will maximize the value of the resource for a wide variety of future projects into the causes and mechanisms of autism.

In mouse and rat models, several generations can be bred in a relatively short period of time, making it possible to study genes related to autism. Though the genetic makeup and neural pathways in mice are much simpler than in humans, they are similar enough to provide an excellent platform for research. Dr. Jay Gingrich, funded by the Simons Foundation, is using a mouse model to investigate the recent finding that paternal age is a risk factor for autism. By identifying the specific genetic loci that are prone to abnormalities because of advancing paternal age, he and his colleagues hope to better understand the mechanism behind this risk factor.

Other collaborating neuroscientists at Columbia are exploring the possibility that autism arises from disturbances in the maturation, remodeling, and stabilization of specific connections between neurons, perhaps those involved in the acquisition of language or social cognition. They have developed and extensively used two learning model systems: (1) pathways between sensory and motor neurons in the *Aplysia* (a sea slug), and (2) the mouse amygdala, a brain region that participates in the formation and storage of memories associated with emotional events. They have cloned genes in the *Aplysia* that correspond to human genes related to Fragile X (a genetic syndrome that can co-occur with autism) and mental retardation and are investigating the role of these autism-linked genes in learning and memory storage as well as associated fear-memory in the mouse amygdala.

Brain

Magnetic Resonance Imaging (MRI) is a sophisticated way to use magnetic fields to safely take high quality pictures of structures inside the body of a living organism, such as the human brain. We are using this valuable technique to search for and study differences between the brains of typically developing children and those with autism. Dr. Daniel Salzman and colleagues are using electrophysiology and MRI to study an area of the brain responsible for regulating emotions, called the *amygdala*, which has also been implicated as a key site of dysfunction in autism.

In our own brain imaging lab, we are using MRI in multiple ways to compare the brains of children and adults with autism to those without this diagnosis. First, we examine the fine structure of the surface of the brain (called the cortex) as well as important structures beneath the surface (subcortical) to see if there are regions that are particularly abnormal, and therefore may teach us about the causes and potential treatments of autism. Second, we use a new MRI technology, called diffusion tensor imaging, to explore the *connections between* various brain regions, guided by evidence that it is these connections, rather than individual areas in isolation, that are more closely related to the difficulties in autism. Third, we use magnetic resonance spectroscopy to examine the concentration of certain brain chemicals in various regions, thereby teaching us about the health of different tissues. Finally, we use functional MRI to look at which parts of the brain are active in specific tasks, such as solving problems or rating the emotional expression of faces. We believe that understanding differences in brain *function* in autism will lead us to understand which regions of the brain are involved and how they got this way.

Behavior

Dr. Andrew Gerber is studying the way in which individuals with autism evaluate a person that they have never met before in the light of past relationships. He predicts that individuals with autism are *more accurate* in their appraisal of new individuals than individuals without autism, because they are less biased by past social experience. This may make social interactions more difficult, though may also make individuals with autism more keen observers of details than others.

Dr. Ken Hoyte is currently investigating the inter-relatedness of social and communicative/language deficits in autism. He employs behavioral and neuroimaging techniques to systematically examine the ability of children diagnosed with autism to use and understand both linguistic and affective prosody (i.e., the melody of speech). Dr. Hoyte's research will have useful implications for earlier detection and intervention in children with autism.

Clinical Research

Our clinical service at Columbia, the Developmental Neuropsychiatry Program, is a founding member of the Autism Speaks – Autism Treatment Network (ATN). The ATN has brought together physicians and healthcare practitioners from leading medical centers around the nation to evaluate the medical conditions present in autism and provide best practices for their identification and treatment. By building an anonymous database, the ATN plans to create treatment guidelines that will be made broadly available to physicians, researchers, parents, policy makers and others dedicated to enhancing the medical care of individuals with autism. At Columbia, we are focusing in particular on children with autism accompanied by sleep or gastrointestinal problems.

We are also evaluating the efficacy of two promising intervention programs created by Dr. Marion Blank and designed to develop basic literacy and math skills in non-speaking children with autism. Reports suggest that many children with autism show great interest in letters and numbers and that these skills presage an ability to develop significant reading and math competence. The programs are being implemented with 16 children (8 receiving the literacy intervention and 8 receiving the math), 4 to 17 years old, with autism and no or very limited spoken language. Both programs will be evaluated using tests designed to measure the children's acquisition of a host of literacy and math skills. At the completion of the programs, it is expected that the children in both groups will have attained a set of skills that, in the past, have been considered beyond the reach of this population.

Finally, Dr. Johanna Lantz conducts research on social skills interventions for children with autism. She is particularly interested in strategies that promote independent and flexible responding including self-monitoring and video self-modeling.

Columbia's autism program is proud to be a part of the inaugural issue of the *Autism Spectrum News*. We aim to communicate with those who share our desire and commitment to understanding the causes of these disorders, and who seek more advanced and effective treatments. Collaboration between members of the autism community has been the key to our achievements thus far and, we believe, will be the cornerstone of our future success.

Dr. Peterson is the Chairman, Division of Child and Adolescent Psychiatry, Director of MRI Research, Department of Psychiatry, Director, Pediatric Neuropsychiatry Research, and the Suzanne Crosby Murphy Professor in Pediatric Neuropsychiatry.

Best Practice from page 21

think about children with autism.

The approaches chosen to study were Applied Behavioral Analysis (ABA), the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH), Daily Life Therapy (DLT), the Miller Method (MM), and Developmental Individual-difference Relationships-based intervention (DIR), which is often referred to as Floortime. Although there are many approaches worthy of studying, my dissertation had to be finished within my lifetime.

We are in a unique moment in time. The diagnosis of autism has been around for about 6 decades. As a result, most of the people involved in the initial work of developing these promising approaches remain available for interview, and in most cases, are continuing to work in this area. Although I never thought it possible, the key developers of these approaches were willing to answer an e-mailed survey and submit to a 60-minute taped interview where they answered questions on areas such as defining autism, explaining and developing interventions to address challenging behaviors, their intellectual histories, and where they saw the greatest gaps in research. Below are some of the results and findings of my research in the area of relating definition of autism to practice of determining appropriate intervention.

Defining Autism

Part of what makes autism such a challenge lies in how the condition is defined. All of the persons interviewed for my study agreed that the characteristics listed in the DSM IV-TR do not accurately and fully describe the autism spectrum. Moreover, none of the people I talked to could agree on a common definition for autism. This lack of agreement suggests that we continue to place more and more people into the concept of "autism spectrum" to the point where there is such great diversity that the term has become almost useless.

Some of the persons I talked to recommended factoring groups of characteristics for better sub-typing of children and adults with autism and therefore better matching diagnosis with treatment. For example, a diagnosis of Type II diabetes engenders specific treatment involving exercise, diet, and possible injections to maintain proper blood sugar. However, the autism spectrum is so general at this point that it's impossible to generate specific interventions from the diagnosis. Like with diabetes, better sub-typing of children with autism will help match diagnosis to intervention.

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the teachers. The teachers spoke of their own willingness to change classroom routines and activities to meet the needs of specific children and to plan carefully to reinforce the strengths of each child. The participating teachers showed increased curiosity about children who were puzzling, and wanted to know about other kinds of delays or difficulties that interfere with development.

Good training for early childhood educators inspires improvement of practice,

An Example of Sub-typing in Autism

The good news is that some of the theorist/developers of these approaches have begun to place children with autism into specific groups. For example Arnold Miller, who has spent over 40 years developing his approach, has parsed out children with autism into two major categories. Closed System Disorder is one of the sub-types and is probably the most familiar. According to Arnold Miller, this is a child who may get over-involved in routines, may insist that all doors be closed, for example, and requires much attention paid to transitions to avoid a meltdown or tantrum when changing activities. The other category, System Forming Disorder, refers to a child who seems to have hyperactivity and "orients to all salient stimuli in the environment, but engages with none" (Personal communication, Arnold Miller, July, 1999). For example, a child in this category would run about a room, look at a shiny object for a couple of seconds, dash over to the therapist to touch her watch, then stare at a shiny point of light reflected in a window, etc.

Serena Wieder, who co-developed DIR with Stanley Greenspan, has developed four major categories of children on the autism spectrum. Like with the Miller Method, practitioners of DIR are better able to match their pool of intervention techniques to the needs of the children on the autism spectrum.

Conclusion

We are at a point in time where there is an explosion of methods, approaches, and techniques for working with children on the autism spectrum. The diversity of the autism spectrum, as currently conceived, suggests the importance of customizing intervention to the needs of a particular person with autism. One important step towards this customization will be to sub-type diagnoses within the autism spectrum and thus better match diagnosis to specific intervention as is shown by the work of Arnold Miller in the Miller Method and Serena Wieder of DIR. It is my hope that the characteristics defining autism in the upcoming DSM V and other diagnostic references will fulfill this need.

Stephen M. Shore, EdD, is the Executive Director of Autism Spectrum Disorder Consulting. An internationally known author, consultant, and presenter on issues related to the autism spectrum, he serves on the Board of Directors for the Autism Society of America and is on the Board of Directors for the Asperger's Association of New England. Please visit his website: www.autismasperger.net.

greater understanding of child development and an enhanced capacity to work with parents and other professionals. It was clear that our program kindled new understanding in teachers and ignited a sense that they could be helpful to families struggling with ASD.

Bruce A. Grellong, PhD, is Chief Psychologist and Director of the Center for Child Development and Learning at JBFCS, and Fern Fisher, MA, MS, LCSW, is Director of JBFCS's Early Childhood Consultation Services.

