

AUTISM SPECTRUM NEWS™

YOUR TRUSTED SOURCE OF INFORMATION, EDUCATION, ADVOCACY, AND RESOURCES

SPRING 2009

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 1 NO. 3

Helping Parents and Family Members Cope with ASDs

Stress, Support, and Coping in Families of Children with Autism

By Cecelia McCarton, MD, and
Mary Jane Weiss, PhD
The McCarton Foundation

When a child is diagnosed with an Autism Spectrum Disorder, there are effects on each family member. The challenges are significant, and families cope very differently with the challenges. While many families report experiencing significant stress, many also report being strengthened by the experience. Understanding the unique stressors associated with having a child with autism is important to serving the needs of these families effectively. In addition, identifying variables associated with successful coping is crucial to maximizing the adaptation of families.

The nature of autism itself presents serious coping challenges. It is well-known that it is more difficult to cope with stressors that are long-term, intense, and ambiguous. Clearly, the chronicity and intensity of autism are significant. Furthermore, the variability in symptoms and course create a highly ambiguous situation, especially in the toddler and preschool years. Addition-



ally, it is harder to manage in circumstances that are significantly different from the experiences of those you know. The stressors and worries of parents with children with autism are quite discrepant from those that their friends and family members experience, and that can create a feeling of isolation.

Specific Effects

The effects on the family of having a child with autism can be wide-ranging. Mothers report the greatest levels of distress (e.g., Bristol, 1984). In particular, they experience more sadness, depression, and worry about the future compared to

fathers, and they seem acutely aware of the extent to which their family's experiences are discrepant from the experiences of other families they know (e.g., Marsh, 1993). This can lead to feelings of isolation (e.g., Seligman & Darling, 1997). The pain experienced by fathers is not as well-studied as that of mothers. However, while it may not be as clearly communicated as that of mothers, it is also significant. It often centers on worries about the future and about the child's acceptance in the community (Moes, Koegel, Schreibman, & Loos, 1992; Rodrigue, Morgan, & Geffken, 1992). The impact on marriages is variable, with some families reporting tremendous strain and some reporting strengthening.

Social Support

It is interesting to speculate about what variables might protect families from the negative effects of stress. Social support seems to be crucial. In particular, the extent to which people perceive social support as available seems to be critically important (e.g., Weiss, 2002; Wolf, Noh, Fisman, & Speechly, 1989). In other

see Coping in Families on page 36

Rice University Study Finds Possible Clues to Epilepsy and Autism

Staff Writer
Autism Spectrum News

Rice University researchers have found a potential clue to the roots of epilepsy, autism, schizophrenia and other neurological disorders.

While studying the peripheral nerves of the *Drosophila*, aka the fruit fly, Rice doctoral student Eric Howlett discovered an unanticipated connection between glutamate – an amino acid and neurotransmitter in much of the food we eat – and phosphoinositide 3-kinase (PI3K), an enzyme that, Howlett found, regulates the activity of neurons.

Howlett and his colleagues, graduate

student Curtis Chun-Jen Lin, research technician William Lavery and Michael Stern, a professor of biochemistry and cell biology, discovered that negative feedback mediated by PI3K regulates the excitability of neurons, an issue in a number of ailments that include neurofibromatosis, and that a mutation in a glutamate receptor gene common to both the fruit fly and humans has the ability to disrupt that regulatory mechanism.

Howlett found the *Drosophila*'s metabotropic glutamate receptor (*DmGluRA*) gene, when mutated, increased the excitability of the neuron by preventing PI3K from doing its job.

Published online by the Public Library of Science Genetics, the study is the culmination of four years of work that built

upon research by Marie-Laure Parmentier and her team at the University of Montpellier, France, to connect glutamate to regulatory functions in the fruit fly.

"As science often goes, we didn't set out with this hypothesis," said Howlett, who began the project on funding obtained by Stern from the Department of Defense to study neurofibromatosis. "This all came about as a control for a completely different experiment, and we said, 'Wow, this is some interesting stuff.'"

What he saw was that the overexpression of PI3K in motor neurons had a dramatic effect. "I noticed under the scope that these nerves were really big, and electrophysiologically, they were really slow. That wasn't what I expected, and it set me on a path of trying to find out what was going on."

Howlett's breakthrough was identifying the negative feedback loop that acts to maintain neuronal excitability at normal levels. "What we found was that glutamate, which is released due to neuronal activity, feeds back onto metabotropic glutamate receptors on the same neurons that released it in the first place. This leads to the activation of PI3K and ultimately to the dampening of the amount of glutamate that is released." Without that regulation, he said, things inside the cell can go terribly wrong.

"He put his heart and soul into this," said Stern of Howlett's exploration of the neuronal chain. "He was working on PI3K because that has a key role in

see Rice Study on page 37

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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

Winter 2009 Issue:

"Understanding the Assessment Process: What Parents Should Know"

Deadline: September 15, 2009

Spring 2010 Issue:

"New Frontiers in Autism Science: What Families Can Learn"

Deadline: December 15, 2009

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From The Publisher

Committed to Providing Evidence-Based Information

“Autism Spectrum News has filled a troubling void in the autism community.”

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

As this is now the third quarterly issue of *Autism Spectrum News*, we continue to receive positive feedback from our readers praising our efforts in providing evidence-based and scientific education and information. What makes this publication stand alone in the sea of other resources is our devotion to providing strictly science-based content. One leader in the autism community let us know that we are headed in the right direction:

“Autism Spectrum News has filled a troubling void in the autism community. Before Autism Spectrum News’ premier, there wasn’t a publication that was specifically devoted to evidence-based treatments and rigorously devoted to science and proven treatments. The autism community has been very confused and inundated with misinformation – and Autism Spectrum News really stands out because it is committed to science including the evidence-based organizations and advertising it only promotes.”

In this issue of *Autism Spectrum News*, we have put together a broad view of many issues devoted to helping parents and family members cope with autism spectrum disorders (ASD).

We lead off with an article from the McCarton Foundation that addresses the effects on the family of having a child on the spectrum. Dr. McCarton and Dr. Weiss bring a positive message to families, saying that “there can be plenty of joy in a family that includes a child with autism, with many families reporting that such joy outweighs the challenges.” They tackle the often overlooked effects of autism on brothers and sisters of the child with autism and found many siblings feeling that “their experiences as a sibling of a child with autism taught them a patience and tolerance they might not otherwise have learned.”

Our other cover story from Rice University brings some exciting results of a recent study of the *Drosophila* fruit fly that reveals potential clues to the roots of epilepsy, autism, schizophrenia and other neurological disorders. Astonishingly, during the final days of the presidential race, a misinformed Vice Presidential Candidate Sarah Palin stated that “fruit fly research has nothing to do with the public good.” Fortunately, scientists and research facilities such as those at Rice University painstakingly study the *Drosophila* fruit fly to unlock the mysteries of autism, in the development of neurogenetics and neurobiology.

In our NewsDesk section on page seven, we take a look at Westchester County, New York’s new Project Lifesaver program, designed to help find children and adults with autism and other developmental dis-



Ira H. Minot, LMSW

abilities with a history of wandering off from their caregivers. Families will be able to purchase “bracelets” for their child so that they can be located by specially trained County Police Officers using the transmitter located in the bracelet.

You will find some very helpful information on page eight from Dr. Fred Volkmar, Director of the Yale Child Study Center. Dr. Volkmar answers many common family questions such as, “My child doesn’t sleep well at night. How can I get him on a better sleep routine?” and “How can you help my child at school?”

In this issue we premier a new column “Law and the Autism Community,” by Douglas K. Stern, Esq., a leading attorney in the field of mental health and developmental disabilities law. On page nine Mr. Stern discusses the important issue of how authorities interact and respond to individuals with autism spectrum disorders. He provides a brief look at first responders, prosecutors and other administrative authorities that interact with individuals with autism spectrum disorders. He writes about the need for more community education about ASDs, a change in people’s attitudes in relation to theories of justice, responsibility and punishment, and removing the stigma attached to living with a disorder on the Autism Spectrum.

In keeping with our theme of helping parents and family members cope with ASDs, it is widely known that early identification is essential for quick intervention and the study of the underlying causes of autism. On page 13, Dr. Charles Cartwright, MD, Director of the YAI Autism Center, and Dr. Amerha Rafiq, MD, Pediatrician of YAI’s Premier HealthCare, promote the importance of developmental surveillance at each pediatric visit throughout early childhood. The rigorous measuring and tracking of children’s head circumferences and the administering of autism-specific screening tools will help to identify many children at risk for autism.

You must read Marianne Clancy’s heartfelt story of a mother’s journey coping with autism, on page 19. She provides many helpful resources for parents to find much needed support, including family and friends, professionals and educators, and even strangers who reach out to give a helping hand. She provides a truly sincere message to families when she writes, “our children with autism enable in us the chance to see what people are capable of. It’s in looking for the goodness in ourselves, in our children and in all people, and it’s through appreciating the efforts that we all make that we find our own strength. That’s how we come to cope.”

Dr. Shana Nichols writes on page 23 of the need to develop a much better understanding of girls with ASDs and how to best support parents and their daughters. Author of the new book, “Girls Growing Up on the Autism Spectrum,” Nichols provides insight on what professionals and educators can do to support clients and families of girls with ASDs.

Every parent of a child with an Autism Spectrum Disorder knows how daunting school IEP meetings can be. The Asperger Syndrome and High Functioning Autism Association (AHA) provides useful and important information on page 25 that will help to make your meeting more productive and will help you to better achieve your main goals for your child. Tips such as preparing an agenda with columns that you can check off during the meeting and requesting a rough draft of the proposed IEP in advance will help to alleviate some of the anxiety and stress that come with these meetings. This article will help you ensure that your child receives an appropriate public education that meets the unique needs of your child and prepares the child for further education, employment and independent living.

In keeping with our tradition of having articles from both practitioners and parents, please take a look at “Coping with Asperger’s at Home” by Betsey Ern on page 27. Her advice for coping is to “do something fun every day.” Her son, now 22, is returning home from four years away at college, and now she is getting ready for the adventure of living once again with Asperger’s at home.

An important aspect to coping with an ASD is finding a good doctor. On page 30, Mary Meyer, Chapter Coordinator of the Asperger Syndrome Education Network (ASPEN), provides a roadmap to finding and keeping an excellent doctor. She writes that it is important to change the emphasis from simply finding a “good doctor” to developing a positive doctor-patient working relationship. She was inspired to write this article after attending a lecture given by Dr. Peter Della Bella, MD, at the AHA Association 2008 Spring Conference at Adelphi University. The title of his talk was “How to Make Your Physician Work for You.”

In our next installment of *Robin’s Blog* on page 31, Robin Morris writes of the triumphs and struggles of her quadruplets,

one with Autism, coming home after a year at college. Her second piece describes her heartfelt tradition of writing letters to each of her children on their joint birthday highlighting their successes and powerful journey.

Take a moment to read our interesting article on training your child to use public transportation on their own. On page 32, Dr. Ernst O. VanBergeijk, PhD, MSW, Executive Director & Associate Dean of the New York Institute of Technology Vocational Independence Program, explains that the “mastery of travel training skills not only increases a person on the autism spectrum’s confidence and employability, but it also reduces the burden on the family of always having to drive or escort the person.”

In addition to the articles mentioned here, there are many other wonderful articles written by parents and experts in the field of autism that will inform and inspire you. We hope you take the time to read through the newspaper to discover for yourself the helpful and educational articles and resources we have put together for you in this issue of *Autism Spectrum News*.

Let me conclude by telling you about our exciting roundup of topics in the quarterly calendar of *Autism Spectrum News*. In our upcoming summer issue, our theme will be “Education for Children & Adults with Autism Spectrum Disorders.” Our deadline for articles and advertising for this important issue is March 15th.

Our calendar continues with our fall issue which will focus on “Addressing the Needs of Adults on The Spectrum.” Next winter we will take a look at “Understanding the Assessment Process: What Parents Should Know,” and next spring our theme will be “New Frontiers in Autism Science: What Families Can Learn.”

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community. As a nonprofit organization, we ship thousands of free copies of each issue of *Autism Spectrum News* to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website: www.mhnews-autism.org. On our site you can subscribe to receive your own personal hardcopy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients or staff.

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

*You Are Not Alone
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Have a Wonderful Spring Season.

AUTISM SPECTRUM NEWS DESK

Autism Speaks Announces Recipients of Family Services Community Grants

More Than \$380,000 Awarded to 21 Community Organizations Across the Country

Staff Writer
Autism Spectrum News

On Thursday, December 18 Autism Speaks, the nation's largest autism advocacy organization, announced that its board of directors approved more than \$380,000 in funding for twenty-one Family Services Community Grants, for a total of over \$1.4 million in such grants to date. These grants will help community organizations across the country expand existing programs to serve more individuals with autism, and create new programs that demonstrate true innovation in providing services to improve and enrich the lives of individuals with autism spectrum disorders (ASD). A list of all grant recipients can be found at www.autismspeaks.org.

"Service providers across the country are doing truly remarkable and innovative work to enhance the quality of life for those living with autism," said Peter Bell, Autism Speaks Executive Vice President of Programs and Services. "We are delighted to support their efforts and encourage others to replicate these model programs."

In July, Autism Speaks invited autism



service providers to submit grant applications that addressed one of the following areas of need: Education, Recreation/Community Activities, Equipment/Supportive Technology or Young Adult/Adult Services. Autism Speaks received 238 applications from organizations in 41 states and Canada.

The funding for the twenty-one grants falls into the following categories: Recreation/Community Activities -- nine grants totaling \$161,340; Education -- six grants totaling \$113,224; Young Adult/Adult Services -- five grants totaling \$88,740; and Equipment/Supportive

Technology -- one grant totaling \$16,849. Geographically, the grants will support eight programs in the Northeast, five programs in the Southeast, four programs in the Western region of the country, and four programs in the Midwest.

The Recreation/Community Activities proposals provide individuals with ASD with a variety of opportunities to develop recreational interests in supportive and inclusive environments. Many of the proposals utilize volunteers to work with individuals with ASD, further expanding awareness and acceptance. For example, one proposal in the Northeast focuses on a volunteer recreational running partner program. Another proposal in the Midwest will fund an after school social skills group that utilizes typically developing peers to foster support and friendship both in the school environment and through community-based activities.

In the area of Education, there continues to be a great deal of collaboration between trainers, educators and families to address the needs of people with ASD. Consistent across the proposals funded in this area is hands-on training, multiple

see Community Grants on page 27

Westchester ARC Executive Director Richard Swierat Receives National Top Honor

Staff Writer
Autism Spectrum News

The National Conference of Executives (NCE) of the Arc of the United States has bestowed its highest honor—the 2008 Executive Excellence Award—to Westchester Arc Executive Director Ric Swierat. The national award, to be presented at the November 5 NCE Awards Dinner in Albuquerque, New Mexico, is given to an individual whose career exemplifies the fulfillment of the mission, core values and position statements of The Arc: To advocate for the rights and full participation of all children and adults with intellectual and developmental disabilities.

The award runs parallel to another milestone for Ric—his 25th year as Westchester Arc executive director. From his first day at the helm, Ric demonstrated a commitment to the agency's longstanding tradition of empowering individuals with developmental disabilities to achieve their hopes and dreams and stressed that agency programs should be "person-first." Through the years, his innovative leadership has redefined the way in which services are provided to people with devel-



Richard P. Swierat

opmental disabilities. Ric has long advocated for their right to live, work and socialize in the community. In recent years, he has taken an active role in the state self-advocacy movement aiding and encouraging these individuals to voice their own

wants, needs and desires.