Social Skills Groups from page 15

- Consider the family's specific desires for skill acquisition?
- Assess satisfaction with the service at the conclusion?

In-school services also need to be examined. Families should request that:

- Services be very specifically described on the student's individualized educational plan
- Those delivering the services have knowledge about both social skill development and the specifics of delivering such services to children on the autism spectrum
- Services be of sufficient intensity to be effective
- School personnel are utilizing evidence-base practices
- Interventions are being delivered in authentic locations such as playgrounds, classrooms, and lunchrooms, rather than only professional offices.

Sometimes parents do not feel sufficiently knowledgeable or empowered to

request the services their child truly needs to promote the best outcome. It is important for parents to be wise consumers by:

- Requesting specific plans and generalization strategies
- Learning how to reinforce social skills through play dates and get-togethers
- Helping their child maximize strengths and interests in social settings
- Negotiating with school treatment teams to implement a true social skills program that is individually designed and data-driven

Meanwhile, professionals who specialize in autism and Asperger Syndrome can help families gain awareness of the current state of knowledge; understand what they as parents can specifically accomplish with their children; and know what critical questions to ask of anyone currently providing social skills intervention in schools or community. Together, parents and professionals should continue to advocate for more treatment-based research on social skills development now.

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Over 800 parents and providers attended this event.

The members of the Autism Advisory Committee are: Judith Omidvaran, Parent/Advocate; Marjorie Madfis, Parent/Advocate; Nina Spooner, M.D., Parent/Advocate; Theresa Pirraglia, Parent/Advocate; Gail Chen, Parent/Advocate; Mary Zingaro, Parent/Advocate; Joanne McMahon, Special Education Consultant; Alison Tepper Singer, Executive Vice President, Autism Speaks; Neil Boyle, Education

Coordinator of Devereux Millwood Learning Center; Betty Crea Davidson, Executive Director of Navigating the Spectrum; County Legislator, Thomas Abinanti; Marlene Perlman Spector, Ph.D., Psychologist and Peter Faustino, Ph.D., School Psychologist. The Department of Community Mental Health is very excited about working with the Autism Advisory Committee over the course of the up-coming year and greatly appreciates the generosity of the members in volunteering their time, expertise and energy on this important endeavor.

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child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include:

(1) Appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills and;

(2) The transition services (including courses of study) needed to assist the child in reaching those goals.

The term "transition services" means a coordinated set of activities for a child with a disability that:

- Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation;
- Is based on the individual child's needs, taking into account the child's strengths, preferences and interests and;
- Includes instruction, related services, community experiences. The development of employment and other

post-school adult living objectives, and if appropriate, acquisition of daily living skills and functional vocational evaluation. [34CFR 300.43 (a)] [20 U.S.C. 1401(34)]

It is essential that the transition section of your child's IEP includes the three mandated areas of: instruction, community experiences, and employment and post-school living objectives.

Many school programs for individuals with autism, especially those with a large inclusion component will slight basic living skills. Unfortunately, the post-secondary goals in the areas of independent living skills are not specifically required by law. It is up to the child's team to determine whether IEP goals related to the development of independent living skills are necessary for the child to receive a Free and Appropriate Public Education (FAPE)." (71Fed at 46668)

The required components of your child's transition plan are described in IDEA 2004. You should make certain that your child's IEP team adheres to these requirements:

- The student must be invited to participate in IEP meetings to discuss his/her goals after high school.
- You can request additional IEP Transition meetings during the school year.
- You can invite local provider agencies to attend your child's IEP meetings.
- The IEP, including the transition

plan, should incorporate person-centered planning, and reflect the student's interests and skills.

- The work experiences or "community based work assessments" chosen should be based on the student interests and skills. Students should not be placed in a community based work assignment simply because it is available.
- Any placement should help the student develop skills in a setting of personal interest to him/her, and where his/ her unique abilities can be utilized and improved with job coaching.
- Annual transition goals in the IEP should lead to successful post- high school outcomes.
- Student progress should be documented and measurable.
- Obtain progress reports about your child's community based work experiences.
- Maintain a portfolio and resume of your child's experiences, progress reports, and favorable reviews from your child's supervisors. (Adapted from Wrightslaw: Transition Planning, Graham & Wright)

Start Today

To prepare for life after school there are several things that you can do:

- Contact adult provider agencies before your child "ages out" to see if they will provide job coaching for your child during the transitioning phase. This may help to ensure that there will be no break in services between school and the beginning of the adult program.
- Invite representatives from adult provider agencies to attend your child's IEP meetings
- You can request that the IEP team allow your child to experience community based college experiences during his final years under IDEA if you feel that is appropriate.
- Contact your state's office of developmental disabilities about enrollment requirements and supports.
- If applicable, contact your state office of Vocational Rehabilitation Services about job training and support. Be aware that the supports provided under this system are time limited.

Some Final Thoughts

Since you are the captain of your child's transition team you will also have to foster a feeling of active cooperation among your child's school district, teachers, future adult service providers, and governmental agencies for several years. Knowing your child's rights, timely

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Latino Children from page 36

These variables cannot only influence or confuse a professional rendering the proper diagnosis, but can create delays in starting very valuable treatment.

Children with autism have deficits in communication that are different than language difficulties related to uneven exposure to two languages and, depending on the severity of the problem, manifest different patterns such as echolalia and the use of phrases they hear from others around them in a robot like manner. These language and interactional problems do respond better to early intervention thus indicating and reinforcing the importance of earlier detection which could be crucial for children who are learning multiple languages at once.

Another variable that affects the timely diagnosis of autism is the socioeconomic level of the family (Palmer, Blanchard, Jean, & Mandall, 2005). Lack of resources often prevents the parents from seeking a second opinion which by definition places many Latinos with a major disadvantage that not only influences obtaining a timely diagnosis and availing themselves of needed resources to help children with autism, but can be misleading in reporting the prevalence and incidence of autism among Latino children, which has been found to be less than among non-Latino children. The end result in underreporting autism in Latino children is a minimization of the relevance and importance of conducting further research studies crucial for obtaining a better understanding of autism within this population.

It is believed that Latino children are diagnosed much later than other children. At the moment, the literature on autism in Latino children have found that the average age in which Medicaid eligible Latino children were diagnosed is 8 years old in comparison with white children, who are often diagnosed two years earlier at age 6. Latino children with autism were diagnosed one year later than African-American children, who are diagnosed on average at more than 7 years of age (Mandell, Listerud, Levy, & Pinto-Martin, 2002).

Another important component in the possible misunderstanding and delays in the prompt diagnosis of autism in Latino Children is the traditional adherence to cultural values such as fatalism by their parents. For example, many Latino parents have a tendency to underreport symptoms. This may be due to the cultural value of fatalism, which determines one to leave things to fate rather than act promptly on a specific concern. This is particularly evident when traditional grandparents feel that things will change, or fear to admit that there is something wrong with their child, thus hoping the problem will go away (Center for Disease Control, 2006).

In terms of diagnosis, it is very important to inform parents of the specific symptoms to look for and in turn inform the child's pediatrician. Many doctors in today's world are very busy and unless parents are assertive and come to the office with a written list of their concerns, many relevant symptoms can long go unnoticed leading to a waste of precious time when a shared observation with the pediatrician would have been of great help. Many Latino parents have shared

with me that they feel intimidated by doctors who are not personable and behave differently than what they have experienced within their culture.

Parents need to be aware of the specifics and possible manifestations of what might be normal versus what might be abnormal in their children. This is particularly difficult among very young children since problems that could fall under what is called neurodevelopmental disorders are difficult to distinguish from each other because they could be representative of other disorders (McConachie et al., 2005; Trillingsgaard, Sorensen, Nemeč, & Jorgensen, 2005). But parents should insist that their child's pediatrician or other professionals assess what they feel is not normal and should make sure that their child's behaviors are not explained as language or culturally related. Parents should not worry that they will appear overly alarmed or fear they will upset the professionals. Similarly, providers should be aware that traditional cultural values adhered to by the parents can affect communication between them.

When the parents are well informed they can be the eyes and ears of their children's doctors by bringing to their attention important information that can help the doctor become aware of and able to recognize autism-related symptoms much earlier in a child (Hutton & Caron, 2005). For example, among the things that parents should understand is that many children with ASDs may not show specific behaviors until they are much older; repetitive behaviors do not show until age 3 or 4. Another significant behavior to note and share with the pediatrician is the lack of initiating joint attention. The doctor

might see the child on a day he or she is not feeling well and consequently appears lethargic or uninvolved, but the parent who sees the child daily knows that this behavior is usual.

It bears repetition to say that it is the parents who must inform the pediatrician, and in terms of culture and language, the better acquainted everyone is, the better it is overall. Parents must understand that once a child has been diagnosed with an autism spectrum disorder, what follows is to find out how to help the child with his or her specific deficits or weaknesses. The existing problems will require specific interventions according to their needs, which could be in the language, social or emotional areas. These interventions should include helping the parents on the management of autism in their child and offering emotional support to the entire family in a culturally and linguistically competent mode.

In terms of research efforts, there is a need to conduct research studies that provide a better understanding specific to Latino children with autism and their families. The following is recommended:

- To better understand how the Latino population accesses help specific to ADS's.
- To determine whether parental cultural beliefs impact the prompt assessment of children with autism.
- To assess whether the child rearing patterns practiced by many Latinos, particularly immigrants who are

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Good Health from page 13

of health care was a pioneer in providing sensitive, specialized services for individuals with disabilities. Unfortunately, this type of care is still unavailable to thousands upon thousands with autism and other disabilities.