With Ric's encouragement, Westchester Arc became one of the first NY-SARC chapters to include self-advocates—individuals with developmental disabilities who voice their own wants, needs and desires—in its Board of Directors. Two self-advocates have served on the agency's board since 1996, assuming all of the responsibilities and making the same contributions as their fellow board members. In 2005, Ric helped launch the first agency-wide Customer Service Council, ensuring that individuals with developmental disabilities provide input on the agency's plans and operations. This group meets on a monthly basis and upon Ric's request was recently made a board-level group. Ric helps the council hold elections for officers, so they can express their right to vote. He also facilitates meetings with special guests including representatives from the county's Paratransit system and former Senator Nick Spano—giving the council the opportunity to voice their thoughts to officials and other members of the community.

"Ric is always there for us self-advocates. He gives us good advice, answers our questions. Whenever I tell him things, I know he is really listening, and he does his best to make sure others, like

staff and people in the community, listen to us, too." comments Patsy Ginese, president of the Customer Service Council.

Ric's involvement with the self-advocacy movement stretches beyond Westchester. He often travels with self-advocates to Albany and Washington D.C., where they meet with public officials and lobby for laws protecting individuals with disabilities. They also attend state conferences sponsored by NYSARC and other organizations, where they exchange ideas with self-advocates from all over New York State. Recently, Ric hosted two regional self-advocacy conferences in Hyde Park, New York, to develop a platform for social issues, rights and responsibilities that were presented to representatives of presidential candidates John McCain and Barack Obama.

Ric's dedication to children and adults with developmental disabilities extends to the staff and families of Westchester Arc. He values the importance of teamwork and freely welcomes the opinions of others. His leadership exemplifies the longstanding traditions of Westchester Arc and offers inspiration to the entire staff.

Ric's leadership has also enabled the

see Top Honor on page 11

AUTISM SPECTRUM NEWS DESK

Dr. Philip H. Levy Named CEO of YAI/NIPD Network

Will Succeed Dr. Joel M. Levy After Transition Period

Staff Writer
Autism Spectrum News

Dr. Philip H. Levy, President of the YAI/National Institute for People with Disabilities (YAI/NIPD) Network, has been named Chief Executive Officer of the organization as of July 1, 2009. Effective immediately, Dr. Levy will assume the title of President and Co-CEO, sharing the responsibilities with Dr. Joel M. Levy, the longtime CEO.

"For more than 50 years the YAI/NIPD Network has enjoyed a remarkable record of strength and stability," said Marcella Fava, Chairperson of YAI/NIPD's Board of Trustees. "The promotion of Philip Levy will ensure that the vitality and vibrancy of the organization will continue into the future.

"To ensure a smooth transition, we are gratified that for the next nine months, Joel and Phil will serve as Co-CEOs." Following his retirement in June of 2009, Joel Levy will remain as a consultant.

Dr. Philip Levy, who has a Ph.D. in counseling psychology from New York University, has been with the organization



Drs. Philip H. Levy and Joel M. Levy

for more than 37 years. During his tenure, he has played a pivotal role in spearheading the organization's growth, from a small agency serving 15 individuals with

developmental disabilities, to a network of seven nationally recognized not-for-profit health and human services agencies with a staff of 5,500 serving 20,000 indi-

viduals and their families throughout the New York metropolitan area, New Jersey, Puerto Rico and the U.S. Virgin Islands.

"Over the last four decades, the field of developmental disabilities has witnessed a remarkable social revolution which has transformed the lives and changed destinies of thousands upon thousands of individuals with disabilities and their families," said Philip Levy. "I am proud that the YAI/NIPD Network has been in the forefront of this revolution. Yet there is so much that remains to be done. I look forward to continuing to collaborate with our extraordinary senior management team, our dedicated staff, and so many partners to create new paradigms and enhance hope and opportunity for people with disabilities."

Dr. Joel M. Levy, who has been with YAI/NIPD for nearly 40 years, is nationally recognized as a pioneer in the creation of community-based programs and services for individuals with developmental and intellectual disabilities.

"An organization is defined by its values, philosophy, culture and the commitment of its staff," said Joel Levy. "I feel privileged to be associated with so many

see CEO on page 38

NYS Senator Suzi Oppenheimer Awards Legislative Grant to Autism Spectrum News

Staff Writer
Autism Spectrum News

New York State Senator Suzi Oppenheimer (37th Senate District, Westchester County) recently awarded *Autism Spectrum News* with a NYS Legislative Grant in support of its mission to provide vital autism education and advocacy to the community. This grant will enable *Autism Spectrum News* to broaden its content and distribution to more families whose lives are affected by autism spectrum disorders and to those organizations that provide services to them.

"I am delighted to support Mental Health News Education, Inc. (MHNE) and their new endeavors with *Autism Spectrum News* to bring autism education to the community," said Oppenheimer. "Their new autism publication will play a vital part in educating families and service providers in the community about autism spectrum disorders. Information regarding the safe and effective diagnosis and treatment of autism can be very fragmented on the internet and in the mainstream media. I feel that this publication provides the community with an ongoing



Senator Suzi Oppenheimer

source of evidence-based information that the community can trust."

Autism Spectrum News is a nonprofit

see Oppenheimer Grant on page 33

Westchester County Announces Project Lifesaver for Individuals who Wander

By Andrew J. Spano
Westchester County Executive

Last year, I appointed an autism advisory committee to help me determine what kinds of services would be beneficial to families with children on the Autistic Spectrum. We don't want to duplicate what is out there, but rather to fill in the gaps.

Families with children with Autism have enough on their minds navigating the system and advocating for their child without having to worry about their child wandering off. For that reason, Westchester County recently launched a pilot program to offer families an electronic tracking system. The program works the same way as our program for seniors with Alzheimer's Disease.

While not all individuals with Autism wander, this program will give peace of mind to the families of those who do. With all that these families have on their mind, I was seeking a way that Westchester County could help ease their minds that their child may wander off. The new service, known as Project Lifesaver and announced in December, is geared to children and adults with Au-



Andrew J. Spano

tism and other developmental disabilities who are living with their families and who have a history of wandering from

see Project Lifesaver on page 35

Dr. Fred Volkmar of the Yale Child Study Center Answers Common Family Questions

**Fred Volkmar, MD, Director
Yale Child Study Center**

Fred R. Volkmar, MD, Director of the Yale Child Study Center, recently shared his comments on some frequently asked questions from parents of children on the autism spectrum:

Q: What type of patients do you see at the Developmental Disabilities Clinic in Greenwich?

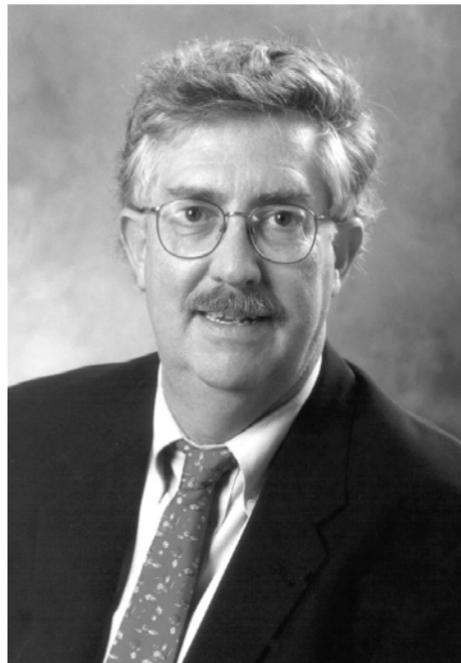
A: We have seen a range in terms of age and levels of functioning but mostly school age and most frequently with a request for either second opinions about diagnosis or review of recommendations.

Q: How can you help my child at school?

A: For the individual child we can review the child's testing and current program and make recommendations for intervention and program changes. Speaking more broadly there are a number of excellent resources for teachers, teachers aides, and others involved in working in schools that are now available - our web site maintains an active list of these resources.

Q: At what age should my child start speech services?

A: Basically as young as possible. An evaluation should be done initially to see what the child needs.



Fred R. Volkmar, MD

Q: My daughter has funny body movements. She often jerks her head back. She has autism, but is it also possible that she has a tic disorder? Are there treatments for this?

A: Tics can sometimes develop in children with autism - these can be only motor tics (jerky movements typically of head and neck but sometimes of body). Occasionally these come to include vocal tics (throat clearing sounds, noises or, sometimes, words). When both motor

and vocal tics are present for a period of time the diagnosis of Tourette's disorder is made. There are medications that can be used in treating tics.

Q: Are ABA services the only type of therapy that is appropriate for children with ASD?

A: A range of services can be useful - including ABA but other approaches as well. The report from the National Research Council on Educating Children with Autism talks about the range of programs which have been shown to work for children with autism. Many, but not all, have a strong ABA base.

Q: My child doesn't sleep well at night. How can I get him on a better sleep routine?

A: There are some excellent resources for parents - notably a series of books by Mark Durand. The issues vary from child to child but often establishing a sleep routine is essential. Keeping a "sleep diary" is a place to start.

Q: My child is 5 years old. He is very destructive and aggressive. Should I consider medication for my son's autism?

A: Without knowing a specific child it is, of course, not possible to say for sure, but this is the kind of thing that medications can help with.

Q: My autistic son will be a teenage soon. Are there special things to look

for at this age? Is there an increased risk of seizures?

A: Some children with autism get better at this time in terms of their behavior, others get worse. There is an increased risk for children with autism to develop seizures during adolescence.

Q: We have one child with autism, but we desperately would like to have another child. How much risk is there that a second child will have autism? Is a second child likely to have another disorder?

A: There is some increased risk - somewhere between 2 and 10% of another child with autism and up to 20% that the child may have some other problems, e.g., in language.

Q: I have a son who has always been a good student, but he has been painfully shy and socially awkward. He is now at a local college. Recently, he was diagnosed with Aspergers. Is it too late to get help for him? How can I help him meet friends and transition better into an independent adult life?

A: More and more individuals on the autism spectrum - particularly those with Asperger's and higher functioning autism, are going to college or other post-secondary schools and becoming independent adults. An entire series of books/resources is available (visit the child study center web site - autism page - www.autism.fm for a list).

Yale Child Study Center Offers Free Lecture Series in Greenwich Connecticut

**Staff Writer
Autism Spectrum News**

The Yale Child Study Center, a department at Yale University School of Medicine, has for nearly 100 years brought together multiple disciplines to further the understanding of child development problems and the impact on their families. The Yale faculty provides innovative, quality clinical care in outpatient and inpatient settings and provides a range of services in schools, homes and the community. Research at the Child Study Center is broad based spanning work on genes and brain neurotransmitters to treatment and community based programs. The clinical research programs are nationally and internationally recognized. In addition, the Center is deeply committed to training the next generation of leaders and offers formal training programs in child psychiatry, psychology and social work. As advocates for children's mental health issues, the Child Study Center works with over 500 schools in 43 states.

As part of the Child Study Center's efforts to expand its clinical reach, the

faculty has started to provide services in Greenwich, Connecticut. The Yale Academic Skills Clinic provides diagnostic services for children who may present with complex profiles that interfere with language and learning. In addition to a comprehensive educational report, faculty provided specific recommendations for treatment goals and treatment approaches, as well as outlining supplemental support services that may be appropriate. The goal of this clinic is not just to test students, but to prepare an academic action plan that is in the best interest of the child. The Yale Academic Skills Clinic sees children of all ages, including college students, who are at risk or experiencing significant academic difficulties. Children with a wide range of profiles may fit under this broad umbrella, including ADHD, Asperger's, Fragile X, Apraxia and many others disorders.

The Yale Developmental Disabilities Clinic provides educational consultation services. Dr. Volkmar, Director of the Yale Child Study Center and a world renowned expert on autism, is available in Greenwich by appointment, to assist in

See Free Lecture Series on page 17

**Debbie Hilibrand
Chair, Executive Council
Yale Child Study Center**

"It has been very rewarding to have the opportunity to assist the Yale Child Study Center in expanding their clinical reach to Greenwich Hospital and to the Westchester/Fairfield communities. Feedback from parents who have visited the clinical services has been quite positive. But, I am particularly pleased at the success of the lecture series and its ability to reach out to a wide audience. Through the marketing efforts of Greenwich Hospital, over 95,000 families receive regular updates on our lecture topics. These parents, teachers, medical professionals, therapists and students make up a broad mix of audience.

I have always had the strong belief that the best way to empower parents to make smart educational choices, to be wise consumers and to be strong advocates, is to ensure that they have an opportunity to be informed on the most recent advances in the field of autism. The lecture series provides an easy access, no



Debbie Hilibrand

cost environment for parents and professionals to enhance their skills. It is also heartening to see familiar faces reconnect with each other, share the progress of their kids and network on resources for the next stage of their journey with autism."

LAW AND THE AUTISM COMMUNITY



How Authorities Interact and Respond to Individuals with Autism Spectrum Disorders

By Douglas K. Stern, Esq.
Abrams, Fensterman, Fensterman,
Eisman, Greenberg, Formato & Einiger, LLP

There is a great deal of debate surrounding the prevalence of Autism Spectrum Disorders in the United States. One recent federal survey indicates that at least 1 in every 150 people in the United States will be affected by an Autism Spectrum Disorder. Whatever the frequency of occurrence may be, the Federal Bureau of Investigation has estimated that people with Autism Spectrum Disorders, ("ASD"), are seven times more likely to have encounters with law enforcement and other first responders than the general public. This is due to a host of factors including being a victim of a crime, an alleged perpetrator of a crime or as a result of wandering or other distress calls. Furthermore, as individuals with ASD achieve more mainstream status (however that may be defined), in areas such as academia, the work force or life in general, the likelihood of an interaction with administrative/disciplinary authorities also increases.

It is axiomatic that an individual who is responsible for enforcing the rule of law, otherwise keeping the peace or providing emergency services is only as effective as his or her training. The problem, typically, is that these "authorities", collectively, are woefully underprepared to safely and effectively deal with interactions with individuals coping with ASD. What is even more troubling is the fact that current, "one-size fits all" training protocols will often lead these authorities into situations that do more harm than good. The purpose of this article is to stimulate debate, lay the foundation for meaningful dialogue and hopefully change minds in relation to this problem. Hopefully this is the beginning of a meaningful process.

The Emotionally Disturbed Person:
One Size Does Not Fit All

According to the New York Police Department's Patrol Guide, an emotionally disturbed person ("EDP") is defined as, "a person who appears to be mentally ill or temporarily deranged and is conducting himself in a manner which a police officer reasonably believes is likely to result in serious injury to himself or others."¹ This is a typical definition. One national report notes that, in 1998, "people with mental illnesses killed law enforcement officers at a rate of 5.5 times greater than the rest of the population,"² and "...law enforcement officers were more likely to be killed by a person with a mental illness (13 percent) than by assailants who had a prior arrest for assaulting police or resisting arrest (11 percent)."³

These are some examples of statistics



Douglas K. Stern, Esq.

and concepts that law enforcement and other first responders are bombarded with in their training to deal with emotionally disturbed persons. Relatively speaking, EDP training is only a small percentage of the overall first-responder initial and maintenance training. Training with respect to interactions with individuals with ASD is practically non-existent for the overwhelming majority of first responders throughout the United States. How can these individuals be expected to handle a situation involving an individual with ASD safely and effectively when there is such a remarkable lack of appropriate training? Unfortunately, at times, the consequences can be deadly. The very techniques a police officer is trained to apply to an individual who is psychotic and out of control can have a potentially deadly impact on an individual with Autism or related illness. For instance, the typical police officer is trained to use varying levels of control and contact to subdue a frankly psychotic individual. The same level of force applied to an individual with autism, due to possible related physical anomalies, may cause cardiac arrest and even asphyxiation. Loud noises and sudden movements may also escalate an already volatile situation leading to the officer's misinterpretation of the level of threat posed by the autistic arrestee. While it is true that these first-responders do not have a crystal ball and they must assess their subjects based upon the facts and observations available at the time of an incident, there must be a mechanism of inquiry in place that may change the course of an interaction when that first-responder learns that the subject has an ASD.