At Premier HealthCare, patients visit general practitioners, specialists, dentists, psychiatrists, physical and occupational therapists and other professionals, in a familiar setting in their communities. Premier employs a diverse multilingual staff who can provide services and information to our patients and their families in a culturally appropriate way. Our health care providers are trained to be sensitive to and aware of the needs of people with disabilities, who may have acute anxiety, trouble communicating or other issues requiring extra time and understanding that may be difficult to find in a standard doctor's office, let alone a hospital emergency room.

"A level of sensitivity is a critical component of serving people in their communities," said Marco Damiani, director of Clinical and Family Services at YAI/National Institute for People with Disabilities. "This has led Premier HealthCare to provide services by clinicians who have special awareness and training about our patients' needs, as well as to a continuity of care, so that patients don't have to get to know a new doctor every time they have a checkup."

And unlike in typical practice settings, medical staff from all different specialties come together at each of our neighborhood centers to learn from one another and to collaborate on behalf of individual patients, eliminating phone tag or communication breakdowns. For example, when a child visits the center, a family doctor can walk down the hall to talk to the neurologist and coordinate medications, and then on the way back, inquire with the social worker about eligibility for a summer camping program, and finally, catch the psychiatrist to ask about the child's behavioral progress.

In 2002, the U.S. Surgeon General recognized Premier HealthCare as a national model in the provision of health care for people with disabilities in their communities.

Health Concerns Specific to Autism

In addition to being aware of the social and psychological needs of individuals with autism, health care providers should also be aware of certain medical issues that arise more frequently in these patients.

By the latest estimates, 40 percent or more of people with an ASD also have an intellectual impairment. In classic autism, the rates are as high as 70 percent. In addition, the medical community has long known that up to a quarter of people with an ASD also have epilepsy. As a condition affecting many areas of brain and behavioral development, autism — whatever its causes are — also affects other

developing body systems.

Current hot research topics in the field include explorations of why people with autism tend to be more susceptible to various gastrointestinal disturbances, immune and inflammatory conditions and sleep disorders. One interesting area of investigation is the so-called "hygiene hypothesis," which proposes that current hygiene practices in western societies prevent children from being exposed to the environment in a way that encourages proper development of their immune systems. And in certain children, including those with a genetic risk for autism, this may have a long-lasting effect on brain development and neurological reactivity.

Autism has also been associated with genetic and congenital conditions such as fragile X syndrome, tuberous sclerosis and congenital rubella syndrome.

Lastly, there are a number of general considerations to keep in mind when working in a medical environment with people with autism. When patients with limited verbal skills experience discomfort or are in pain, they may express their distress through aggression or self-injurious behaviors, by yelling or by withdrawing. What, to untrained staff, may at first appear to be a behavioral issue could actually be a serious health concern and lead to a medical emergency.

A common feature of autism is the prevalence of repetitive behaviors: rocking, hand-flapping, jumping, pacing. Be-

cause these behaviors are used by some people with an ASD to cope with anxiety, they can be used by providers as a guideline for assessing the patient's level of discomfort and stress. Increased rocking may mean increased pain or anxiety.

People with autism are typically hypersensitive to many types of sensory stimuli, easily ignored by the general population. Packed waiting rooms, glaring and buzzing fluorescent lights, scratchy upholstery and cloying deodorizing agents can all turn a routine medical visit into a very challenging day for our patients. A welcoming waiting room experience that is predictable, cool and away from the bustle can result in a happy and easy-going patient for the long term.

We as doctors, dentists, nurses and other clinicians must understand our obligation to explain procedures to our patients in a way that diminishes fear, enhances our patients' understanding of their health and empowers them to make healthful choices.

Peter DellaBella, M.D. is the Associate Medical Director and Chief of Psychiatry at Premier HealthCare, a member of the YAI/National Institute for People with Disabilities Network. For more information on medical services for children and adults with autism spectrum disorders and other disabilities, please contact YAI LINK at 1-866-2-YAI-LINK; TDD: 212-290-2787, link@yai.org or visit www.yai.org.

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Seaver Center from page 40

studies investigating genetic factors in autism and related disorders. In association with the Greater New York Autism Research Center of Excellence (GNY-ARCE), the Family Studies Program performs extensive clinical evaluations in an attempt to determine how autism-related difficulties with social interactions, communication skills and/or restricted and repetitive behaviors and interests may run in families. We work with all available family members to assess behavioral traits that may run in families and attempt to locate genes associated with these characteristics in individuals with autism and their families.

Prior published work from the Family Studies Program reported on evidence that repetitive behaviors and age of phrase speech development are more similar within affected siblings that are both diagnosed with ASD than between siblings without ASD (Silverman et al., 2002). This information was used to subgroup families with autism according to these different "familial" and likely genetically-based characteristics. In turn, this subgrouping helped inform a study that looked across the genome for a chromosomal location where an autism associated gene might reside and found evidence for a site on chromosome 2 (Buxbaum et al., 2001). Subsequent to this work, a specific gene related to autism was found in the region previously identified on chromosome 2 (Ramos et al., 2006). Finally, we examined specific autism related traits

associated with this gene (Silverman et al., 2008). Other related work from the Family Studies Program found that children with autism and high levels of intense interests, unusual preoccupations, rituals, and compulsions were more likely to have parents with Obsessive Compulsive Disorder (OCD) or OCD traits (Hollander et al., 2003).

Participation in our studies involves interviews with the parent/caregiver, an observational and interactive interview with any child diagnosed on the autism spectrum, intelligence testing for all children within the family, and a small blood draw for all members of the family. All interviews can be done during the day, evening, or weekend hours and timing can be adapted to busy schedules. We also travel to your home for all assessments.

For more information about family studies, please contact Lauren Brickman (lauren.donnely@mssm.edu) at 212-659-5654.

The Neuroimaging Program at the Seaver Center uses multiple imaging techniques to look at the activity of the brain regions and circuitry involved in autism. There have been valuable contributions to our understanding of autism from imaging studies. At the Seaver Center, several investigators are working to understand the differences in structure, function, and neurochemistry in individuals with autism. As part of the STAART Centers Program initiative, the Seaver Neuroimaging Program has been investigating key elements of the serotonin system using Positron Emission

Tomography (PET) radiotracers to explore the hypothesis that ASD is associated with deficient serotonin innervation in forebrain cortico-limbic areas.

Dr. Evdokia Anagnostou is leading an fMRI study examining the function of the orbitofrontal network in autism, a network likely involved in repetitive behaviors and the executive dysfunction observed in individuals with autism. Individuals participating in this study also receive oxytocin to examine its effect on orbitofrontal circuitry (funded by the Seaver foundation). Dr. Anagnostou has also received funding by NARSAD and Autism Speaks to study differences in glutamate concentrations in the orbitofrontal circuitry and other brain chemicals that may be related to neuronal integrity and metabolism in children and adolescents with ASD. In other, related work, our group is examining the developmental trajectory changes of the white matter tracts in children and adolescents with autism using DTI.

Dr. Ting Wang and Dr. Latha Soorya have received funding by NARSAD and Autism Speaks to assess both the neural and behavioral effects of our 12-week social skills groups for school-age children with ASD. Using a randomized treatment design and fMRI technology, the study compares the effects of a cognitive behavioral approach and a play-based approach on behavioral measures of social cognition and on the neural circuitry underlying key aspects of social cognition. Dr. Jin Fan, the Director of the fMRI lab at Mount Sinai, is interested in investigating possible abnormalities in the neural circuitry involved in all aspects of

attention in individuals with autism and was recently funded by NIMH to study the circuitry involved in empathy in autism. And Dr. David Grodberg is investigating the neural circuitry of self produced tactile stimulation in an attempt to provide a neurobiological explanation for self stimulatory and self injurious behaviors seen in ASD.

For more information about neuroimaging studies, please contact Nicole Feirsen (jessica.feirsen@mssm.edu) at 212-241-3692.

Conclusion

The Seaver and New York Autism Center of Excellence is an interdisciplinary, translational, and collaborative effort between clinicians and scientists at Mount Sinai School of Medicine and several institutions across the United States and abroad. We are extremely grateful to all the individuals and families who participate in our research. Our team believes the key to success lies in translating the knowledge gained from research to developing breakthrough treatments that meaningfully impact community care.

Eric Hollander, MD, is the Esther and Joseph Klingenstein Professor, Psychiatry, Alexander Kolevzon, MD, is Assistant Professor of Psychiatry and Pediatrics, Joseph D. Buxbaum, PhD, is Professor of Psychiatry, Neuroscience, Genetics and Genomic Sciences, Jeremy M. Silverman, PhD, is Professor of Psychiatry, and Evdokia Anagnostou, MD, is Assistant Professor of Psychiatry.

Autism Spectrum News Upcoming Theme and Deadline Calendar

Winter 2009 Issue:

**“Understanding and Treating Autism Spectrum Disorders”
Deadline: September 15, 2008**

Spring 2009 Issue:

**“Helping Parents and Family Members Cope with ASD’s”
Deadline: December 15, 2008**

Summer 2009 Issue:

**“Education for Children & Adults with Autism Spectrum Disorders”
Deadline: March 15, 2009**

Fall 2009 Issue:

**“Addressing the Needs of Adults on The Spectrum”
Deadline: June 15, 2009**

Inclusion from page 29

With consistent practice and reinforcement they can be faded out in hopes that this appropriate social behavior has been internalized and the script is no longer necessary.

Learning strategies to help and teach students to become part of their social world is not an easy task. However as inclusive practice continues this is perhaps the greatest challenge for classroom teachers. An overwhelming classroom is not a place conducive to learning. Stu-

dents need to feel welcome and comfortable so they can focus their energy on the tasks at hand. The classroom is a place that holds many challenges for children with autism, not the least of which is just learning how to become a part of it all.

Diana Friedlander is a special education inclusion teacher in elementary education in Ridgefield, Connecticut and a Doctoral student at Western Connecticut State University. You may contact her at uspanel@aol.com.

NARSAD from page 7

“We don’t think the platelet itself contributes to autism,” Dr. Blakely clarified, “but rather we believe that the brain’s serotonin transporter may be controlled by integrin proteins in a very similar manner.”

Elevated SERT Activity and Autism

Drs. Carneiro and Blakely believe that too much SERT activity imposed by abnormal integrin interactions could restrict availability of serotonin in the brain during development, as well as in the adult. “What is even more striking is that this is the second time we have found elevated SERT activity associated with autism,” said Dr. Blakely. In a 2005 study, Blakely and Vanderbilt collaborator James Sutcliffe,

Ph.D., identified mutations in the SERT gene that triggered elevated SERT activity.

Dr. Carneiro is now hot on the trail of integrin interactions with brain SERT and is engaged in engineering mice that express human integrin beta3 mutations. “These new animal models offer an unprecedented opportunity to peel away the complexity of autism and possibly develop new therapies,” Dr. Blakely commented. The research also may uncover new ways of treating depression. “Current antidepressant mechanisms still essentially work in the same way they did 25 years ago – by targeting transporter uptake of neurotransmitter [i.e., serotonin] directly,” Carneiro said. “Now we may have a completely new way to go about it.”

This article was adapted by NARSAD with permission of Vanderbilt University Medical Center. Visit www.narsad.org.

Latino Children from page 46

struggling economically, affect the prompt diagnosis of autism. Among these is the custom of sending children back home to be cared for by relatives who may minimize the existence of autism. Others may use folk medicines or seek a curandera before contacting a health care provider, a practice that may delay the diagnostic process.

- To further understand whether uneven exposition to two languages or dual language acquisition in Latino children bears any relationship to the delays in the proper diagnosis of autism by professionals.
- To determine whether Latino parents compare their child’s language delays related to autism with other children who had experienced language

delays related to autism leading to a waste of precious time.

- To refine the classification process and how treatment decisions are made once the diagnosis is made.
- To conduct more studies that determine whether there is a misdiagnosis of autism in Latino children overall including the major Latino groups in the United States.
- To conduct studies that offer Latino parents and professionals a better understanding of autism, including rearing practices that can confound developmental delays, such as fostering over dependence versus independence and autonomy should be a priority (Vazquez, C. 2004; Rhodes, Ochoa, & Ortiz (2005).

As a Parent from page 30

keep up with “normal” children. I remember reading about the Rosenthal study of the 1960s in California about the “Self-Fulfilling Prophecy” and how the teachers profoundly affected the children’s development simply by their attitude and behavior towards the children in the study. I have learned that when I expect more from my children, they do more, learn more, develop more.

I remember to this day, when each child’s personality changed and each lost language. The road back was more difficult than anyone can imagine. At this time, the twins are about 2-3 year behind academically, BUT they do interact, they do relate, and they do participate. They are catching up and they speak well. They still cannot shop for food in a supermarket, or some other tasks or activities that

others their age can do, but they are learning. The trick is to break down any task and present the structured sequence to them. If they like the activity, they get it right away. If not, more repetitions and motivation is needed.

My goal: if they can catch up to the others by the time they are 18-21 and can be self-sufficient and productive and go to college), then I will be satisfied. I take a spiritual long view and I am always grateful when I see improvement. I think the most important things are: 1) to not give up, even when it seem hopeless and 2) always picture in your mind how they will be down the road...imagination and working towards the child’s goals are interlinked.

Beatrice Block
Parent

As a Psychologist from page 31

families to assist in achieving a sense of normalcy to their adolescence. As these adolescents transition into adulthood, it behooves professionals to become familiar with the array of services for adults with ASD and how increased advocacy at that juncture is necessary to promote community inclusion.

The growing body of research on Autism today has concentrated on the benefits of early intervention and the myriad of treatment modalities that can be incorporated into an effective, individualized treatment milieu; this focus has impacted professionals to widen their existing modes of treatment and truly achieve the most individualized (and hence most effective) methods of intervention. While

the increased focus on Autism Spectrum Disorders and their associated etiologies has brought many issues to light, I believe we still have more work ahead to assist individuals with Autism overcome the daily challenges they face. The rising numbers of individuals being diagnosed with Autism have seemed to inspire educators, medical professionals, social workers and psychologists alike to embrace these individuals and move towards positive change; therefore the promise of research in this area does not seem as daunting as it once may have been.

Danielle M. Torre, M.S.
Behavioral Health Specialist
NYS Certified School Psychologist
Cardinal McCloskey Services

As a Society from page 31

fully accessible.

Through the arts, we aim to give rise to the full realization and expression of thoughts, emotions, and ideas that might otherwise be untapped. In conjunction with necessary medical, therapeutic, and educational interventions, arts involvement is a critical component in serving the whole person. Research has shown the efficacy of the arts in enhancing skill levels and contributing to overall academic achievement in young people with and without disabili-

ties. We are challenged as a community to apply and adapt arts learning to enhance the development of those with autism and to include the arts in approaches to treatment.

Furthermore, and perhaps most significantly, the shared arts experience links us to one another in ways that are beautiful and profound. The arts call us to acknowledge our commonality and address the multi-faceted nature of each individual with autism.

Vanessa Young
Executive Director
VSA Arts of New Jersey

see Partnership on page 35

individuals with ASD (Watanabe & Sturme, 2003) and have been successful in improving outcomes for adult consumers at F·E·G·S.

The implementation of visual-support structures in F·E·G·S day habilitation services also provides the groundwork to develop research programs on the effectiveness of staff training programs in adult ASD, an area with limited research. This capitalizes on the individual expertise of F·E·G·S (on staff training) and MSSM (on best practice interventions).

The promising partnership between F·E·G·S and the Seaver Center on developing evidenced based practices for adults with ASD is firmly in line with the mission of FEGS. As stated by Jonas Waizer, Ph.D. and Chief Operating Officer of F·E·G·S: “F·E·G·S is experienced in helping individuals with ASD and we continually invest in staff development to

provide the best services possible to the individuals we serve and their families. The partnership with the Seaver Center reflects a commitment to advance the field for families and professionals. F·E·G·S upholds its commitment to working with the unique wants and needs of each person served, in an environment that embraces excellence, caring, dignity, integrity, and respect.”

F·E·G·S Health and Human Services System, one of the largest and most comprehensive not-for-profit health and human services organizations in the United States, assists individuals with mental, developmental and physical disabilities, those who are unemployed, immigrants, families, youth, the frail elderly and many others. Each year, the F·E·G·S network reaches more than 100,000 individuals and families each year, at more than 350 facilities, residences, and off-site locations in New York City and on Long Island.

OMRDD Platform from page 1

to implement a "People First" system of comprehensive services; and

- Providing families with information.

In May 2008, Ritter unveiled OMRDD's Autism Platform in response to the mounting concern of those living with autism and those whose life work and calling is to educate and support individuals with ASD to achieve and contribute. She highlighted two key components of the platform, a statewide collaborative research consortium, The New York State Autism Consortium, and an interagency Task Force. The promise of each of these initiatives lies in combining the talent, knowledge and ingenuity that reside within New York – in its scientific, educational and service community and in its policy leaders - and applying the full force of those combined resources to the shared mission of examining and responding to autism and ASD.

"New York State already boasts some of the finest medical and educational facilities in the world, as well as some of its finest service agencies; however each such institution, standing on its own and limited by its own institutional interests, will not best serve the State's autism constituency," said Gov. David A. Paterson, who believes the state must take a leading role in autism research. "The potential presented by a collaboration of these outstanding institutions would be greater than the sum of its parts."

A New York State Autism Consortium

The New York State Autism Consortium, under the leadership of the OMRDD's research arm, the Institute for Basic Research in Developmental Disabilities (IBR), will create an autism "brain trust" in New York State, gathering many of the state's finest scientific minds within medical centers, universities, research centers, service providers and foundations to collectively research, treat and address autism and autism related disorders.

The consortium will be the first of its kind, engaging expertise of a wide range in initiatives that will address the most pressing needs surrounding autism today. One groundbreaking component of the consortium will be development of a voluntary registry of individuals with autism. This registry will bring to New York for the first time the opportunity to study incidence of this disability in relation to other factors as well as the response of individuals to education, treatment and services. The registry will also allow the tracking of medical, demographic and neonatal screening data and early childhood screening results.

"The registry would enable New York's policy makers, educators and state and voluntary service providers to understand the magnitude and over time, the

IBR Wins \$1.9 Million Grant From DOD

OMRDD's Institute for Basic Research in Developmental Disabilities (IBR) recently won a \$1.9 million program project grant from the federal Department of Defense Autism Spectrum Disorders Research Program to examine how autism changes the brain throughout a lifetime.

"This grant will allow us to greatly expand research that has recently been started at our facility," stated IBR Director W. Ted Brown, MD, PhD.

The research will establish correlations between structural and biochemical abnormalities in a brain with autism and the clinical symptoms of the disability. The study could help scientists understand the brain abnormalities connected with autism, develop methods for early diagnosis, develop an approach to preventing the progression of developmental changes early on, and possibly reduce the severity of autism symptoms. IBR scientists Jerzy Wegiel, PhD.; W. Ted Brown, MD, PhD.; Abha Chauhan, PhD.; and Thomas Wisniewski, MD, will lead the study by examining the postmortem brains of individuals with and without autism to identify structural and chemical abnormalities. This research may lead to potential treatments of the disease.

nature, of the crisis in autism facing New York families," said Ritter.