More often than not there are cues available to the first-responder which serves to indicate that a subject has an

ASD. From family and self-reporting to external observations of behaviors, speech and affect, a first-responder stands a reasonably good chance of determining that the subject has an ASD. With this information, the first-responder could employ an entirely different protocol from that of the standard EDP call in effectuating an arrest or rendering treatment. The possible techniques are numerous and their discussion would be better served by a separate article.

None-the-less, an example of how easily a situation can turn fatal or cause grave physical or emotional harm is as follows: A police officer encounters an individual, "John", who is believed to have committed a misdemeanor offense. John is screaming the same word repetitively while banging his head with his hand and pacing throughout his parents front yard. The parents are home. The officer approaches John which causes him to yell louder and increase the intensity of his self-abuse. The officer calls in a code for back-up to assist with an "EDP." The officers training dictates that he subdue the EDP as quickly and "safely" as possible with the least amount of physical force in order to prevent harm to the subject, the officer or others. The officer approaches John and asks him to calm down. John begins to yell profanities at the officer.

The officer then asks John what drugs he has taken, this causes John to pace even faster and more erratically. The officer yells at John, telling him that he is under arrest and must stop moving and yelling or he will be forced to use physical force. John begins to run. The officer gives chase and tackles John which causes him to flail. By this time back-up has arrived and two other officers are assisting the arresting officer in subduing John. John continues to struggle, with great strength, although he now has difficulty breathing and his blood pressure is dangerously high due to the medications that he is taking. The arrest is made and John suffers from a massive heart attack. The alternative? The officer arrives on the scene and observes the above referenced scenario but notes that John's pacing is limited in geographic scope, his self-abuse is superficial and verbal ramblings are of no consequence. The officer waits for back-up and upon their arrival approaches the house to see if anyone is home in order to establish whether or not this is the subject's residence. The officer learns that the subject resides at this address with his parents and that he has an autism spectrum disorder. Within a five minute inter-

see *Authorities on page 40*

Carolyn Reinach Wolf, Esq.
Douglas K. Stern, Esq. of

**ABRAMS, FENSTERMAN, FENSTERMAN, EISMAN,
GREENBERG, FORMATO & EINIGER, LLP**

Attorneys at Law

Devoted to the Practice of Law for the Autism Community

The Firm represents more than twenty major medical centers, as well as community hospitals, nursing homes and outpatient clinics, in the New York metropolitan area in the field of mental health litigation, consultation, advocacy, and related disciplines.

In addition, our team of attorneys, with more than forty years combined experience, offers legal representation to families and individuals affected by developmental disabilities. We provide a broad range of legal services and counsel on such matters as: mental health case management and continuity of care; discharge planning; Assisted Outpatient Treatment (Kendra's Law); Mental Health Warrants; Hospital Treatment over Objection and Retentions; Patients' Rights and Guardianships.

Our firm regularly contributes to a number of publications concerned with Autism and related Health Care issues and participates in seminars and presentations to professional organizations and community groups.

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Join over 20,000 people who aren't content to sit and wait for answers to Autism.



No one understands the twists and turns of autism better than a parent whose child is living with it every day. That's why tens of thousands of families across



the country have joined together online to give researchers the insight that only they can provide. It's called the IAN Project and it's putting researchers in touch with families. It's allowing

parents to reach out to other parents. And it's creating a resource for anyone who wants reliable information on the latest treatments and findings.

We all have questions.

Together, we'll find answers.

IAN
interactive
autism network

Join today at www.IANproject.org

Linking autism researchers and families

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



Approved 07/08/2008

A web project of Kennedy Krieger Institute • Sponsored by Autism Speaks

Autism Speaks Announces New Policy to Give Families Easy and Free Access to Key Research Findings

Staff Writer
Autism Spectrum News

Autism Speaks has announced that as of December 2008, all researchers who receive an Autism Speaks grant will be required to deposit any resulting peer-reviewed research papers in the PubMed Central online archive, which will make the articles available to the public within 12 months of journal publication. This new policy will make the results of Autism Speaks-funded research easily accessible – at no charge – to individuals with autism, families and other advocates, as well as interested researchers. Autism Speaks is the first US-based non-profit advocacy organization to institute this public access requirement.

Posting articles on PubMed Central not only makes the results of research more accessible, it also integrates them with other research and data, making it easier for scientists worldwide to pursue autism research and make discoveries. Equally important, families, clinicians, patients, educators, and students reap the benefits by having open access to Autism Speaks-funded research. PubMed Central's trusted repository of full-text biomedical journal



articles is freely available online at www.pubmedcentral.gov.

While families are now able to view a wide range of information about autism research online, they often do not have easy access to primary sources, including peer-reviewed scientific literature. This new policy will allow everyone to access complete articles that in the past may

have been available only through fee-based journals.

"Families with autism are, by nature, motivated advocates constantly seeking new and reliable information to educate themselves," said Sophia Colamarino, PhD, Autism Speaks Vice President of Research. "They are also particularly sophisticated in their ability to read and in-

terpret scientific literature pertaining to autism. This is an effort to give those families and their physicians access to important information about the latest developments in autism research."

"With each additional paper added to PubMed Central, the archive's value grows, and the peer-reviewed scientific literature becomes more open and better integrated with other data resources," said David J. Lipman, MD, director of the National Center for Biotechnology Information, the National Library of Medicine division that maintains the archive. "I'm pleased that Autism Speaks approached us – I know their public access program will be good for research, and for patients and their families."

"With this groundbreaking step, Autism Speaks is demonstrating great vision and leadership," said Heather Joseph, executive director of SPARC (Scholarly Publishing and Academic Resources Coalition) and a leader of the movement for open access to research findings. "By taking advantage of the opportunity for open information sharing on the Internet, they will both accelerate the pace of research and address the public's need to better understand autism. We hope other research funders will emulate this powerful example."

Autism Speaks Offers 100 Day Kit for Families

Staff Writer
Autism Spectrum News

Autism Speaks, the nation's largest autism advocacy organization, is offering families of children newly diagnosed with autism a "100 Day Kit", a personalized resource to assist families in getting through the critical time following an autism diagnosis. In addition to receiving the contents of the kit, which includes information about services and service providers in a family's community, those who register will also be connected with a regional Autism Speaks Autism Response Team member who can provide further insight and guidance. Kits are available in both English and Spanish.

The 100 Day Kit includes basic information about autism and dealing with the news of a diagnosis. The personalized kit

lists local service providers, support groups, recreational activities, sources of legal information, conferences, local autism and disability organizations and information about the local chapter of Autism Speaks. It provides insight into getting services for a newly diagnosed child and explains various available treatment options. A week-by-week action plan helps walk a family through the steps it needs to take to ensure that it is on the right track. The kit also includes a glossary of terms associated with autism, as well as a safety plan and a list of recommended books and informational web sites.

A personalized version of the 100 Day Kit is available by visiting www.autismspeaks.org/community/family_services/100_day_kit.php, where parents of a newly diagnosed child will be asked to fill out a short survey. In response, an Autism Response Team coordinator will contact the family to get addi-

tional information so that the 100 Day Kit can be tailored to include resources specific to their child's age and location. The family will receive a binder with pertinent information, as well as contact information for an Autism Response Team coordinator in their region who has been trained specifically to answer questions they may have.

"When a child is diagnosed with autism, his or her parents are often left feeling overwhelmed and confused about what to do next and where to turn for help," said Peter Bell, Autism Speaks Executive Vice President for Programs and Services. "This kit will be a valuable tool for these families and will help make the first few weeks and months after diagnosis a little less daunting."

"Parents need to know that they are not alone," said Lisa Goring, Autism Speaks Director of Family Services. "The 100 Day Kit and the Autism Response Team will help families get informed, get organized

and get connected to important resources and support services in their community."

The 100 Day Kit was created by the Autism Speaks Family Services staff in conjunction with a professional advisory committee comprised of twelve autism professionals, a parent advisory committee that included parents from across the country, and members of the Autism Speaks Family Services Committee. The Autism Speaks 100 Day Kit is created specifically for families, to make the best possible use of the 100 days following the diagnosis of autism. The kit contains information and advice collected from trusted and respected experts on autism as well as from parents of children with autism. There is a week by week plan for the next 100 days, as well as organizational suggestions and forms that parents/caregivers can use to help with the paperwork and phone calls, as they begin to find services for their child.

Top Honor from page 6

agency to move toward the future. In the fall of 2008, the agency closed its door to its longtime headquarters at 121 Westmoreland Avenue in White Plains and moved to its new Gleeson-Israel Gateway Center in Hawthorne. With the move came a dramatic shift in the way the agency provides services to individuals with developmental disabilities. Rather than focusing on center-based services

and offering sheltered workshops, as it did in White Plains, Westchester Arc would now provide more opportunities for community inclusion. The Gleeson-Israel Gateway Center houses art galleries that showcase the creative accomplishments of people with disabilities, provides enhanced person-centered services and offers state-of-the-art meeting spaces utilized by families, staff and fellow community organizations—all of which inspire the community to value

the inclusion of people with developmental disabilities.

"There aren't enough words in the dictionary to describe the compassion, dedication and knowledge of Ric Swierat," remarks Anne Majsak, Westchester Arc President. "He exemplifies what a leader should be—focused, driven and always willing to hear what others have to say. His tireless efforts have opened many doors for individuals with developmental disabilities and their families. On

behalf of the entire Westchester Arc community, I congratulate Ric on this well-deserved honor."

Westchester Arc is the oldest and largest agency in the county serving children and adults with developmental disabilities such as autism spectrum disorders, Down syndrome, cerebral palsy and learning disabilities. The agency has long been committed to social inclusion because of the benefits to the entire community.



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.

Tools for Identifying Autism in Infants and Toddlers

By Charles Cartwright, MD and Amerha Rafiq, MD
YAI/National Institute for People with Disabilities Network

All of us in the field of autism spectrum disorders — parents, doctors, therapists, researchers and activists — agree that early identification is essential for enabling early intervention and investigating underlying causes. Many of the tools, such as the Modified Checklist for Autism in Toddlers (M-CHAT), that doctors use to screen young children for autism are effective for children older than 18 months. However, identifying children at risk for autism within the first year of life will enable them to receive intervention and treatment during crucial early stages of brain development, thereby maximizing their potential.

It is recommended that developmental surveillance take place at each pediatric visit throughout early childhood. Screening for autism and other developmental disabilities should be instituted if concerns are identified during the surveillance assessment. Pediatricians should refer their patients who are at risk for autism to a developmental pediatrician, a pediatric neurologist or a child psychiatrist for further evaluation.



Charles Cartwright, MD

The Link Between Head Circumference and Autism

In younger toddlers and babies, objective, quantitative guidelines may prove to be useful for identifying an increased risk for autism before children begin to show the behavioral indicators of autism. Head circumference may be an important biological marker that would aid early diagnosis of autism within the child's first

year, months before the M-CHAT or other developmental checklists are implemented. Between one and 12 months, babies with autism experience head growth at faster rates than typically developing babies.

As far back as 1943, studies conducted by Kanner found that increased head circumference could indicate attributes consistent with autism spectrum disorders. More recent studies (Elder et al 2008, Dawson et al 2007) have also examined rates of head growth during the first few years of life in order to explore whether toddlers with more rapid head growth are more likely to develop autism.

These studies identified significant acceleration in head circumference growth during the period from six to 12 months of age in those infants who went on to show signs of autism. In addition, between the ages of 12 and 24 months, rates of head growth returned to a rate that mirrored typically developing children. These studies concluded that rates of head circumference growth between 6 and 12 months may be useful in identifying children who are at risk for developing signs of autism.

In a retrospective study by Fukumoto and colleagues (2008), a pattern of significant increase in rate of head circumference growth for children who went on to receive the diagnosis of autism was noted as early as one month of age. The authors concluded that the rate of head circumfer-

ence growth could be easily monitored using accurate measurements of head circumference by pediatricians and noted that the period between one month and three months should be an area of particular focus.

Pediatricians may be able to use measurements of head circumference during well baby checkups to identify children at increased risk for autism, particularly younger siblings of children with autism. It is recommended that physicians measure babies' heads at birth, one month, three months, six months, nine months and 12 months. The pediatricians could then closely monitor their patients and refer them for further evaluation, if necessary. This approach would enable pediatricians to identify those of potential risk of autism up to a year earlier than is currently the case, resulting in earlier intervention and possibly more favorable outcomes for children with autism spectrum disorders.

Behavioral Indicators of Autism

While rates of head growth may be used to identify risk for autism in babies, most children with autism are diagnosed after manifesting behavioral signs. Because of their routine evaluations of children younger than age 3, primary care physicians play a vital role in the identification of children at risk for autism spectrum disorders.

see *Identifying Autism on page 35*

Searching for a School-Age Program

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

Cathy began searching for a kindergarten for her son, who has an autism spectrum disorder, in 2007. Even though her son was only 3 at the time, other parents had warned her that it could take years for her to find the right kindergarten.

Now, her son is 4. As graduation in June looms large in her mind, her search for the right school continues.

"It's so stressful," said Cathy, who asked that her last name not be used. "I'm just hoping we're going to find the right school."

"There's anxiety anytime a family goes through one of these transitions," said Erica Levy, a social worker with the New York League for Early Learning (NYL) Gramercy School in Manhattan. NYL is a member of the YAI/National Institute for People with Disabilities Network. "Some parents are realizing that their children are not ready to be mainstreamed. While they're making progress in preschool, they may not be progressing like most 4- or 5-year-olds."

Couple those emotions with the fact that many private schools require a commitment in November or December, a time when many parents are working with



Bernadette Flynn, EdD

teachers, therapists and other professionals to assess if their child will even be ready for kindergarten by the following September. Meanwhile, public schools in New York City don't provide placement until June.

According to the National Research Council's "Educating Children with Autism," "The characteristics of the most appropriate intervention for a given child must be tied to that child's and family's needs. Effective services will and should

vary considerably across individual children, depending on a child's age, cognitive and language levels, behavioral needs and family priorities."

Start Early

Mia Simon, the parent of 5-year-old Zach, has an intimate knowledge of the challenges of finding an appropriate school. "We fought very hard for one specific school because we knew it was going to make a difference in his life."

She urges parents to follow Cathy's lead and begin looking for schools a year before graduation from preschool. Talking to parents and visiting schools are crucial first steps.

"Look at a number of different schools to get a sense of the options available to your child," Mia said.

She also suggests that parents pay attention to Department of Education proposed rules and changes for children with special needs, and their related services, in this tough economic time.

For example, the New York State Commission on Property Tax Relief released a report late last year recommending several potential cuts to the special education budget. Among the recommendations were a move to reduce or remove payment for transportation of special education students, and eliminating class size mandates, allowing each school to establish class size based on students' needs.