The consortium will also develop a professional training program, responding to the increasing need for qualified and carefully trained practitioners to accurately diagnose and treat individuals with ASD. The program will reach practitioners from all disciplines across the state with a curriculum that will include a general track for all professionals, as well as more specialized tracks created specifically for the various disciplines. It will be implemented through individual medical centers, schools, residential schools, developmental centers and community based clinics that will participate as separate training institutes.

Through teleconferencing and videoconferencing, practitioners from all regions of New York and from disciplines ranging from speech therapy to pediatric medicine and psychology will be able to advance their capacity to serve individuals with autism.

The consortium will be poised to compete for funding on a larger scale than is possible by any of its individual members, funding for expanding current research in early identification of at-risk infant siblings of individuals with autism and other populations and to explore the efficacy of

various treatment protocols through the development of laboratory schools providing both state-of-the-art services and education and facilitating intensive observation and applied research. The consortium will also pursue development of an unmatched brain tissue collection that will allow New York State to support the most extensive brain tissue research to date.

Organizations that have already joined the consortium include Columbia University, the University of Rochester, New York University Medical School, Nathan Kline Institute, The Regional Center for Autism, NYS Institute for Basic Research/CUNY College of Staten Island, Wadsworth Center, Psychiatric Institute of New York State, Albert Einstein College of Medicine, the State University at Albany, Mount Sinai Medical Center and the University at Buffalo.

Gov. Patterson believes the state must take a leading role in autism research. He stated, "New York State already boasts some of the finest medical and educational facilities in the world; however each such institution, standing on its own and limited by its own institutional interests, will not best serve the State's autism constituency. The potential presented by a collaboration of these outstanding institutions would be greater than the sum of its parts."

"New York has taken an important step forward today, recognizing that autism is a growing healthcare crisis warranting special attention from the state and its agencies," said Alison Singer, Executive Vice President of Autism Speaks and the mother of a daughter with autism. "The creation of the Autism Consortium under OMRDD and the establishment of the autism platform will encourage more of the state's best scientific minds to collaborate on autism research, and increase the state's focus on delivering key services to individuals with autism and their families."

"We are thrilled to play a key role in the New York State autism consortium," Ritter said. "Creating a New York State research consortium will provide the infrastructure, resources and collaboration necessary to best advance basic and applied research in this critical area, and to best support people with autism and related disorders."

The Interagency Task Force

The Interagency Task Force will bring together leaders across state government to pursue a person-first, coordinated system of wide ranging supports for individuals across the full range of their needs and throughout the different stages of their lives. During the May press conference Rebecca Cort, Deputy Commissioner of VESID for the State Education Department, which will co-chair the task force with OMRDD, acknowledged five key initiatives SED will carry out in the 2008-09 year to promote availability and effectiveness of education programs for stu-

dents with autism. These include identifying useful education programs for autistic students; endorsing evidence based practices for classroom management; encouraging pre-service and in-service training in the area of autism; and funding new short-term assessment and behavioral intervention projects for students with autism and other developmental disabilities who present behavioral challenges.

The Interagency Task Force on Autism will include officials from the Department of Health; State Education Department; Office of Mental Health; Office of Children and Family Services; Council on Children and Families; Commission on Quality of Care and Advocacy for Persons with Disabilities; and the Developmental Disabilities Planning Council.

In addition to establishing the Autism Consortium and the Interagency Task Force, OMRDD's Autism Platform initiates a comprehensive list of system-wide service and practice improvements, many of which will serve a broader range of individuals in the OMRDD system, but which may have particular significance for those with ASD. These include developing best practice models in residential services, standard diagnosis guidelines, positive approaches to behavioral intervention and management, statewide training for first responders, developing models for intensive person centered planning and developing a statewide program for intensive, but short term, assessment, treatment and stabilization for adults with ASD among others. As the Autism Platform generates discussion among OMRDD's many partners – families, service providers, self advocates and practitioners – the agency will seek to respond to the new and emerging needs of those faced with autism and ASD, and the Autism Platform will evolve.

These ambitious goals have been well received among different circles that are connected to autism.

Assemblyman Peter M. Rivera, Chair of the Assembly Standing Committee on Mental Health, echoed Alison Singer's claim of an autism crisis when he stated, "With one in 150 children being diagnosed with Autism Spectrum Disorder there is an immediate need for diligent and focused public policy efforts. We know that early intervention and other treatments hold promise in helping adults and children with autism live better lives. The work of the autism consortium will help bring those treatments into full practice and secure needed answers to why we have such dramatically increasing rates of autism in our communities."

"We are thrilled to play a key role in New York State's autism efforts. As part of our agency-wide commitment to Putting People First and providing person-centered, individualized care, we are dedicated to advancing our understanding of autism and developing state-of-the-art services and supports for individuals throughout the state," said Ritter.

Have an Upcoming Conference or Special Event? Advertise in Autism Spectrum News

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Be Sure Your Special Event is Advertised Well in Advance of Our Release Date Schedule***

Strategic Plan from page 1

to the RFI, the research workshops, and various public meetings have been consolidated into roughly 30 initiatives. While this may seem like a daunting "to do" list, the initiatives have been organized around 6 general questions, questions that are commonly asked by individuals and families when facing the challenges of ASD:

- WHEN should I be concerned?
- HOW can I understand what is happening?
- WHAT caused this to happen and can this be prevented?
- WHICH treatments will help?
- WHERE can I turn for services?
- WHAT does the future hold?

To address each of these questions, the plan will include not only research opportunities, but short and long term objectives with metrics for evaluating progress and proposed budgetary requirements.

Science rarely progresses as expected. Most scientists recognize that some of the many important discoveries have been serendipitous, neither scripted nor planned. Nevertheless, the IACC believes that by beginning with consumer-focused questions and formulating objectives that reflect urgency and are accountable, the strategic plan will help facilitate breakthroughs in autism re-

search. In addition, the IACC is committed to fostering collaboration, partnership, and scientific excellence to accelerate progress.

In addition to the IACC research strategic plan, the National Database for Autism Research (NDAR) will be a critical tool in fostering communication throughout the global ASD research community. NDAR will provide a common platform for research data to be shared among investigators, encouraging synergy, and accelerating research endeavors. Developed in 2007, NDAR will begin accepting data from the NIH Autism Centers of Excellence (ACE) awardees in the summer of 2008. The ACE program awards represent a joint venture between five NIH institutes, supporting 6 centers and 5 networks to coordinate autism research.

The challenges that ASD present to society as a whole, and affected individuals and families specifically, demand a rapid and coordinated response. The vision for the Strategic Plan is that it will, "accelerate and inspire research that will profoundly improve the health and well being of every individual on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement." In addition, the Plan will be a living document, revised annually as new insights emerge or new challenges arise. The IACC looks forward to continued input from many stakeholders so that the Plan will be informed by both the most important needs and the most significant scientific opportunities.

Dr. Hollander from page 26

obsessive-compulsive-related disorders such as body dysmorphic disorder, pathological gambling, and autism. Dr. Hollander has spearheaded affiliation agreements between Mount Sinai School of Medicine and service providers such as the YAI/NIPD Network. He serves as Chair of the DSM-V Research Planning Agenda for Obsessive Compulsive Behavior Spectrum Disorders.

Dr. Hollander has received a Research Scientist Development Award from the National Institute of Mental Health to investigate the psychobiology of obsessive-compulsive and related disorders. He has received orphan drug grants from the Food and Drug Administration to study new treatments for body dysmorphic disorder, child/adolescent autism, and adult autism, and a grant from the National Institute of Drug Abuse for a study on the neurobiology of pathological gambling. He has received several grants from the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke, to develop treatments for borderline personality disorder, adolescent body dysmorphic disorder,

and autism. Dr. Hollander has received two national research awards from the American Psychiatric Association and a Distinguished Investigator Award from the National Alliance for Research in Schizophrenia and Depression.

During his career, Dr. Hollander has published more than 450 scientific reports in the psychiatric field. He has edited 19 books, including *Autism Spectrum Disorder* (2003), the American Psychiatric Publishing Textbook of Anxiety Disorders (2002), and *The Clinical Manual of Impulse Control Disorders* (2006). Dr. Hollander also serves as a reviewer for 8 medical journals.

Dr. Hollander is listed in NY Magazine's "Best Doctors", and "Best Doctors in America". He has made frequent media appearances on the Today Show and Dateline NBC and has had interviews in People Magazine and the New York Times. He is co-author of a book with Marc Summers, *Everything In Its Place: My Trials and Triumphs with Obsessive Compulsive Disorder* (Penguin Putnam, 1999) and co-authored with Nick Bakalar, *Coping with Social Anxiety: The Definitive Guide to Effective Treatment Options* (Henry Holt and Company, 2005).

Adulthood from page 46

planning and acting in incremental steps will help to make the process less stressful. It will also enable you and your child to have time on your side.

Resources for Transition Planning**Print Resources**

Smith, M.D., Belcher, R.G. & Juhrs, P.D. (1995). *A Guide to Successful Employment for Individuals with Autism*. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P., (2001). *Life Beyond the Classroom: Transition Strategies for Young People with Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P. & Kregel, J. (1994). *More Than A Job: Securing Satisfying Careers for People with Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P. & Targett, P.S. (1999), *Vocational Curriculum for Individuals with Special Needs: Transition from School to Adulthood*. Austin, TX: PRO-ED.

Web Sites

U.S. Department of Education, <http://idea.ed.gov>.
IDEA 2004 legislation and regulations.