Michelle, who requested her last name not be used, began compiling a list of schools about a year before graduation and visited 17 different schools throughout New York City and New Jersey. The list was based on suggestions from therapists, teachers and other members of her son Jonathan's team. She classified the schools based on their focus, e.g.: autism, speech and language delay; type, e.g.: private, state approved or public; and curriculum, such as ABA. Michelle found it helpful to tour differently structured classrooms.

"You have to be realistic about your child and what he can accomplish," she said. "You want him in a place where he can thrive and be successful."

Dr. Charles Cartwright, Director of the YAI Autism Center, suggests that families pay particular attention to a school's environment. Get a sense of how the environment and educational strategies are implemented to meet the goals of the students and families. How is the school addressing the objectives specified in a child's Individualized Education Plan, or IEP? Look in the classrooms. "If you see children walking off into the corner or engaged in repetitive behaviors without staff redirecting the behaviors, that's not a good sign," Dr. Cartwright said.

Prepare questions for teachers and listen carefully to how they respond. - "You can

see *School-Age Program on page 37*

NYS OMRDD - Committed to Supporting Families

By Leslie M. Fuld
Statewide Family Support
Services Coordinator
NYS OMRDD

Families of individuals living with an Autism Spectrum Disorder (ASD) often need assistance to meet the challenges the disability brings to their loved one and to the family as a whole. At times, they need intensive clinical therapies to ensure that their family member with ASD can remain living successfully in the home. Other times, families simply need a break from therapies and interventions and the chance to be "just a family" rather than a family living with ASD. To meet these needs, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) provides both clinical support and services that nurture and strengthen through a program called Family Support Services (FSS).

The FSS Program is a statewide system of comprehensive support services such as information and referral, counseling, recreation opportunities, sibling services and family support groups. One of the most popular Family Support Services OMRDD provides is respite, or temporary relief from the demands of care giving that can help reduce stress and keep families together. Most family support ser-



Leslie M. Fuld

vices are available through OMRDD's network of voluntary (non-profit) service provider agencies. Over the past 24 years, OMRDD's FSS program has grown from serving 200 families to serving more than 42,000 individuals and their families. Of these, almost 8,000 individuals have a diagnosis of ASD.

Many parents and family members believe that Family Support Services has been

instrumental in supporting them and their loved ones through very difficult times. One such parent is Stacia Weinstein, the mother of Jakab, a young man diagnosed with autism who recently turned 18.

Jakab has significant behavioral and communication needs. Approximately three years ago these needs intensified. Jakab and his family found themselves in crisis and in need of help. This crisis not only affected Jakab and his family at home, but also created problems at school. At about this same time, the Franziska Racker Center in Cortland, N.Y. was awarded a Family Support Services contract with OMRDD. This award allowed the Center to develop a program that provides intensive crisis intervention and support at home, including development of individualized behavioral strategies with the support of a behavior specialist (or another clinician) to assist in training family members and others to implement these strategies. This program has come to be known as "Supporting Success."

At first, Weinstein was unsure of what to expect. She knew that Jakab and her family needed help, but she wasn't convinced that this program would be what they needed. Weinstein's fears were quickly put to rest in October 2006 when Behavior Specialist Jessica Jones began working with Jakab. Jones listened, watched, asked questions and she began her work. She built a relationship with Jakab and provided services for him that were based on

a growing understanding of who he was. For both Jakab and his family, this was key. The services provided by Jones also helped the family with difficulties involving Jakab's school. To this day, Jones' services continue to be vital to Jakab's success. She provides any necessary training for staff involved in Jakab's life. Jakab's family is confident in Jones taking this role because they know she truly understands Jakab.

The "Supporting Success" program allowed Jones the time needed to get to know Jakab to meet his individual needs. Consequently, she was able to provide him with individualized, quality services. With these services in place, his mother is confident that Jakab's, and her family's, quality of life will continue to be enhanced.

Another program which helps involve and support parents and other family members is found in Greene, N.Y. This program, called "The Magic Paintbrush Project," is unique and was created by Jennifer O'Brien, who is the mother of two beautiful girls, ages 8 and 6, both diagnosed with Cerebral Palsy (Jennifer also has a family member diagnosed with Retts syndrome).

The Magic Paintbrush Project was based on the idea that families want to be engaged and have fun with their loved ones. As a mother, O'Brien discovered

see Supporting Families on page 21

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A New Genetic Perspective on Autism Spectrum Disorders

By **Joseph D. Buxbaum, PhD**
Director
Seaver Autism Center for
Research and Treatment

Recent genetic studies in autism spectrum disorders (ASDs) support an important role for what are being termed multiple "rare variants" in these conditions. "Rare variants" include what we think of as mutations, and can be the cause of an ASD when they are found. This is an extremely significant finding because the identification of causal variants may lead to earlier diagnosis, genetic counseling, the conceptualization of new approaches to therapeutics, and the development of model systems in which new therapeutics can be tested. There is therefore plenty of cause for optimism in the field.

The most dramatic example of this new approach is the recently initiated large-scale clinical trial in Fragile X Syndrome (FXS). FXS accounts for approximately 2% of ASD cases and FXS screening is already standard in most cases with an ASD. When a clinician identifies the FXS mutation in a child affected with an ASD, the clinician will conclude that the FXS is the cause of the ASD. This, in turn, leads to opportunities for genetic counseling and also to earlier behavior intervention, which is associated with



Joseph D. Buxbaum, PhD

better long-term outcomes. What is perhaps less appreciated is that with such a causal genetic disorder, it is now possible to genetically modify laboratory animals to re-create the genetic alteration for further study. Detailed analysis of a genetically modified mouse that modeled FXS

gave rise to a hypothesis that overexpression of specific proteins in the brain produced the cognitive deficits in FXS. As a result of this hypothesis, drugs that targeted this pathway were tested in these genetically modified mice and were shown to correct some of the cellular and behavioral deficits observed in the mice. As a result of this, beginning in January 2008, there is now a large-scale clinical trial in FXS with a drug targeting this pathway. While the results are not yet in, there is great optimism that this general approach will produce new therapeutic approaches to the ASDs.

By way of background, it is important to note that twin and family studies in ASD have indicated that the ASDs are the most heritable (i.e., genetic) of psychiatric conditions. This could be quantified with an estimate of heritability of over 90%. For many years it was thought that this genetic liability to ASDs was primarily caused by the interaction of several common genetic variations in an individual. In this model, a common genetic variant by itself was not deleterious and could even have a positive effect on one who carried it, but when too many were present in the same individual, the total effect was negative. Imagine, for example, if one genetic variant made a person more organized or focused but several more genetic variants with the same effect, acting additively, would result in excessive organization or

a focus that was too narrow. This has been called the common variant model.

In contrast, in the multiple rare variant model, a large number of rare, and even very rare, genetic variants underlie a disorder, typically with just a single rare variant found in each individual. Unlike the common variants, where each one has only very modest effects, these rare variants can have quite substantial effects and may contribute the major part of the risk for a given individual. The rare variants that we are all most familiar with are the rare deleterious mutations found in many disorders, such as that found in FXS. There have been theoretical arguments in favor of rare variants in ASDs, and recent studies have provided empirical evidence for this model.

Even before the advances of the last two years, it was already known that a variety of genetic conditions can present with ASDs. These include FXS, but also Angelman syndrome (AS), Prader-Willi syndrome (PWS), and the chromosome 15q11-13 duplications. More recently, rapid advances in genetic technology have allowed for researchers and clinicians to scan the chromosomes to identify new genetic conditions caused by small (submicroscopic) chromosomal deletions and duplications (often called copy number variants or CNVs) and to rapidly scan

see Genetic Perspective on page 35

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Applied Behavior Analysis and Verbal Behavior

By Adrienne Robek, PhD, BCBA
ABA Clinical Director
Los Niños Services



Adrienne Robek, PhD, BCBA

In 1981 O. Ivar Lovaas published his groundbreaking ABA manual, *Teaching Developmentally Disabled Children: The ME Book*. Countless therapists and families have been able to help their children learn life-altering skills such as socialization, language, and activities of daily living thanks to the work of Dr. Lovaas. His manual outlines how one should go about teaching basic skills to children with developmental delays. It suggests the first skills that should be taught are how to sit appropriately in a chair, how to establish eye contact, and to refrain from engaging in disruptive behaviors. The instructor should then teach the child to imitate, match identical or similar items, and follow simple instructions. Thereafter, the child should be taught to imitate simple sounds and/or words and label items/actions. It is assumed that once a child can label a preferred item/activity, he or she will spontaneously say the name of that item/activity when they want it. Sadly, more often than not, this does not happen.

All too often we teach children with autism hundreds of words only to have them stand in the middle of a room and tantrum when they want something rather than using the words they were taught as a

way to request preferred items or activities. Why does this happen? If a child wants juice and can label and identify juice, why does he or she tantrum as a way to get juice rather than simply saying "juice?" According to Skinner's *Verbal Behavior* (1957), the same word can have very different meanings depending on the context in which it is taught. For example, the word "juice" can function as a mand (request), a tact (labeling), an echoic (repeating some-

one else saying the word "juice"), an intraverbal (saying "juice" when someone asks the child what their favorite drink is), or as receptive language (the child points to juice when asked where the juice is). In other words, simply teaching a child with autism to say the word "juice" when shown a cup of juice or to point to a cup of "juice" when asked where the juice is will not ensure the child understands they must say "juice" when they want some juice.

Sundberg and Partington (1998) suggest that the first type of language a child should be taught is a mand. This line of thinking is in stark contrast to traditional ABA in which the first type of language taught is typically receptive language (identification of items and following simple directions). After the child has mastered identifying various items they are then taught to label those items. Teaching a child to request preferred items does not usually occur for quite some time, if it occurs at all. It is usually assumed that a child will request simply because he or she has been taught to label a preferred item. Sundberg and Partington (1998) propose that teaching the child to mand before anything else is most beneficial because it teaches the child how to get their needs and wants met without the use of tantrums. Furthermore, teaching children how to mand is developmentally appropriate since manding is the first type of language to develop in

children. For instance, the first words spoken by a child are names of items/people/activities he or she wants such as "mama", "dada", "up", or "baba" (bottle). Because many children with autism are non-verbal, mand training is usually started by prompting the child to use sign language in order to mand for a preferred item. For example, if watching television is a highly enjoyable activity for a child, the instructor would take the child's hands, prompt them to make the sign for "TV" while the instructor says the word "TV", and immediately turn the television on. After a minute or so, the instructor would turn the television off, prompt the child to make the sign for "TV" while the instructor says the word "TV", and immediately turn the television on. A procedure for fading this prompt is outlined in Carbone (2007).

As a ten-year practitioner of traditional Lovaas ABA, transitioning to a Verbal Behavior format required quite a change in the way I was used to doing things, but I must admit, I have had more success and dealt with fewer tantrums since making the switch. That is why our ABA program at my agency, Los Niños Services, exclusively uses a Verbal Behavior format which we have found very successful.

For more information on this topic feel free to contact Adrienne Robek at adrienne.robek@losninos.com or go to www.losninos.com.



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Free Lecture Series from page 8

the early diagnosis of young children on the spectrum and to advise parents on their children's educational program.

In addition to clinical services, the Yale Child Study Center, in collaboration with Greenwich Hospital, has been hosting a monthly lecture series on current topics in child development. Many of the lectures focus on autism, but other topics

include learning disabilities, anxiety, trauma, and school education. The lectures are free and open to the public. Please join our electronic mailing list to receive regular updates on these free events.

The Yale Child Study Center's Lecture Series in Greenwich will resume on March 23, 2009 at 7pm and will focus on "School Bullying: Relationship between Psychopathology and Suicide" at Greenwich Hospital. School bullying is a common form of

school violence. In the past people felt this was part of normal growing and does not leave any consequence. Is that really true? Dr Young Shin Kim, MD, MS, MPH, PhD, Associate Professor, Yale Child Study Center, will review cumulative scientific evidence examining the psychological consequences of bullying either as a victim, perpetrator or victim-perpetrator.

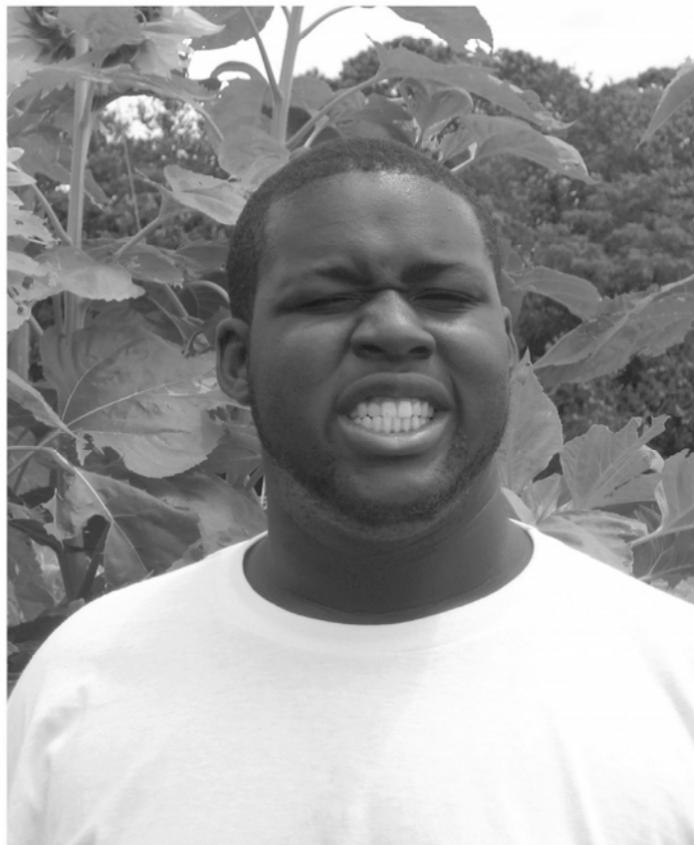
The lecture will take place at Greenwich Hospital in the Noble Conference

Room, 5 Perryridge Road, Greenwich, CT. 06830, and is free with advance registration. Register online at www.greenhosp.org or call (203) 863-3627 or toll-free (888) 357-2409.

If you would like more information about any of these programs, or would like to be placed on our mailing list, contact Emily Deegan at emily.deegan@yale.edu or (203) 785-5759. More details about the Yale Child Study Center are available on our website www.childstudycenter.yale.edu.

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Coping with Autism: A Mother's Journey

By Marianne Clancy
Board Member, ASAT

People often ask "How do you cope with autism?" Having been down this journey for a dozen years with my 14-year-old son with autism I'd hope to "know the answer" as if it was that straightforward, but I know rather that the right balance and type of guidance and comfort that helps each family cope is as individualized as each family and as individualized as each child with autism. As parents, we all have our unique coping needs and mechanisms, which evolve for us during our journey as parents, as our children and also our circumstances evolve and change. We face our own personal challenges as well as shoulder those of our family members. We all have our particular strengths, vulnerabilities and dependences. Yet, our families are all united in a very unique way because of our journey, just as our children are all united in some way because of their autism, diverse though they are as individuals. We are connected to other families by our quest to help our children, the common barriers we face, the challenge to make the best possible choices regarding treatments, and in the familiarity of each other's lives.