National Dissemination Center for Children with Disabilities (NICHY), <http://www.nichcy.org>
Central source of information on disabilities, IDEA and effective educational practices.

WrightsLaw, <http://www.wrightsLaw.com>,
A comprehensive website about special education law and advocacy.

Division on Career Development & Transition (DCPT), www.dcdt.org
A wealth of information on how to access career/vocational and transition services for persons with disabilities.

Dimensions from page 39

intrinsically motivating materials and on following the child's lead in language instruction. NET also uses Skinner's Verbal Behavior language classification system/analytical tool to guide language instruction (Skinner, 1957).

Elements of naturalistic instruction include providing an environment in which learners request spontaneously. In addition, naturalistic teaching interactions that facilitate rapport building, and pair the instructor with reinforcement, are also desirable. The following data were collected in 12 samples of 8 children with 10 instructors. Mands occurred an average of 1.4 times per minute, indicating a high level of initiation training. Instructors also delivered an average of 6 non-contingent reinforcing statements in 5 minutes, demonstrating good adherence to pairing (rapport-building) procedures.

Summary

Quality programs for children with autism spectrum disorders are essential to

success. Children with autism who receive non-specialized and ineffective instruction do not make significant gains, and have significantly less positive educational outcomes and achievements. It is imperative that parents understand the hallmark characteristics of quality programs, as educational placement directly affects ultimate outcomes. Programs delivering high quality services operationally define their instructional goals, use empirically verified instructional strategies, and rely on ABA teaching technology to provide both formal and naturalistic instruction. High quality programs also ensure the fidelity of the implementation of these approaches, and collect data to guide the treatment decisions made for each learner.

Mary Jane Weiss, PhD, BCBA, is Clinical Consultant, Cecelia M. McCarton, MD, is the Founder and CEO, Ivy Feldman, PhD, BCBA, is Educational Director, and Jackie Hickey, M.S, BCBA is Associate Educational Director at The McCarton Foundation.

Brain Stimulation from page 23

cortex in ASD patients and healthy controls. We also perform fMRI and compare levels of activation of specific brain areas during passive social tasks. Our hypothesis is that patients with ASD have higher excitability of motor cortex and lower level of activation of mirror neuron system during the social tasks. A single session of rTMS is used to see if activating a specific brain area can produce temporarily improvement in social functioning or repetitive behaviors. This will lay the ground work for developing future treatments in autism.

We also have a treatment trial for repetitive/stereotypic behaviors in autism, sponsored by the Autism Speaks. The concept stemmed from the similar studies in Obsessive-Compulsive Disorder

(Mantovani, Lisanby et al. 2006), where applying low frequency TMS to the supplementary motor cortex significantly reduced repetitive behaviors.

Finally, we are exploring the language symptoms of autism and have introduced an fMRI strategy to study language processing even in very low functioning subjects. Our preliminary data indicate that high functioning ASD subjects use alternate brain connections for language processing, while low-functioning subjects have not established the alternate pathways. We are preparing a treatment trial to specifically increase functioning in a target brain area identified by the fMRI-guided approach.

Utilizing fMRI image-guided targeting of a specific brain area to treat symptoms of ASD is a break-through in autism investigation and treatment development.

**Send Us Your Comments
And Suggestions
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An Indispensable Resource Written by the Experts

Edited by FRED R. VOLKMAR, MD, RHEA PAUL, PhD, AMI KLIN, PhD,
and DONALD J. COHEN, MD, all of The Yale Child Study Center

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Dr. Koplewicz from page 27

of child psychiatric disorders. Founded in 1997, under Dr. Koplewicz's direction the Child Study Center has experienced extraordinary growth and now has over 200 faculty members and staff, an annual operating budget of over \$20 million, and a research grants portfolio in excess of \$40 million.

Dr. Koplewicz has designed the Center so that its research initiatives advance the understanding of the causes and treatments of child psychiatric disorders and these findings are then incorporated into state-of-the-art clinical care. To support this model, the Center is built around a group of research Institutes with associated clinical arms, a structure that allows the Center to expand its patient population, recruit patients for numerous ongoing research studies, and provide "real-world" testing for successful controlled-environment findings. Dr. Koplewicz has recruited some of the nation's leading researchers and scientists, each with stellar reputations and research accomplishments in their areas of expertise.

A graduate of Albert Einstein College of Medicine, Dr. Koplewicz completed his psychiatric residency at New York

Hospital Westchester Division, a fellowship in Child Psychiatry at Columbia University College of Physicians and Surgeons, an NIMH Research Fellowship in Child Psychiatry at the New York State Psychiatric Institute, and the Executive Program in Health Policy and Management at Harvard University School of Public Health.

Dr. Koplewicz is the recipient of many awards, including the 1997 Exemplary Psychiatrist Award from the National Alliance of the Mentally Ill, the 1999 Humanitarian Award from Marymount Manhattan College and the 2000 American Grand Hope Award from the Aprica Childcare Institute. From the American Academy of Child and Adolescent Psychiatry, he received the 2002 Catcher in the Rye Award, the 1998 Reiger Service Award in recognition of his work in the development of school-based mental health programs, and the 2007 Irving Philips Award for Prevention, its highest honor, for his dedication and outstanding achievements in the field of child and adolescent psychiatry.

He has served as a member of the National Board of Medical Examiners and as

a Commissioner of the New York State Commission on Youth, Crime and Violence and Reform of the Juvenile Justice System. Since 1997, Dr. Koplewicz has been the Editor-in-Chief of the Journal of Child and Adolescent Psychopharmacology. He was also a member of the working group organized by the U.S. Assistant Surgeon General and the U.S. Department of Health and Human Services to address the effects of terrorism on children's mental health.

As a clinician and pediatric psychopharmacologist, Dr. Koplewicz evaluates 100 new patients a year from all over the world. Castle Connolly Medical Ltd. has repeatedly named him one of America's Top Doctors, as has New York Magazine, and Good Housekeeping has named him one of "America's Best Mental Health Experts." Viewed as one of the leading authorities in the field, he frequently appears in the media to educate the public about child mental health issues and to help families understand the impact of world events on their children and how best to manage those effects. Radio and television appearances have included NBC Today, National Public Radio, Good Morn-

ing America, LIVE with Regis and Kelly, CBS This Morning, Oprah, The View, CNN American Morning, CNN Weekend Housecalls, NBC Nightly News, ABC World News Tonight and Dateline NBC.

Dr. Koplewicz's research and publications have focused on diagnosis, treatment, and prevention of mental disorders, and he has been at the forefront of public education to dispel the myths and stigma surrounding mental and emotional disorders of children and adults. Author of more than 65 peer-reviewed articles and chapters on child and adolescent psychiatry, Dr. Koplewicz is also the author of several books, including the textbook *Depression in Children and Adolescents* (Hardwood, 1993); *It's Nobody's Fault: New Hope and Help for Difficult Children and their Parents* (Times Books/Random House, 1996), which received the Parent's Choice Award and was a "Books for a Better Life" finalist; *Childhood Revealed: Art Expressing Pain, Discovery & Hope* (Harry Abrams, Inc., 1999); and his most recent work on adolescent depression, *More Than Moody: Recognizing and Treating Adolescent Depression* (Putnam, 2002).

Our Next Deadline Date is September 15th - Mark Your Calendar
Our Theme: "Understanding and Treating Autism Spectrum Disorders"
See Page 3 For Our Annual Calendar

IMFAR Conference from page 7

“CHAMACOS” which follows mothers in California who have received high levels of pesticide exposure. She assessed exposure through biological measures and self reports, and followed children from birth through development and examined the presence of PDD through assessment on the child behavioral checklist. Her results indicated that almost 6% of these children went on to develop symptoms of PDD, and that in many of these children, a genetic mutation may account for susceptibility to pesticides. This gene, abbreviated PON, is responsible for detoxification of pesticides. Other research has studied the PON gene and found an association in families affected with autism, and the early finding by the Eskenazi group will be replicated and explored further.

In contrast to Dr. Eskenazi's use of direct data collection on individual subjects, Dr. Roberts presented his data published earlier this year in *Environmental Health Sciences* that examined the rate of autism and pesticide exposure using purely administrative data, which is available almost exclusively in the U.S. through the California DDS system and geographic information systems. Although this data provides a unique opportunity to examine different exposures and their developmental outcomes, Dr. Roberts also carefully outlined the weaknesses and limitations of this design. He found that linking exposure of pesticides through agricultural applications with birth record data supported a link between organochlorine exposure in the first trimester of pregnancy. A number of confounding factors make this an interesting study which needs to be replicated further, especially since the number of affected children in the highest exposure group was relatively low. However, the pairing of these final two presentations, each using different approaches to examine the same question, illustrated the absolute requirement for multiple parallel approaches to studying gene x environment interactions in autism.

“Several groups are exploring the interaction between a genetic susceptibility and environmental factors. Understanding how subgroups of children may be vulnerable to specific environmental risk factors is critical for discovering the causes of autism and for developing prevention methods,” said Geraldine Dawson, Ph.D., Chief Science Officer, Autism Speaks.

Genetics: This year's IMFAR meeting highlighted both the complexity of the disorder and the international nature of genetic research. Using Autism Speaks' AGRE samples, researchers from Japan presented the first results to suggest an autism association with a new set of genes, called ROBO, involved in neurodevelopment. From the other end of the globe, a group of researchers at the Icelandic genomic company deCode, Inc. showed an association of copy number variations in specific chromosomal regions, validating recent findings in previous large scale genetic studies such as the Autism Genome Project. “Because of the complexity of autism, independent confirmation of previous results is one of the most important outcomes of such large international conferences,” explained Geraldine Dawson, Ph.D. Autism Speaks Chief Science Officer.