Find the Worthiness Within Ourselves

"Your child will teach you things about yourself that you never knew." Words of wisdom spoken by a gifted behavior analyst. As parents, we are called upon to nurture, to love, to advocate for, and to empower our children in ways we had not necessarily envisioned when we chose to become parents. We can find the way. Our children lead us there through their triumphs, trials and tribulations. We seek parenting guidance in literature and workshops, we take those extra steps needed to teach and enable our children, we hold our heads high during those challenging public moments, we advocate and collaborate to provide our children's education and we encourage others to interact with and help our children. Our role is multi-faceted, as all the things we do have significant implications for our children with autism, yet taken together we can find the wholeness in our role as parents.

What can help along the way? Self strength can be gained through a variety of sources, such as through: attending autism workshops and reading reliable autism literature, consulting with autism experts (BCBAs) for our children, and participating in support groups. Personal self-improvement avenues might prove beneficial, such as counseling, stress-management techniques such as relaxation, meditation, or quiet walks outdoors, and exercise pro-

grams. Many parents also garner strength from their religious communities.

Part of worthiness comes from forgiving ourselves for missteps along the way, as well as realizing that small set backs, albeit frustrating, do not detract from the bigger picture of helping our children be the best they can be and avail themselves of the array of life's experiences.

See That Which is Special in our Children

We need to cherish our children's individual accomplishments, realizing how much harder it is for them to achieve as compared to others. We must appreciate them for this, and value their personality and character and those idiosyncrasies that make them unique. Together parent and child walk through the journey of life, hand in hand, finding and appreciating each other and helping each other along the way. Our children may not think and act as others do, but they do learn and grow. We should embrace the persons they are, respect how they think, how they learn and what motivates them to do so. We can't simply take away their autism, but we can add in to our parenting some specific tactics that take into account their being, their thinking, their ways, and their needs. Let's nurture our children and in a manner that they can understand. Let's teach them how to interact with the people and places in our society to their greatest potential.

Appreciate the Goodness in Others

People touch our children's lives and our lives in remarkable ways, ways that may not be as obvious to parents without special needs children. Appreciating the goodness in those people who purposefully or innocently have a positive role or impact in our children's lives is one of the blessings in parenting children with autism.

We are blessed if we can derive support from any of these sources:

Family and friends can provide considerable support to both our children and to ourselves. Their love and their availability, whether in person or remotely, their unconditional support, their familiarity with us and our families surrounds us and protect us. They want to be included and they want to ease some of our hardship. They empathize, they understand our pain and our needs, they accept us, and they share in our joys. They can provide real comfort in our world because they make us whole and enable us to feel worthy.

Professionals who educate our children play a crucial role in their development, more so than for typically-developing children. Our children with autism need knowing adults to lead their way as they may not be able to dictate the direction

see A Mother's Journey on page 38

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Photo by Matthew Septimus, 2008

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The Shield Institute Expands Supports for Parents of Children with Autism

By Dr. Susan Provenzano, MA,
Mary McKillop, MA, CCC-SLP, and
Suzanne Kucharczyk
The Shield Institute

Over the years, The Shield Institute has experienced and responded to the increasing number of children in New York City who have autism spectrum disorders. The Shield's response has included a comprehensive implementation of structured teaching methodology, as developed by Division TEACCH at the University of North Carolina- Chapel Hill. Additionally, Aided Language Stimulation techniques have been incorporated to improve preschool students' receptive language development and/or to facilitate expressive language development during mealtimes, circle time, literacy, cooking and play time activities. Consistent with both Aided Language Stimulation and structured teaching, The Shield Institute utilizes positive behavior supports to foster constructive behaviors and address challenging behaviors, which hamper a child's learning and development. These three approaches have been the core elements of The Shield's education programs for young children who have autism.

While the implementation of structured teaching, aided language, and positive behavior supports have proven to be effective strategies for children attending its educational programs, the Shield Institute recognized a need for more intensive supports for parents. Staff Development Director Mary McKillop found that parents approached her and other staff asking for deeper content and specific ideas for them to use to address their child's needs.

Thus in 2008, through a grant provided by the New York City Council, Department of Health and Mental Hygiene, under the Autism Spectrum Initiative, The Shield Institute expanded its supports for parents who have children on the autism spectrum. Workshops for parents, help with practical application of techniques, newsletters with helpful tips and resources that complement these workshops, and a lending library of resources was developed and provided for parents.

Prior to development and implementation a survey was conducted to ensure that supports created met the needs of fami-



Parents and professionals work together in making individualized books for their children.

lies. Consistently parents stated that their challenges were understanding and addressing their child's communication and behavior needs. Given this, workshops were developed and expert speakers were brought in for parents whose children attend the preschool programs.

Topics addressed at workshops have included: (1) an introduction to autism spectrum disorders, (2) understanding, making and using visual supports at school and home, (3) biofeedback relaxation techniques, and (4) toilet training children who have autism. Speakers included Barbara Bloomfield who spoke on The Visual Teaching Style for Families of Children with Autism and other Severe Learning Challenges, Lindsey Biel who discussed practical techniques that help children with sensory issues, Dr. Frank Cicero on toilet training and Janice Smead on autistic spectrum disorders. Parent feedback reinforces the importance of these workshops, as well as the other elements of family supports being provided. Mrs. Nury Igrisa, mother of a child with autism, says "sharing with other parents has been very beneficial as well. Sometimes they ask questions that have helped me to be more clear about some issues. Some other times they make comments about things they have tried at home with their kids, that I have tried as well and have worked with my son too. And a couple of times they have asked questions that do not

relate to my son, but for some reason in the future I have had to use them as well."

While workshops have provided a platform to share knowledge with parents, helping parents apply this knowledge has proven to be the important bridge between the school and the home environment. Workshops not only provided opportunities for parents to gain new knowledge or expand their existing knowledge, but, more importantly, they have given parents opportunities to put their new knowledge into practical application in the home. For example, during the visual supports workshop parents reflected on the types of visual supports that would support their son or daughter in the home. These were then developed by an autism assistant whose work is supported by the Autism Spectrum Initiative grant. Mr. Nelson Cabrera, a parent of a child with autism, says "we have been using the visual supports at home and in the community and they have worked like a charm. We have been able to communicate with (our child) much better...the visuals have helped her tremendously. She follows her schedules really well which has helped her to be more independent too."

In addition to this practical application, parents have ready-made resources available through a lending library and a monthly newsletter, which also reinforces information presented in the workshops.

Books and DVDs, as well as hands on materials such as adapted storybooks and visual timers are available to use with their children. These materials and resources offer consistency for children since materials are used at school and at home. A summary of workshops and information on resources is incorporated into a monthly parent newsletter. In order to provide access to Spanish-speaking parents, newsletters, resources and some workshop information are available to parents in English and in Spanish. These resources have made it possible for individualization of supports for each family requesting assistance.

Since the implementation of these parental supports, the principals of The Shield Institute's educational programs have found that families do not feel alone. Lourdes Costa, the Principal of the Bronx education program says "parents have been participating in more school activities, visiting classrooms, and making appointments to meet with school faculty and administrators." According to Susanna Mendoza, Assistant Principal of the school, "they are able to speak to other parents, gain a different perspective as well as hear valuable information from qualified speakers who 'have been in the trenches' and provide strategies for our parents to try and then to come back and discuss." While the incorporation of workshops for parents, a lending library, a monthly newsletter and support in the practical application of new knowledge have made an impact on many families, The Shield Institute recognizes the need for further development of family supports. Moving forward, The Shield will bring school psychologists and social workers together to facilitate parental support groups. It is hoped that these groups will further offer parents opportunities to see that they are not alone, as well as to share experiences and resources with other parents.

Dr. Susan Provenzano, MA, is Executive Director of The Shield Institute. Mary McKillop, MA, CCC-SLP, and Suzanne Kucharczyk are with the Shield Institute Staff Development and Training Department. The Shield Institute is a JBFCS affiliate. For further information, please contact Mary McKillop, Director of Staff Development and Training at 718-269-2044 or mmckillop@shield.org.

Supporting Families from page 14

that therapy sessions could be exhausting both physically and emotionally for her daughters. As an alternative, she began using simple art to encourage motion and stretching. When O'Brien realized these activities could help others who care for people with developmental disabilities as well, she launched The Magic Paintbrush Project and began providing facilitated workshops to help other families engage in fun, artistic projects. In 2007, the Magic Paintbrush received FSS funding from

OMRDD to support participation by individuals and their families.

The Magic Paintbrush Project has impacted the lives of more than 8,000 participants to date, many of them with a diagnosis of ASD. One parent writes of the Magic Paintbrush Project: "When I first heard about the Magic Paintbrush Project, I was not sure exactly what to expect. In my head I wondered how we could possibly attend, when my daughter does not know how to hold a paintbrush... and had no interest in learning to hold one. As the project was explained to me more, I felt myself becoming very ex-

cited. There were no prerequisite skills needed, just the desire to spend time together. It is a time to learn and a time to have fun, a time to inspire each other, a time to support each other, and most of all, time spent together as a family. It's a time for all family members to be equal, no barriers, no disabilities, only abilities. The Magic Paintbrush Project is a place where goals are reached with little effort. It's a place where my children interact and learn to play together — and I'm sure any parent of an autistic child will tell you, when that happens, it is truly magical!"

More information about the Magic

Paintbrush Project is available at www.magicpaintbrushproject.org.

These programs are just two examples of the many Family Support Services Programs provided by OMRDD to further its mission of helping people with developmental disabilities live richer lives. For more information about Family Support Services, visit OMRDD's Web site, www.omr.state.ny.us, or contact your local Developmental Disabilities Services Office. A complete listing of local DDSOs is available on the OMRDD Web site.

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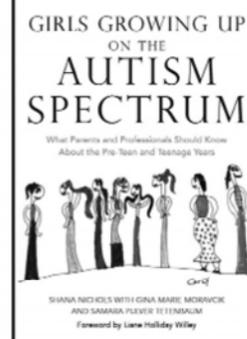
Girls Growing Up on the Autism Spectrum

What Parents and Professionals Should Know
About the Pre-Teen and Teenage Years

Shana Nichols with Gina Marie Moravcik
and Samara Pulver Tetenbaum

Foreword by Liane Holliday Willey

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"This book is not only reassuring; it is inspiring, and bursting with ideas and achievable strategies. The authors write with authority and conviction, and tackle even the most difficult and delicate of topics. If ever you needed to be convinced that girls with ASD can overcome the difficulties and challenges of puberty and adolescence, have successful friendships and relationships and enjoy a healthy sexuality, then take the time to read this book—it is a must-have for families, teachers and therapists alike."

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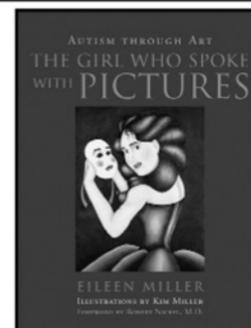
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My Son Was Autistic... Is He Still?

By Jayne Lytel
Executive Director
The Early Intervention Network

Paging through 176 MRI scans of my 9-year-old's brain on my home computer, I discovered a button that let me play them as a movie. Gray swirls burst onto the screen, dissolving into one another and revealing a new set of patterns. Beams of light faded in and out, some curving and traveling around the different regions of his brain. I saw the squiggly folds of his cerebral cortex, the gray matter that is the center of human intelligence.

These scans, the most intimate pictures I had ever seen of my son, Leo, may help researchers understand what's going on in his head -- and relieve him of a diagnosis that I have devoted several years to helping him overcome.

Leo, identified as No. C1059, underwent the scans as part of a research study at the Olin Neuropsychiatry Research Center at Hartford Hospital in Connecticut. He was thrilled to earn \$200 for taking part. I smiled along with him, because I could remember the days when he had a limited range of emotions, and pride was not one of them.

The study is examining 35 children, ranging in age from 8 to 17, who once had an autism-spectrum diagnosis but no



Leo Lytel, labeled autistic at age 2, works on a puzzle that tests his reasoning skills.

longer do. Leo was invited to participate based on how I had described changes in his behavior and communication skills since he was given an autism diagnosis seven years ago. It is one of several studies underway to clarify the experiences of a growing number of children who are apparently emerging from autism and its related disorders to function almost indist-

inguishably from their peers; it aims to reveal whether it is indeed possible to recover from autism.

According to many experts, recovery from an autism spectrum disorder -- a pervasive impairment in thinking, feeling, language development and the ability to relate to others that affects one child out of every 150 in the United States -- is real.

But the meaning of recovery differs from researcher to researcher as much as it does from parent to parent.

I know what recovery means for me: to have a conversation with Leo, especially about love and friendship, and to see him play a team sport. When Leo asked to join his school's soccer team this fall, I thought back to the distressing days when he ran aimlessly around the back yard, clueless about the purpose of the two goals I had set up.

The idea that a child can recover from an autism spectrum disorder is controversial. Skeptics argue that recovery is impossible from a disorder they view as lifelong: more like being born with clubfoot than twisting your ankle. And if the condition is "cured," they say, then it can't have been autism to begin with. No one knows how many children have lost their diagnosis since there are no nationwide statistics accepted by the medical establishment.

"If I absolutely had to guess, I would think that the percent that are capable of recovery might be in the neighborhood of 20 percent," said Deborah Fein, a professor of psychology at the University of Connecticut and lead researcher of the study my son participated in.

Some experts don't like to talk about recovery, because it implies no detectable difficulties.

see My Son Was Autistic on page 38

A Girl's Eye View: Understanding and Supporting Families and their Daughters with Autism Spectrum Disorders

Shana Nichols, PhD
Clinical Director and Researcher
Fay J. Lindner Center for Autism

About a year ago, when doing research for my recently published book *Girls Growing Up on the Autism Spectrum* (Jessica Kingsley Publishers), I stumbled upon a Yahoo! group, "Autism in Girls" (Autism_in_Girls-subscribe@yahoogroups.com). With approximately 1500 members, and a core group of active posters including parents, professionals and women with ASDs, this group has been a blessing for families with daughters and a wealth of information for professionals and educators who work with girls with ASDs. New members are asked to briefly introduce themselves, and every time a mother or father posts, I am struck by how alone and isolated many of these families feel. Some families have yet to receive a diagnosis for their daughter, some are reeling from the findings of a recent evaluation, and others are reaching out to finally join a community that they can connect with. Despite differences in age, level of functioning, geographic location and culture and beliefs, a familiar refrain is echoed in every new post -- "I am so glad to have found this group."



Shana Nichols, PhD

As a professional working with families of girls with ASDs over the last ten years, I greatly appreciate the sense of connection experienced by members of the Autism in Girls list serve. Parents and individuals with ASDs have shared with me that they feel alone in an autism community that until very recently has not

truly considered sex differences in understanding autism spectrum disorders. Girls who participate in our girls growing up programs share that they "finally feel like I'm not the only one," and parents often lament not being able to find resources that are geared towards girls with autism. Just this month, issues raised at our clinic by females with ASDs and their families have included: medication effects and side effects; body image disturbances and eating disorders; self-injury; managing premenstrual syndrome; limited understanding of pregnancy prevention; girl bullying and fitting in with a peer group; frustration with receiving a late diagnosis; and supports for older women with ASD.

In a recent article in the *New York Times* (August 5, 2007), entitled "What Autistic Girls are Made of," Ami Klin, director of Yale University's autism program, described females with autism as "research orphans," suggesting that because research studies primarily include samples of males with ASDs, their findings may not be applicable to females and therefore may do little to shed light on the experiences, development, biology, assessment, and treatment of girls and women on the autism spectrum. Taking this "orphan" analogy further, many families of girls with ASDs feel as if they are orphaned in all areas -- that they lack community supports, resources, and access to experienced professionals. Fortunately,

this is starting to change.