Many of the genetic presentations at this year's IMFAR actually took advantage of the variable nature of autism, utilizing either the similarities or differences in individuals with autism as a way to identify genes involved in the disorder. For example, a collaborative group of researchers from Vanderbilt University and Massachusetts General Hospital for Children showed an increased association between the gene MET and subjects with autism who also presented with co-occurring gastrointestinal symptoms. Valerie Hu, Ph.D. from George Washington University displayed a very novel approach to reducing the heterogeneity of autism by first using exploratory statistical techniques on diagnostic ADI-R data from AGRE subjects that allowed her to identify four different “types” of individuals with autism that grouped naturally together based on their symptoms. She then measured gene expression profiles of individuals from each classification, finding clear genetic differences between each of the four autism groups and controls. “Through careful consideration of specific autism phenotypes, researchers are making significant strides in identifying genetic risk factors in autism,” said Andy Shih, Ph.D., VP of Scientific Affairs for Autism Speaks. “These genetic risk factors will lead to knowledge of the biological pathways that have been impacted in autism.”

Multiple causes: The conference also included a talk by Francesca Happe, Ph.D. who argued that, except in rare cases, it is unlikely that the full syndrome of autism can result from a single cause. She based her argument on twin studies that suggest that largely nonoverlapping genes acting on each of the separate traits of autism (social impairments, language impairments, repetitive behaviors). She noted that many individuals can exhibit one of these traits in isolation. In fact, one important implication of her argument is that many people who may have isolated impairments in one domain, such as social functioning, may not receive the clinical services they need. John Constantino, Ph.D. presented a related perspective. He noted that, when autism runs in families (familial autism), it is common (significantly more so than in the general population) for clinically-unaffected male family members to exhibit features of autism, but not the full autism syndrome. This may not be true for females or for non-familial autism. This is important because it suggests that parents who have one child with autism should be vigilant for mild impairments in a second child. Dr. Constantino also showed how quantitative characterization of the autism symptoms can aid in the search for core genetic and neurobiologic components of autistic syndromes.

International Autism Epidemiology Network (IAEN): One important technique often used to parse genetic and environmental risk factors is epidemiology. Since its inception in 2004, the International Autism Epidemiology Network (IAEN) has developed into a unique and expansive partnership of investigators representing nearly 30 countries and specializing in various areas of autism research and treatment. With the support of Autism Speaks and the Centers for Disease Control and Prevention, the network

has provided a forum for international research collaboration in autism epidemiology, aimed to better our understanding of autism etiology and natural history across the globe. Approximately 70 epidemiologists and clinicians convened the fourth annual IAEN meeting at IMFAR.

As one of the results of this meeting, many of the representatives from countries that maintain large, population-based health registries joined together to form a workgroup to develop a multi-national database that will allow for ambitious, previously unfeasible research projects. Initial studies stemming from this project will look at associations between autism and pre- and peri-natal exposure to potential environmental risk factors. Another focus of the meeting was to outline the challenges and propose solutions to standardizing epidemiologic methodology prior to initiating the studies. Overall, the presentations of autism epidemiology studies in the developing world fueled the discussion of approaches to characterizing and diagnosing autism across culturally diverse settings and measuring the prevalence of disorder in these territories thereby improving much needed resources.

Biology

For those studying the biology of autism, the meeting offered symposia and workshops on topics ranging from brain imaging to animal models to immunology. One of the primary biological hypotheses of autism highlighted by several at the meeting was the concept that autism may be the result of “synaptic” dysfunction. Synapses are the parts of nerve cells that are responsible for transferring information from cell to cell. Keynote presenter Thomas Bourgeron, Ph.D. discussed discoveries from his and other laboratories that have implicated mutations in several “synapse” genes in autism. Such genes include SHANK3, neurexin, and neurexin, all of which encode for proteins that work together to make synapses properly operate.

Such results not only help direct geneticists toward studying other “synapse” genes as potential autism risk factors but, most importantly, they are beginning to shed light on the underlying biological features of autism. The concept of altered synapse functioning is consistent with the “functional underconnectivity” theory of autism, which hypothesizes that nerve cells are not connected together as normal and that the net result is difficulty in passing information between parts of the brain, leading to the unusual behaviors collectively called autism. Several groups presented data expanding upon the evidence for functional connectivity deficits in autism by using EEG to read electric signals between brain regions, finding them to be altered. Additionally, preliminary data from some of the first studies to use the newest brain imaging technology, Diffusion Tensor Imaging, revealed structural irregularities in the white matter, the part of the brain that ferries the electrical signals from one region of the brain to another. This is again suggestive of connectivity problems in the brains of individuals with autism.

Immunology: Another major step forward this year was that IMFAR hosted its

first symposium examining the relationship between autism and the immune system. Lisa Croen, Ph.D., a researcher with Kaiser Permanente, reported that some autoimmune diseases such as food allergies and rhinitis are co-morbid conditions in autism, and Paul Patterson, Ph.D., professor of biology at the California Institute of Technology, demonstrated that maternal infection, which results in the elevation of cytokines in the fetal environment, may be a risk factor for developmental disorders. The activation of neuroglia in the brain of autistic patients was discussed by Carlos Pardo, M.D. (Johns Hopkins University), pointing to a role for the innate immune response, though this role is still undefined and requires additional investigation. William Johnson, M.D. (UMDNJ) presented preliminary research which found that certain MHC class II molecules may be risk factors, but which interestingly appear to act on the mother rather than the child with autism. Other data discussed at this exciting symposium involved studies on the adaptive immune response, and how the results of such studies have been variable. The symposium presenters concluded that the full range of immune functions in individuals with autism is one area that absolutely requires further exploration to determine any contributions to the condition.

Neuropathology: Christoph Schmitz, M.D. at Maastricht University in the Netherlands and Jerzy Wegiel, Ph.D. at the NY Institute for Basic Research presented the first results of a multiyear neuropathology study termed the Brain Atlas Project. Autism Speaks' Autism Tissue Program (ATP) began the Brain Atlas Program in 2002 with the objective of deciphering the neuropathological features of autism in multiple brain areas in order to provide us with important missing information about how autism impacts brain structure. Initial results reported by the investigators revealed substantial brain cell size differences according to the age of the donor. The youngest brain donors with autism (age 4-7) had smaller neurons by up to 43% in certain brain regions compared to older donors with and without autism. The investigators also reported preliminary findings on the fusiform gyrus, the site of face processing in the brain, which imaging studies have shown to be less active in individuals with autism than control subjects. So far using 7 postmortem brains from patients with autism and 10 controls, they have found significant reductions in neuron densities that in theory could anatomically account for the abnormal function found in this brain area.

The Brain Atlas Project will continue through 2009 until all regions of 28 donor brain hemispheres have been analyzed. The ATP Tissue Advisory Board members attending the meeting urged the autism community to support brain donation to further the exploration of brain development. Family members and unaffected individuals are encouraged to register to be brain donors as well and can get more information at www.autismtissueprogram.org. An important step in this direction was the launch of the UK brain donation program to complement the one in the U.S. “Research is finally coalescing to provide testable

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hypotheses that can bring us to a biological understanding of autism," concluded Sophia Colamarino, Ph.D., VP of Research for Autism Speaks.

Diagnosis

Baby Siblings Research Consortium: Several investigators studying infant siblings of children with autism met prior to IMFAR to discuss their findings on early identification and new methods for treating at risk infants. Mark Johnson, Ph.D., Mayada Elsabbagh, Ph.D., and Geraldine Dawson, Ph.D. led a workshop titled "From Neuroscience to Intervention: Progress in the study of infants at-risk for autism." Scientists discussed new approaches to detecting the first signs of autism in infants using eye-tracking methods, structural and chemical brain imaging and electrophysiology. It was noted that infant sibs who go on to develop autism are more likely to exhibit acceleration in head growth starting at about 4-6 months. Infants with this unusual head growth trajectory often exhibit behavioral symptoms emerging at about 8-10 months, which include a failure to respond to name, distress reactions, passivity, a lack of eye contact and communicative babbling, and poor imitation skills.

The workshop also focused on new approaches to early intervention with infants and toddlers who exhibited emerging signs of autism. Although several different approaches were highlighted, most of these interventions shared certain common features. Most were parent-delivered and focused on facilitating early social-communicative skills within an affectively-rich parent-infant interaction. The hope is that by identifying infants at risk and providing early intervention before the onset of the full syndrome, autism symptoms can be reduced or even prevented.

During IMFAR eleven sites from the Baby Siblings Research Consortium (BSRC) reported their findings. They compared head growth in 761 high-risk infants (each with an older sibling with a confirmed diagnosis of ASD) and 400 low-risk infants (no family history of ASD). Preliminary analyses indicate that high risk infants who are subsequently diagnosed with ASD show more rapid growth in head circumference in the first 2 years of life than non-diagnosed high-risk and low-risk infants, although the absolute differences are small. Further analyses will help determine whether subgroups of high-risk infants exhibit more pronounced head growth early in life, and the potential utility of this finding for early detection.

In addition to collaborative projects, members of the BSRC each presented preliminary data on siblings from age 3-9 months of age. Researchers are using sophisticated analysis of eye tracking data and analysis of specific neurophysiological measures to interpret very early changes in attention, including shifting of attention and joint attention. In fact, a few researchers referred to the effect as "sticky" attention, as they discovered there are subtle differences in the duration of the gazes away from the mother's face in a scene. Some of the differences are seen in children "at risk" for autism, regardless of diagnosis, and further research will better determine if these early signs

may be indicative of ASD or part of a genetic liability.