A recent increase in media attention during the last two years, including articles in the *NY Times* (August 2007), *Newsweek* (November 2008) and *Psychology Today* (Flora, 2006), news coverage on ABC's *Night Line* (January 2008), and a contestant with Asperger's on *America's Next Top Model*, has resulted in the spotlight finally being turned to differences between girls and boys with ASDs, and what these differences may mean for issues related to assessment and treatment. Though limited in number, research studies are also emerging which contribute to a small but growing body of literature addressing sex differences in ASDs. Studies have begun to examine differences in symptom presentation, developmental trajectories, prevalence rates, assessment, and diagnosis (e.g., Carter et al., 2007; Hall et al., 2006; Kalyva, 2008; Koenig & Tsatsanis 2005; McLennan, Lord & Schopler, 1993; Reese et al., 2005).

As a field we need to develop a much better understanding of girls with ASDs, including how best to support parents and their daughters. However, I am encouraged that we are moving in the right direction towards learning how to help girls and women with autism spectrum disorders reach their full potential.

See A Girl's Eye View on page 40



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How to Be Your Child's Best Advocate During IEP Meetings

By the Asperger Syndrome and High Functioning Autism Association (AHA)

Sitting at the long table during CSE (Committee on Special Education) meetings and annual reviews can be unnerving. Even the savviest advocates can become anxious and unfocused during meetings. As CSE and annual review season approaches, we decided to ask some of our most experienced members to share their knowledge. AHA facilitators Amy Perri, Joan Trojak, Donna Benkert, Sue Bachemin, Sue Kinsey, Mike Buffa, and Joan Hourihane contributed their thoughts. There were commonalities in their responses; most notably, the real work should be done before the meeting. There are some excellent suggestions below on organization, making contacts, and preparation. If you are well prepared you'll be more confident and have a more clear idea of your child's needs and what your focus should be during the meeting.

Preparation for the Meeting

When you receive an important document (e.g., evaluation, report card) write the receipt date in pencil and put it in one master file or binder. Take time to organize your paperwork and the main goals for your child. As you move into the meeting,



stay focused on those goals. Before the CSE meeting, make certain you meet with the teachers and therapists, etc., to find out your child's present levels of performance. An IEP is only good if it has helped your child make progress during the year, so find out exactly how much progress your child really has made. Get into the school and meet the staff to create a good working relationship before there are any problems, and get involved in the school (PTA, class parent).

You also need to understand how progress has been monitored. Though parents often think they must wait three years, the triennial is actually the minimum frequency: Parents are allowed to ask for standardized evaluations once a year. Yearly testing will give you a clearer picture of whether the IEP needs to be revised to help your child progress.

If you get a sense that your child's services may be in jeopardy, obtain a reputable private evaluation well before your meeting

(note that there are often long waiting lists for good evaluators) and give the reports to the Committee before the meeting.

A week or so before the CSE, prepare an agenda. Read relevant reports in the master file - evaluations and home/school communication notes. Make a general list of problems and potential solutions: put some thought into what you'd like to see for your child in terms of six months, a year, and future success as an independent adult on the autism spectrum. Make a list of goals, services, manpower supports (OT, PT, speech, one-to-one aide, peer sensitivity training, etc.) and important modifications to your child's school day (e.g., extra time between classes, extra time for test-taking, specific peer support like Best Buddies or other club, safe place or designated personnel like a counselor who can aid if things reach critical mass).

Before the meeting, create from this list a clear, one-page, bullet-point Parent Agenda for the IEP with three columns: 1st column - "What we're asking for," 2nd column - "School's response, yes or no," and 3rd column - "If yes, when, how and who. If no, reason why not."

Fill in empty columns 2 and 3 at the CSE. This is the only piece of paper you need in front of you at meetings: it will help you stay on track under pressure. (See the Wrightslaw article "How to Use

see *IEP Meetings* on page 42

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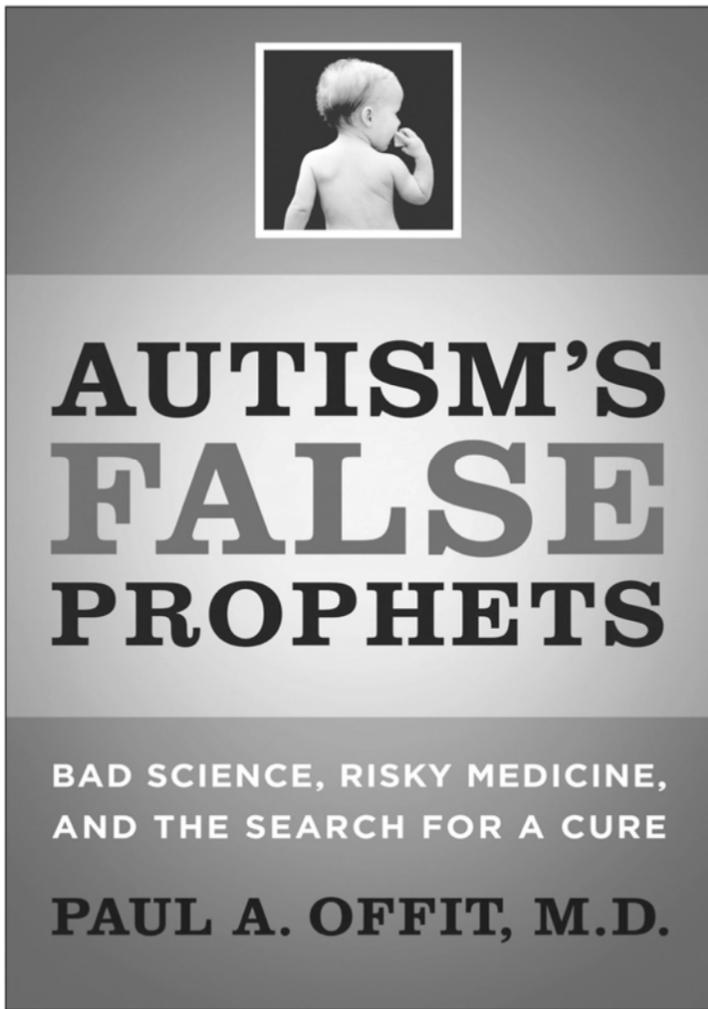
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Coping with Asperger's at Home

By Betsy Ern, MA
Parent of a Young Adult
With Asperger's Syndrome

Raising a child with Asperger's Syndrome defined my experience of motherhood. Andrew was our first child and the first grandchild in both my husband's and my families, and Asperger's wasn't well known at that time.

We found out right away that Andrew wasn't going to be easy. The first three months he cried every night for three hours. He nursed well but had projectile vomiting. He seemed to be in a constant state of frustration, never able to do what he wanted or to change activities. Being young Andrew's mother required a lot of energy.

Andrew's school years were challenging. The emotional and physical effort it took just to get him up and out of the house was enormous. By the time he was off to school, I often felt like I had already done a full day's work. Dealing with teachers who found him a difficult student was also trying. We didn't fully understand what we were dealing with, and it didn't help that some members of our family attributed Andrew's difficulties to our poor parenting.

When we finally first heard about Asperger's, Andrew was in fifth grade. It



Betsy Ern, MA

was a relief to have an explanation for what we were experiencing. Yet Andrew's disability is so invisible that to this day we are faced with people, professionals and educators who misinterpret his behavior. Andrew has progressed yet he remains Andrew, and it can be as difficult to co-exist with the young adult Andrew as it is to have to interpret his behavior for others. Coping is an ongoing battle.

I'm no martyr; taking care of myself was essential to being young Andrew's mother. I worked part time except during Andrew's most difficult middle school years. On some mornings after Andrew and his younger brother were off to school, I would go back to bed; sometimes I had to start the day over again in order to carry on. I went to the gym religiously, two or three times a week. I tried to eat well.

I saw a therapist regularly, at times, once a week. The therapist was especially helpful when I was too close to a situation to see how circumstances had changed. I also not only brought Andrew to his psychiatrist but visited him myself separately to better understand Andrew's and my relationship from his perspective. I sought out as much information as I could handle, reading articles and attending the occasional seminar for insights and strategies for managing a household with an ASD member in it.

Humor helps a lot, and Andrew's different perspective provides plenty of it. When he was in middle school, he was constantly late for school. By Thanksgiving, he'd been late so many times we got a letter from the school advising that Andrew would be suspended from school if he were late again. Andrew read the letter then tossed it aside saying, "That's stupid. They're the ones who are wrong. School starts too early."

I don't belong to any support groups, but have one good friend who also has a son on the spectrum with whom to trade stories and lean on. Once my husband and I knew what we were dealing with, we made it a point to share information with our families. The support of family is crucial.

I found an energizing release in writing about my experiences with Andrew, and he seemed to enjoy that, too. He'd read my drafts and correct me where I had omitted or mistaken details. I also had my doll collecting hobby to distract me from my daily struggles.

My best strategy for coping is to do something fun every day. Maybe I'll talk with my sister on the phone, walk around the mall for an hour, or buy a pie for dessert. We also focus on what's especially good about Andrew. We call this the "Andrew advantage." He wasn't a clingy child and would go happily off with members of my family if we were going away. He liked having babysitters and he's always been a good sleeper. From the time he started talking he's had an amazing command of the English language and he's witty. Andrew is very bright, and we know that in his own time and on his own terms, Andrew will succeed.

My son is now 22 and about to return home from four years away at two different colleges. I'm ready for the adventure of living once again with Asperger's at home.

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Community Grants from page 6

training sessions and ongoing supervision and support for those being trained. Parent training is also a strong component to increase the generalization of skills across different environments. Among the innovative proposals is one in the Southeast that will train teachers and therapists in a summer camp setting for students with ASD. This model is the expansion of a successful existing program and provides support and services to students during the summer months while increasing the cadre of trained specialists that will work with children during the school year. Another educational proposal from the Western region of the country focuses on the ongoing training and development of paraprofessionals working with students with ASD (K-12) in inclusive educational settings.

Young Adult/Adult Services continues to be an area of heightened importance for families as increasing numbers of children with ASD are entering adulthood. For

this round, the proposals in this category represented 11% of the applicants, yet this category represents 23% of the funding. There are a variety of innovative programs that address important needs of young adults and adults with ASD. One such proposal in the Southeast focuses on the transition process and providing the information needed to successfully transition from educational services to adult services. Another successful proposal in the Northeast provides ongoing training and support for individuals with Asperger Syndrome and will focus on life skills such as money management, housekeeping, nutrition, hygiene and grooming, and health and sexuality.

A two-tier review process was used to assess each grant application. In the first tier, each proposal was reviewed by both the parent of a child with autism who had experience in the area of need and an autism professional with expertise in that same area. To help ensure objectivity, proposals were assigned to reviewers located in a different geographic location

from the applicant. A total of 111 proposals that earned an established minimum score were reviewed by members of the Autism Speaks Family Services Committee (FSC).

The reviewers considered the following criteria for each proposal:

Field building – the grant's impact on increasing services (new opportunities) and the capacity of service providers;

Numbers served – the number of individuals currently being served by the program and its ability to expand to serve more people;

Innovation – the creativity of the proposal;

Ability to replicate – the viability of the program as a model for the development of similar programs;

Clarity – the extent of the proposal's defined interim and outcome measures;

Cost effectiveness – proposals must dem-

onstrate cost effectiveness and include a reasonable, detailed line item budget;

Credibility – the qualifications of the organization, its principals and advisors;

Sustainability/viability – the ability to continue the project beyond this funding cycle.

All appropriate applicants will be listed in Autism Speaks' Family Services Resource Guide as part of an ongoing effort to connect families with resources in their area. During the first half of 2009, Autism Speaks will begin to publish the outcomes from its first and second rounds of Family Services Community Grants on autismspeaks.org and through e-Speaks. The hope is that this initiative will provide the information needed to replicate successful programs and the expansion of services for individuals with ASD.

A request for applications for the next round of Family Services Community Grants will be announced in early 2009.

Introducing the Editorial Board of Autism Spectrum News

Richard P. Swierat
Executive Director
Westchester ARC

Since 1975, Richard P. Swierat has worked with people having developmental disabilities. He has been executive director of Westchester Arc for the past 25 years. He frequently speaks at state and national meetings on such topics as guardianship, quality metrics, corporate compliance, person-centered planning in residential and vocational services, board training, family advocacy and the development and management of direct service worker career systems. He is deeply committed to Westchester Arc's self-advocacy movement, and was a driving force behind the creation of the agency's Customer Service Council—its first board-level group comprised of individuals with developmental disabilities. He regularly joins the council for meetings, often travels to state and local conferences with them, and ensures that their input directly affects agency strategies and operations.

Swierat is an adjunct professor at Western Connecticut State University's Ansell School of Business in Danbury, Connecticut. He is on the staff of the graduate school of health care management, with specialties in strategic and financial management. On behalf of the university, he has taught in the Bahamas as a member of the systems change team for health care organizations. Swierat



Richard P. Swierat

periodically works on these issues with other community organizations as a private consultant.

He has a master's degree in special education from the State University College at Buffalo and is currently pursuing a Ph.D. in administration and decision management sciences at Walden University. His dissertation focuses on the recruitment and retention of direct service workers in the field of developmental disabilities.

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

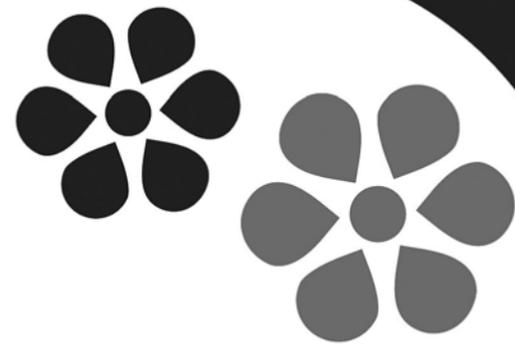
This support group serves families located in the New York Metropolitan area. We usually meet on the Fourth Sunday of each month from 10:30 AM - 12:30 PM at Blythedale Children's Hospital in Valhalla (Westchester County). Blythedale Hospital is located close to White Plains just off the Sprain Brook Parkway and also near the Valhalla Metro North train station (about 45 minutes from Grand Central Station).

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

For further information contact the facilitators:

Bonnie Kaplan - email: Parenttalk@gmail.com

Judith Omidvaran - email: Judyomid@aol.com



SPECIAL NEEDS at The JCC in Manhattan

The JCC in Manhattan provides a wealth of resources and programs for families and individuals with special needs in a warm and open community environment.

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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.

Funding provided by Council Member David I. Weprin, Chair Finance Committee and The New York City Council.

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Summer Camp: The Gift of Friendship

By Debbie and Eric Sasson
Directors of Camp Akeela

Overnight summer camp teaches skills in a variety of disciplines - sports, arts, nature and the like. However, the enduring value of summer camp is not the skills that it teaches, but the values and traits of character that it imparts. A camp experience teaches children to work together more cooperatively, resolve conflicts, assume responsibility, and develop self-reliance and self-confidence.

Parents of kids and teens with ASDs may be reluctant to send their children to sleep-away camp. Yet, children who struggle socially - specifically those on the autism spectrum - stand to benefit the most from the right camp experience. More than anything, great camps teach socialization skills. Overnight camp is an environment in which children learn about living, working, and playing together in a supportive community. Many children form their fondest memories and their deepest friendships at camp. This is especially true for children on the spectrum, who may struggle to make friends at home.

Of course, children on the spectrum have unique needs which not every camp is equipped to address. Finding the right camp is paramount to a successful experience. Here are some suggestions for navigating the process.