Motor reflexes: Many parents have questioned whether, in hindsight, unusual motor activity may have been one of the earliest indications of their child's disability. A group led by Carole Samango-Sprouse, Ed.D. from George Washington University is exploring whether early motor tone, as measured through a standard test of primitive motor reflex known as the head tilt reflex (HTR), can be used to accurately identify infants with neurodevelopmental disorders when coupled with the accelerated head growth already described. Their goal is to increase the likelihood that doctors can easily spot infants at-risk for an ASD or other neurodevelopmental disorders during well-baby medical checkups.

The HTR is an extraordinarily simple exam designed to test the reflex normally developed at 9 months of age which maintain one's head vertical when tilted off midline. The researchers tracked infants that failed to develop the HTR and who underwent unusual acceleration in head growth during the first year of life. Out of 216 babies screened, 21 infants were flagged for "at risk" status due to these two criteria and were given full neurodevelopmental evaluations. In none of these cases did the parents or pediatricians have any previous suspicions. Their preliminary data suggests that the combination of increased head circumference and HTR may be an indicator of possibly both ASD and developmental language disorders. Given the nature of the test (quick, easy, a very early indicator, and at no extra cost to the doctors or parents), the investigators are continuing to pursue whether the "tilt test" and acceleration in head circumference may provide early "biomarkers" for a subgroup of infants at risk for developing autism or other neurodevelopmental disorders.

Interactive Autism Network (IAN): Other current research for assessing the special needs and interests of children with autism, and parental experiences raising a child with autism, utilizes the internet and web-based methods. The Interactive Autism Network (IAN; www.IANproject.org), developed by a team at Kennedy Krieger and funded by Autism Speaks, is collecting information online from families of children with ASDs throughout the U.S. The team illustrated the breadth and depth of their data by presenting on a variety of key autism research topics, each based on information by IAN families. Through this, autism researchers learned about resources IAN can provide to facilitate their crucial work. These free resources include access to the IAN dataset (currently containing information shared by families of over 8,000 children with an ASD); the launch of a new online community and workspace for autism researchers; and assistance finding qualified participants for researchers' local studies. With the exception of subject recruitment, which is offered only to U.S. researchers, these services are available to autism researchers throughout the world. Many international researchers at IMFAR learned about IAN for the first time and expressed an eagerness to access IAN data for their own research.

Treatment

Not long ago, autism was thought not to be treatable. Many parents were told there was very little that could be done to change the course or outcome for their child diagnosed with an ASD. Fortunately, this is no longer the case as evidenced by numerous presentations given in the area of treatment and intervention.

Treatments for autism generally fall into two categories, biomedical and behavioral, and can vary by country. Some of the biomedical treatments discussed at this year's IMFAR included pharmacological, complementary and alternative medicine, and dietary interventions. Behavioral studies covered such diverse topics as theory of mind training, vocal imitation training, sleep hygiene education, pivotal response and discrete teaching methodologies, and social skills training. One discussion presented a retrospective analysis of cases in which children with autism achieved recovery status (lost their original diagnosis of autism). With new groups forming to address the medical aspects of autism (such as the Autism Speaks Autism Treatment Network and Clinical Trials Networks), it is anticipated that more research will become available targeting specific symptoms associated with autism.

Family Services: As the population of adolescents and adults with autism is rapidly growing, more researchers are beginning to explore issues that affect older people with autism including puberty, sexuality, substance abuse and social relationships. Researchers from North Shore Long Island Jewish Hospital discussed their employment of visual supports, role play, cartoons, social stories, and video modeling in weekly group sessions. Issues regarding sexuality, development, hygiene, safety and dating behavior were addressed in groups of adolescents with autism, as well as in groups of parents, resulting in improved comfort for the participants in discussing these sensitive topics and achievement of personal goals such as learning to set boundaries. Research is ongoing in terms of further curriculum development and evaluation.

Several researchers also addressed educational issues such as teacher training and integrating students with autism into a general education environment. Expanding the quality of evidence-based research in service delivery is a critical need and several researchers presented their initial findings on the efficacy of specific community-based service programs. Some researchers are now studying ways in which families access services and the strategies they use to get them. Another theme among the service research presentations included evaluations of autism resources including materials for parents of newly diagnosed children and comprehensive treatment programs. Researchers explored the use of technology-related products to aid in the delivery of services.

Technology: One exciting theme that received increased attention this year was the many ways technology can be used to provide novel forms of assessment and intervention. Researchers from the U.S., U.K., Germany, Greece, and Israel presented findings on many new technology-related innovations. Highlights included a diverse set of computer software applica-

tions created to assist those impacted by autism. These ranged from interactive visual scheduling systems to a variety of video games that were developed for assessing and enhancing cognitive strengths and weaknesses, improving face processing and emotion recognition, and assessing and teaching language. Personal digital assistant (PDA) technology was explored in teens with autism to teach flexibility, feelings and sensory states. Other presenters showed detailed virtual reality platforms specially developed to study how children with autism respond to increasingly more complex visual environments, with hopes that such carefully regulated environments may ultimately be used to understand and reduce sensory overload. New research is also beginning to focus on how robotic therapists and 3D virtual peers can be used to teach affective language intonation and make social communication more motivating for this population. These burgeoning and innovative uses of technology carry great promise for accelerating and enhancing the pace of autism research and treatment in the years to come.

Progress and Themes

The most often repeated theme to this year's IMFAR meeting was the incredible amount of recent progress the field of autism has made. This sentiment was echoed perhaps most eloquently by the recipient of the 2008 Autism Lifetime Achievement award, Isabel Rapin, Ph.D., a pioneer of autism research whose career has extended almost the entire history of autism. Dr. Rapin was praised by her colleagues for her several lifetimes worth of achievements for autism. In her acceptance speech, Dr. Rapin reflected upon the 60 years since autism was first clinically described and provided commentary about how our understanding of autism has changed and grown during her career. From the initial psychological theories, to the advent of genetic research, through the explosion of information about brain function from imaging studies, she credited most of the advances in our understanding of autism to the rise of the many unforeseen technological advances exhibited at the meeting.

As a fitting close to an extraordinary week for autism, Autism Speaks UK organized a reception for researchers, parents, and legislatures at the House of Commons, hosted by Janet Dean, MP, chair of the All-Party Parliamentary Group on Autism. Autism Speaks U.S. was represented at this special event by Mark Roithmayr, President; Glenn Tringali, Executive Vice President of Fundraising and Development; Sophia Colamarino, Vice President of Research, and Dana Marnane, National Director of Communications and Marketing. Autism Speaks UK Chief Executive Hilary Gilfooy addressed the group highlighting the great strides being made in research around the world and in the UK, including the breakthroughs achieved by the Baby Siblings Research Consortium and the Autism Genome Project. Gilfooy's overall message to the crowd was one of hope. "Only two years ago, the honest answer to the question 'What causes autism?' was 'We don't know,'" said Gilfooy. "Now we can say that we have explorable hypotheses and

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interventions to respond to the first signs of autism.”

“Having a forum where scientists, clinicians, and parents from around the world can congregate and share findings and perspectives has really helped move the field forward,” remarked Geraldine Dawson, Ph.D., Chief Science Officer, Autism Speaks. “There is an openness to exploring many different possible causes of autism, including both genetic and environmental factors, and an increasing emphasis on new treatments. People from around the world are joining together to accelerate the field of autism research. It was wonderful to be a part of it.”

To read individual abstracts, please visit <http://imfar.confex.com/imfar/2008/webprogram/start.html>. Data presented at the annual International Meeting for Autism Research (IMFAR) is the sole

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of corrective feedback, there should be three to five instances of praise.

Also, look to see if staff and students are generally happy, but keep in mind, children with autism are not happy all of the time. Are both sets of people smiling? Do the activities seem fun and exciting? Are the students allowed to make choices throughout each activity during the school day? Research has shown that the use of preferred items during instruction and giving students the opportunity to make choices leads to higher rates of learning and fewer behavioral issues.

Staff-to-staff communication and opportunities for family involvement, both in their own child's program planning as well as at the school planning level, should also be explored. What mechanisms exist to allow staff to plan and develop activities, discuss specific child and classroom issues, and meet with families, clinicians, related service personnel and administrative staff? Are there formal mechanisms to solicit parent input and feedback about school components and future development?

Parents should also clarify the school's policy regarding observation procedures and policies of students before enrolling

their child.

Finally, does the school help families to learn how to use interventions in the home setting? Most schools, will at minimum, offer seminars and trainings that are open to families. However, not all programs will invite parents into the classroom to practice techniques with staff or be open to coming out to a student's home to show parents how to implement interventions in that setting. In the end, good schools will recognize that learning doesn't end at 3:00 p.m., and that continuity across school and home will greatly benefit each child.

As parents face a variety of difficult issues with their child with autism, finding an appropriate school program will enhance the quality of life for the student, as well as their families. The process of finding the best program for the child may not be easy, but it is well worth the effort. Our School Program Evaluation Form is designed to facilitate this process.

For more information, please contact the authors at Devereux CARES (610-873-4930). CARES is an approved private school located in Downingtown, PA. It serves students with autism ranging in age from 5 to 21, using applied behavior analysis instructional techniques and natural environment teaching.

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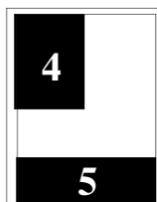
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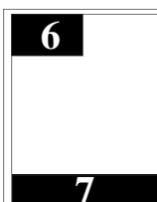
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