Eric and Debbie Sasson

Selecting a Summer Camp for Your Child with ASD

The first step should be to discuss the process as a family. Make sure you and your child are on the same page. It's never a good idea for him/her to find a brochure in the mail before you've talked about camp!

Questions to Ask Yourself and Your Family

- What is on my "must-have" list? (e.g. certain program offerings, minimum session length, ...)
- What type of environment is neces-

sary for my child to make progress in his social/emotional/educational development?

- Will my child "regress" without certain interventions?
- Is my child prepared to live in a more independent way?
- What kind of support does my child need to be successful?
- What are my goals in sending my child to camp?
- How important is it to me what the other campers are like? How similar to my child do they have to be in order for him/her to fit in well?

You're now ready to do some research. Use the internet, a camp advisory service, or resources within your community to identify potential camps. Request and review camp websites and brochures. Next, speak with the camp directors. These are the people who will have ultimate responsibility for your child's well-being. You should feel comfortable enough to speak candidly with them about your family. Most of all, they should understand ASD and be passionate about

see Summer Camp on page 36

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How to Find (and Keep) an Excellent Doctor: A Roadmap

By Mary K. Meyer, BA
Chapter Coordinator
Asperger Syndrome Education
Network (ASPEN)

When we decide we need a new doctor, it often is not a tranquil time. The opportunity for thoughtful analysis and careful evaluation isn't there. On the contrary, it may be an emotional or frustrating time. But why do we need or want a change? The current situation is not working. This roadmap was created to help you find that excellent doctor for yourself or a loved one, and a professional environment that does work.

The goal of our search is a positive doctor-patient working relationship. Achieving that goal requires an effort for both the patient (or the patient's parent) and the doctor. The payback: less stress, less misunderstandings, better results. Studies have shown that the best predictor of success in treatment is a positive doctor-patient relationship.

The good news is that we are living in an age where such a relationship is definitely possible. The internet enables patients to gather a great deal of information. It also facilitates accurate health records, and email communication. Many doctors welcome a patient who wants to be involved in the treatment process.



The Process

The process of finding and keeping a good doctor requires diligence. It is not necessarily difficult, but it requires preparation. The first step is to list your needs – what do you expect/need the doctor to do? This will be critical as you begin your screening process.

Screening

Make a list of potential doctors. Re-

view your insurer's list of doctors; some provide results of customer surveys with questions such as "does your doctor listen and explain things to you." Network with anyone you believe has good information, especially advocacy organizations like the AHA Association (www.ahany.org).

Contact potential doctors with your prepared list of questions and information ready. Doctors value time, information and relationships. Your list should include: Who referred you; Your needs – be clear and concise; His experience? If the

parent of an adult, how is communication with the parent handled? Session management? Method of payment?

Develop a list of alternatives and evaluate your options, using the information you have gathered, plus important factors like how quickly your initial phone call was returned, and do you like and feel comfortable with the doctor?

Initial Session(s)

Bring copies of old evaluations. Bring your medicine bottles or a current list. Teach your doctor (family history, drug reactions, intervention record, traumatic incidents). Bring a master list of key providers, with contact information.

Bring questions into visit time. Ask about alternatives; Is there anything that doesn't fit in the diagnosis? Is there anything else it could be? Could there be *more than one* problem? Do not leave without a clear understanding of what is wrong, the treatment plan, why, and the specifics.

Your Contribution to the Process

A good doctor-patient relationship is *not* a spectator sport. You and your child, whether adult or school age, are a vital part of that relationship.

Be informed - Especially if you are the

see Excellent Doctor on page 38

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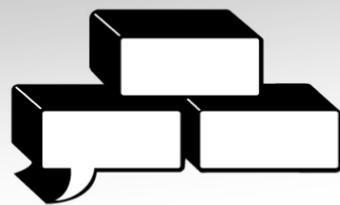
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Robin's Blog

A Resilient Mom's Commentary on Autism



The Triumphs and Struggles of Autism, Quadruplets and College

By Robin Morris
Freelance Writer

I am a mother of 21 year old quadruplets, one affected by autism. Prior to the birth of my children I was an actress and free lance writer. I now devote my time to writing and sharing our story of autism, both triumphs and struggle. I advise other parents by helping them tease myth from truth in pursuing the best solutions for their children, while traveling this arduous journey.

Letting Go

Parents are faced with an inevitable heartache when they send their first child off to college. It is a rite of passage that we endure; nevertheless, whatever the relationship, be it stormy or smooth, when a child moves on, it can rock our world.

I remember that I thought it particularly trite when a friend said she was in a depression as her daughter left for college, many years ago. To be truthful, she said she was "in mourning." My secret response was "oh please, you have a healthy child that is going off to school, how dare you mourn?"

That was my reaction... me, the mother of a child with autism. My dream sends



Robin H. Morris

our child to a real college, and he can use his "uber" memory for academic prowess while autism guides him through powerful accomplishments. It is a dream deferred, maybe deterred, because he continues to grow in his own way.

My sentiments prevail, yet I do understand that parents have permission to be sad and lonely when their kids move on. My own mother tells me that she cried all the way home after dropping me off at college. An uncanny twist on that emotion

occurred three years ago when we took our first child to college. He paused at the car, said goodbye to the five of us remaining and declared "I've left a personal note for each one of you, waiting at home." History is a funny thing. Like my mother, I sobbed all the way home.

The truth is that separation is a life altering experience, but if we have done our jobs; our children will thrive and flourish, and hopefully come home again. My Mother always quotes Thomas Wolfe's title, *You Can't Go Home Again*. Perhaps the particulars will change, but home can mean many things, and for me, home means family, wherever we are.

Two years have passed and we are now empty nesters. Delivering our children to the arms of college and beyond renovates a family's order. What is equally transforming is the art of welcoming them home. How do you fit a square peg into a round hole? My Mom again reminded me of Thomas Wolfe's creed. The connotation notwithstanding, I have developed my very own translation. Our square pegs arrived home from school last May, equipped with carloads of paraphernalia, acquired from a year of memories gone by. Along with the sentiment were carvings of independence and stakes for corners of our house. I knew not where we ended and the new life began; hungry

for "same old" yet ensconced in the now, which was pretty overwhelming.

Suddenly reality bit; in a flash, everything changed. Paul, our son with autism, winced with a pain in his back. I asked him where it hurt and he continued to yell and point to his back and begged to go to the doctor. Paul's medical history chronicles a lung surgery at 6 months old. Given that it was 20 years ago, we relaxed into a life of agony over autism. Now, autism was taking a back seat. Rewinding the years was effortless. Fate propelled me into that frightened mother of 1987, now cradling my man-child as we rushed to the hospital. The doctors feared a pneumothorax, a collapsed lung, a reminiscent term I knew too well. Thankfully, this time we dodged a bullet. Testing determined that he was safe. Miraculously, our boy was okay. What struck me as the sound of angels, were Paul's three siblings, teary and worrying about their brother. We arrived home, hungry and tired. It was a group effort...the square pegs united in one voice, one heart. We took our places at the table; same old, same old; home again.

I once heard a phrase that "when you become a mother you stop being the picture and start being the whole frame." When September arrives, I will see them off to school and fill my frame with the luxury of "home."

Birthdays and Autism

By Robin Morris
Freelance Writer

There is something about celebrating your child's birthday that evokes raw emotion. Years ago I began a tradition of writing a letter to each child, reviewing their triumphs throughout the year. Given that we all remember the bumps and bruises, rather than ignore the "elephant in the room" I celebrate their successes in moving on.

What strikes me is almost mechanical, my tears flow like clockwork, as if someone turns on the switch every time I write these birthday messages. Is it about me? Or is there some greater force that envelops the human condition of parenting.

It occurred to me that these letters began shortly after we tried communicating with our autistic son, when he was only 4 or 5. We created the "good thing - bad thing" conversation at the dinner table. All four children were required to participate, each offering a piece of information about the day. What was so interesting was that we learned about all four kids, while trying to pull language from one. We heard various school details, chroni-



cling who got in trouble or who stole whose lunch was good for a chuckle. I realized then, that the fabric of our lives was now a tapestry, rich in laughter and emotion.

Consequently my birthday letters were born. I tailor each message with keen tenacity, as if the words will protect them long after I am gone. I try to cushion their falls, while praising their spirits. They are

my joy, our four grown children, not babies any more.

Perhaps this is the key. It is about giving life and wings. And so I shed a tear again.

They were born on the Harmonic Convergence. All of the planets in our solar system were lined in perfect harmony. This marked the most stunning event in my life, the birth of our quadruplets.

Today, 8.16.08, they are 21 years old. I

ask myself how we got to this place. Historically I write a birthday letter each year, highlighting their successes and powerful journey. Last night, I feverishly put pen to paper (metaphorically fingers to keyboard) attempting to be original, yet stellar and inspiring, while laced with purpose.

I want to let them know how they have propelled me to be a better person. I want them to know that Danny and I have partnered this passage as a team, by loving each other and raising them with passion. I want them to know that the trials were only measured by how we played the game. I want them to know that adversity can be cunning and devastating, but the mortar by which we have stayed strong. I want them to know that autism can either break you or make you stronger. Finally, I want them to know that "We Are Family" in a way that it transcends the song. My Mother used to say that she "loved us more than life itself," and she completed the sentence...."you'll never know, until".

And so, I pass that baton to our children...."you'll never know, until".

Robin Hausman Morris is a freelance writer and can be reached at RobinHausmanMorris@gmail.com.

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**Travel Training for Higher Functioning
Individuals on the Autism Spectrum**

By Ernst O. VanBergeijk, PhD, MSW
Executive Director & Associate Dean
New York Institute of Technology
Vocational Independence Program



Ernst O. VanBergeijk, PhD, MSW

For most teenagers learning to drive is a rite of passage. For teens on the autism spectrum learning to drive can be overwhelming and anxiety provoking. In order to be able to drive safely a driver needs to be able to anticipate the intentions of others. This necessary skill directly confronts individuals on the autism spectrum with their impairment in their ability to demonstrate Theory of the Mind, or the ability to perceive how others think. This deficit significantly limits their ability to be independent and to be employed. The lack of reliable transportation is one of the most significant barriers to employment for individuals with a variety of disabilities. Since many individuals on the autism spectrum cannot drive, then they must rely upon public transportation.

In order to be able to use public transportation independently, individuals on the autism spectrum must be trained systematically. Ideally, habituating the individual would start early in childhood. Taking trips with parents on buses, subways, and trains is a wonderful way to incorporate both travel training and environmentally friendly transportation. If the use of public transportation is incorporated into the family's daily life then the shift from traveling with parents to traveling independently will not be as dramatic.

Parents are a child's most important teachers. While on the trips with their child, parents can take the opportunity to explicitly teach their child important safety issues; procedures to enact if they become separated from their parents, what to do if they are lost, and who are safe people to ask for help. Cell phone usage in emergency situations should be a part of the discussions. Helping the child pre-program telephone numbers in the cell phone is extremely helpful. Having emergency contact numbers pre-programmed in the speed dial feature will help to avoid panic if the child forgets a telephone number when faced with a stressful travel situation.

As the child gets older, parents can give the child more responsibility for the planning and leading of the family outings on public transportation. Many children on the autism spectrum have an affinity for computers and the internet. This is a perfect opportunity for the child to help plan routes and familiarize themselves with maps and schedules. One caveat in reference to schedules should be noted: the schedules are approximate times and there are many changes. Some children on the spectrum will suffer melt downs if a bus or train is late or a route has been changed. Help them anticipate inconsistencies in the schedules and routes. Map reading skills are a critical skill to teach in this early phase.

The eventual behavior we hope the individual will achieve is the independent

use of public transportation. This is a complex behavior with several layers of skills. Parents should use successive approximations to reach the desired behavior. In other words, start by leading a trip with the child and explicitly discuss where are they headed and how do they know where they are going. During later trips on the same route, the parent should turn to her son or daughter and have them tell the parent where they should board the train or bus and when they should get off. Have the child identify where public maps and other information are displayed. Review on each trip safety procedures and what to do when something unexpected occurs. The next step in the process involves having the older child travel one stop along a familiar route unescorted by the parent. Enlist older siblings or family friends in the process. They can wait for the individual with autism at the next stop or they can unobtrusively observe the individual on the train or bus and give feedback to the parent as to the appropriateness of his or her behavior. The number of stops that the individual travels unescorted should be extended as the person's skills and confidence level increase. Once the individual masters a given route, then other routes can be explored as well as transferring between different modes of transportation, i.e., from buses to trains and vice versa. To increase the individual's intrinsic interest in the travel training the final destinations should be meaningful and pleasurable (e.g. a favorite museum, restaurant, store, a friend's house, an aquarium, etc.).

Part of the planning of the outings should include how to deal with sensory integration issues. Many individuals on the autism spectrum are sensitive to sounds and smells. The sound of screeching subway car brakes or the hiss of pneumatic lifts on buses can be excruciating and may trigger an emotional outburst. MP3 players or portable video gaming systems with earphones can help the individual cope with the overwhelming

see *Travel Training* on page 40

A "Heroed Generation"

The Challenge of Caring for Both a Child with an ASD and Aging Parents

By Margaret McTigue, MsEd, MA
Behavior Therapist
Abbott House

It has been fairly common to hear about the "sandwiched generation." This refers to those who are caring for young children or who are helping young adults navigate the waters of college applications and starting a career path toward their own independent life while at the same time helping their aging parents who are starting to become physically or mentally frail and are in need of assistance. This is a very real challenge faced by a whole generation of middle-aged people. It is indeed a very daunting road to travel.

What of the parents whose young or adult child has Autism, Asperger's Syndrome, and/or mild, moderate, or severe mental retardation? Perhaps they are not only the "sandwiched generation" but, in this age of supersizing, it would be more appropriate to refer to them as a "heroed generation." Indeed, fast forwarding 20-25 years, what happens when they find themselves getting older with more health concerns and find it increasingly difficult to meet the needs of their child who is now 30 - 40 years old?

In some cases, these parents have cared for their adult child virtually on



Margaret McTigue, MsEd, MA

their own in the family home. Others have chosen placement in a group home for their son or daughter. In either case it continues to be a very big challenge. It becomes increasingly difficult to meet all the needs of the adult child or family member as they have done all their lives. It is simply physically and emotionally draining for these older parents. Yet there are some things that can make things a

little less stressful and overwhelming.

The first thing is to develop and utilize a network or support system. Speak to other parents in the same situation. This not only offers emotional support, but also a sharing of knowledge about medical specialists, programs, and community resources. In particular, parents who are caring for their child in the home should be made aware of respite programs. These are opportunities for temporary care in a group home. This would be useful in cases of emergency, if the parents will be away from home, or if they simply need a day or two for a break. Utilizing a respite program also helps everyone become more comfortable with an increased level of independence from each other. It is often desirable to participate in respite care as a way to transition to group home placement if this is an eventual goal.

It is also important to reach out to family, friends, etc. who have a relationship with the family member and to let them help. If they can take over or assist with even one aspect of care, it can make a great difference. It will also be very gratifying to the family member that other people want to spend time with them and participate in their lives.

It is also critical to keep an open line of communication with the professionals that work with the family member. This is a good opportunity to compare notes. It

is also a chance to see what could be carried over from the program or residence that parents can utilize at home. This would be especially true if there are behavioral issues and a behavior intervention program is utilized. A program in place in a residence or day program can often be of some help when the family member is at home with parents and family. Parents should be aware what behaviors are targeted and what interventions work or don't work as the case may be. It is important to know what reinforcers and rewards are utilized. It is also a good idea to talk with residential staff after a weekend home visit for example as this would be a good opportunity to recap what went well and what didn't. It is also helpful to keep in mind that schedules are fluid and can always be adapted or changed. Just because parents always picked their son or daughter up from the residence on Friday and brought him or her back on Sunday doesn't mean it can't change. This schedule may cease to be convenient and it simply could be time to revamp the time schedule. A simple thing like this can alleviate a great deal of stress.

Behavior is probably one of the biggest concerns that parents have. It can often make a long planned and much anticipated outing or trip a disaster. Unfortunately,

see *A Heroed Generation* on page 37

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Oppenheimer Grant from page 7

quarterly publication that provides readers with a trusted source of news, information and resources on scientific research, evidence based clinical treatment, and family issues that are of vital interest to the autism community. Directed towards a broad audience of families, treatment professionals and service providers, *Autism Spectrum News* is widely distributed throughout the tri-state region. In addition to its quarterly newspaper, MHNE provides free and full readable copies of current and back issues of *Autism Spectrum*

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"We are so appreciative of Senator Oppenheimer's support, which will help us reach out to the many families with autism here in Westchester," said Janet Z. Segal, MHNE board member and Executive Vice President of Four Winds Hospital in Katonah, New York. "Senator Oppenheimer has always been a dedicated supporter of the mission of Mental Health News Education, Inc. and on behalf of our entire Board of Directors, I wish to thank her for supporting our new *Autism Spectrum News*."

Coping with Autism Spectrum Disorders *Societal Stigma and Social Support*

By **Oren Shtayermman, PhD, MSW**
Assistant Professor
New York Institute of Technology

Goffman (1963) suggested that the term stigma could be used to refer to an attribute that makes a person different from others. Goffman distinguished between experiencing a stigma due to a visible disability or a hidden disability (Riddick, 2000). Research on the families of individuals diagnosed with disabilities has indicated that these families experience what Goffman referred to as "Courtesy Stigma" (Gray, 1993). This is a process in which members of such families experience stigmatization due to their affiliation with the stigmatized individual rather than through their own characteristics (Gray, 1993). Mor and Berkson (2003) noted that people develop impressions of others who are influenced by the physical characteristics and nonverbal behaviors of others around them. Moreover, people often use movement cues of others when forming impressions of others, and an individual's responses and perceptions to physical cues may also serve as a basis for the construction of stereotypes and for social interactions (Mor & Berkson, 2003). Body rocking is one of the more common repetitive behaviors of an individual with autism spectrum disorders. Mor and Berkson (2003) found that people make more negative trait inferences about people who engage in body rocking than they do about those who do not.

The main concerns for parents caring to a child diagnosed with autism spectrum disorders are related to the child's dependency and potential for independent living (Bouma & Schweitzer 1990; Koegel et al., 1992). Hasting & Johnson (2001) suggest that behavioral, social and cognitive dimensions of the autistic disorder are the ones associated with elevated stress levels among the parents. Social support for parents caring for a child diagnosed with autism spectrum disorders can potentially influence their capability to support and care for their child. It was shown in the literature that social support has differentiated high and low stressed mothers of children diagnosed with autism spectrum disorders; mothers who perceive social support as more accessible reported fewer stress-related somatic



Oren Shtayermman, PhD, MSW

problems and depressive symptoms (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). Social support is a multidimensional construct and no one definition adequately captures the nature, quality or range of behaviors associated with it (MacNeil, Stewart & Kaufman, 2000). Schilling, Gilchrist and Schinkie (1984) defined social support as either individuals, groups, or institutions that can provide assistance of varying degrees and forms to help another individual combat stress that take a toll on a person's resources. Since groups and institutions are part of the social support system that can provide needed support for parents caring for a child diagnosed with autism spectrum disorders, services should include support groups and psycho-educational groups for parents and other family members. These services would not only assist parents and family members to cope with the diagnosis of autism spectrum disorders, but they will also aid in the adjustment to societal response to the disorder.

Oren Shtayermman, PhD, MSW, is an Assistant Professor of Mental Health Counseling, is the Mental Health Counseling Program Coordinator and is a Research Associate at the New York Institute of Technology School of Health Professions, Behavioral and Life Sciences located in Old Westbury, New York.

Autism Spectrum News - Summer Issue
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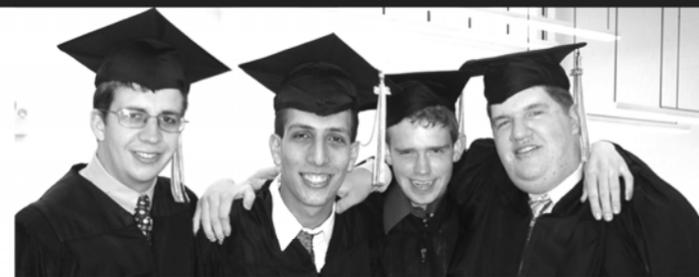
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Project Lifesaver from page 7

their caregivers. The county departments of mental health and public safety will be responsible for the operation of this program, in partnership with Westchester Jewish Community Services. Families will be able to purchase "bracelets" for their child so that they can be located if they wander by specially trained county police officers through the transmitter located in the bracelet. The bracelet resembles a small sports watch and is easily tolerated by most children.

Project Lifesaver has been providing Westchester County with the tracking system for use by seniors with Alzheimer's Disease who wander. They also have experience with, and special equipment for, individuals with Autism who wander. Westchester hopes to have 100 individuals signed up. The program requires monthly battery changes by trained staff and daily checks of the battery by

Identifying Autism from page 13

The American Academy of Pediatrics recommends that all children be given autism specific screenings at 18, 24 and 36 months of age. These screenings should take place even if the general developmental screening tools did not indicate a risk. A recent study (Pinto-Martin et al, 2008) found that a general developmental screening tool missed the majority of children who were found to have an autism spectrum disorder when screened using the Modified Checklist for Autism in Toddlers (M-CHAT). The study supported the American Academy of Pediatrics' guidelines that an autism-specific screening tool should be administered during routine developmental surveillance, in addition to an established general developmental screening tool. The study found that if pediatricians were to rely solely on the outcome of the general developmental screening tool, they would miss a significant proportion of children

Genetic Perspective from page 15

individual genes for mutations. Some of the recent CNVs that have been identified in ASDs include the chromosome 16p11 deletions, chromosome 22q13 deletions, CNTN gene deletions, and NRXN1 gene deletions. Some of the recently identified gene mutations identified in ASDs include mutations in the SHANK3, NLGN3, NLGN4, and PTEN genes. In each of these cases, the CNV or mutation is the major cause of the ASD in that instance. Every time such a cause is identified, the family can be counseled as to recurrence risk (the chance that another family member will have an ASD), and the disorder can be identified earlier in its course (allowing for earlier intervention). Moreover, genetically modified mice can be developed to study the development and prevention of the disorder. As a concrete example, our laboratory has mice that capture several of these genetic conditions that lead to ASDs, including the 22q13

deletion and the SHANK3 mutation, and we are studying the changes in the mouse brain resultant from these mutations. We are already considering ways to manipulate these animals to reverse the mutation-induced changes.

As we as a field find more and more of these rare variants, one can ask how well we can identify the genetic cause of ASD in a particular case. With modern methods, the better sites are successful in as many as 20-30% of the cases and there is every reason to expect that this rate will double in the next 2-3 years.

parents. This is one of the many projects we hope to embark on to improve services for families and children on the autism spectrum in Westchester County through the work of our Autism Advisory Committee, which was convened last April, and is made up of parents, advocates, educators and service providers in the field of Autism.

I formed the Autism Advisory Committee to assist the Westchester County Department of Community Mental Health in identifying research, services, resources and funding mechanisms that would expand and enhance the opportunities for children and adults in Westchester County on the Autism Spectrum and their parents. They are also working to assess the existing services available to individuals and families in Westchester County and determine where gaps exist in the current service delivery system and the types of services that will help to fill those gaps. In 2008, there were more than 800 children in Westchester school districts with a di-

agnosis on the spectrum. This number does not include adults with Autism who are no longer in school and are being cared for by families.

In addition to Project Lifesaver, the county has recently done the following to meet the needs of families with children who are on the autism spectrum:

who are at risk of developing autism. The M-CHAT is a useful tool for pediatricians and parents because it has demonstrated significant sensitivity and specificity, usually in children older than 18 months. The checklist is based on identifying the social and communication delays in children with autism. The items on the questionnaire focus on the child's joint attention, eye contact, interactions and behaviors.

A growing body of research aims to identify early reliable indicators of autism. One of the most common behaviors separating infants with autism from typically developing infants is an abnormal response to their names being called. The failure to respond to their own name at age 12 months of age may be a reliable marker of autism (Nadiq et al, 2007), especially if the infant also shows reduced eye contact and a lack of interest in other people's faces.

Testing for name response at 12 months during well-child pediatric visits may be an effective way to screen for autism. If a child does not respond to his or her name being called, pediatricians are encouraged to make a referral for a more comprehensive assessment.

Challenges

While it is clear that rigorous measuring and tracking of children's head circumferences and the administering of autism-specific screening tools will identify many children at risk for autism, these strategies take time. Primary care physicians and pediatricians are under more pressure than ever before to see more patients in less time. Crowded waiting rooms present a real-world challenge for doctors who spend an average of 10-15 minutes with their patients. Carving out time for diagnostic screening and surveillance is perhaps the biggest obstacle confronting doctors in the early identification of children with autism spectrum disorders.

- The county launched a special section of its Web site dedicated to autism issues and services (www.westchestergov.com/autism). The site provides information about local resources and events in the field of Autism and includes access to a directory of resources through Autism Speaks, a national organization. It also includes an autism events calendar on which organizations can list their events, workshops, meetings, etc. Our hope is that this website will be a resource to both families and professionals in Westchester.

- As many parents have expressed concern about their adult child's behaviors being misunderstood or misinterpreted in the community, The Westchester County Department of Public Safety has included Autism Awareness training for law enforcement recruits in their curriculum at the Police Training Academy. This portion of the training is conducted by a police officer who is also a parent of a young man with Autism. The first training occurred in October and was very well received.

Registration for Project Lifesaver will begin in January. Families interested in the program may download the application from the Department of Community Mental Health Autism Website, www.westchestergov.com/autism or the Westchester Jewish Community Services website, www.wjcs.com

Charles Cartwright, MD is Director of the YAI Autism Center at the YAI/National Institute for People with Disabilities Network. Amerha Rafiq, MD is Pediatrician for Premier HealthCare at the YAI/National Institute for People with Disabilities Network.

The Child Neurology Society has identified the following red flags that would indicate an immediate need for an evaluation. These include:

- No babbling or pointing or other gesture by 12 months of age.
- No single words by 16 months.
- No two word spontaneous phrases by 24 months.
- Loss of language and social skills at any age.

variants in ASD continue to be identified, animal models that recapitulate the genetic change(s) can be developed. These models can clarify the progression of ASDs, and will be useful to evaluate novel pharmaceutical interventions. An exciting development that serves as a model going forward is the new understanding of the basis of FXS, which has led to the initiation of a recent large-scale clinical trial in FXS. As additional rare variants associated with ASDs are identified, novel therapeutic approaches will be developed, some of which may be specific to a given rare variant ("individualized medicine") and some of which may prove effective across ASDs with differing etiologies.

Research forms the cornerstone of these approaches and I encourage all families to learn about current research and consider joining in this important endeavor. The Seaver Autism Center for Research and Treatment has received support from the Seaver Foundation, the

Handler Foundation, the National Institutes of Health, Autism Speaks, the Simons Foundation, and many individual donors. The Seaver Autism Center is a site where families can access exceptional clinical care in ASDs, including comprehensive behavioral and genetic evaluations and state of the art treatment. Individuals with ASDs and their families will also find the Seaver Autism Center a welcoming place where they can learn more about ASDs and participate in research dedicated to discovering the cause(s) of ASD and developing new medical and behavioral treatments. For more information, please call 212-241-0961.

Dr. Joseph D. Buxbaum, PhD, is Director at the Seaver Autism Center for Research and Treatment, Chief of the Division of Basic Neuroscience in Psychiatry, Head of the Laboratory of Molecular Neuropsychiatry, and Professor at the Departments of Psychiatry, Neuroscience, and Genetics and Genomic Sciences at Mount Sinai School of Medicine in New York.

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Coping in Families from page 1

words, people who feel that they have individuals in their lives that they can speak to about their feelings and experiences cope much better than those who do not report the availability of such support. This makes sense, in that the absence of such support when needed would increase isolation and feelings of aloneness. Another form of social support that has been identified as important includes formal support services such as parent training and respite services. Such support services help individuals to develop instrumental coping strategies by imparting specific skills (e.g., parent training) or by alleviating the daily burdens of the situation (e.g., respite). It has also been shown to be helpful to know others in a similar situation (e.g., Farran & Sparling, 1988; Honig & Winger, 1997). This reduces isolation and provides a unique form of support from others that are facing similar issues on a daily basis.

Individual Characteristics That Facilitate Coping

In addition to such instrumental coping strategies, people are helped in adapting to stress by palliative coping strategies, or strategies that provide comfort, control, or meaning. It may be that certain individual characteristics insulate people from the negative effects of stress by providing and fostering such comfort and meaning. Having a strong belief in one's own ability to control events is linked to better coping, as it reduces feelings of helplessness and leads to effective problem-solving. Holding philosophically comforting life views is also associated with posi-



Cecelia M. McCarton, MD

tive adaptation. For example, many families develop broad perspectives on the positive benefits of the experience and ascribe important meaning to the experience on an individual or familial level. Furthermore, having a high level of involvement in helping one's own child and/or other individuals with autism seems to help families adapt. Families who involve themselves deeply in their own child's program join as full members of the educational team, and can steer the course of their child's treatment, ensuring that important goals are addressed. Families who involve themselves in broader involvement in the autism community can feel a sense of purpose in advancing the cause of meeting the needs of all people and families affected by autism. Finally, having an optimistic attitude toward life's challenges may help protect individuals from succumbing to the negative effects of stress (e.g., Albanese,

San Miguel, & Koegel, 1996; Gill & Harris, 1991; Weiss, 2002).

Having a child with an ASD is intrinsically stressful. While families must cope with a difficult reality that they may have never considered, they must also find the resources to address the child's significant needs. Families sense and are told that time is of the essence, and that they must act immediately to obtain effective services once the diagnosis is received. Such services are often hard to find or are simply unavailable, multiplying the stress. We have heard from parents that finding professionals and appropriate school programs leads to reduction in stress. For many families, securing treatment after challenging and frustrating experiences is associated with a great feeling of relief.

As we mentioned above, the nature of the stressor is a chronic, long-term circumstance – more of a marathon than a sprint. Therefore, parents need to conserve some energy for the long haul. Finally, as also noted above, the ambiguity is high, because of the diversity within the diagnosis. Outcomes include having life-long dependence on others and becoming indistinguishable from peers, and everything in-between these two possibilities. In the toddler and preschool years, in particular, it is often not possible for clinicians to predict a particular child's path. Tolerating this level of ambiguity is a serious challenge for most parents, and can delay the process of acceptance until the impact of the disability is clear for this particular child.

Growing up With Autism: The Sibling Experience

Effects of autism also extend beyond the parents to the brothers and sisters of the person with autism. Children with autism engage in behaviors that may be upsetting or perplexing to brothers and sisters. Kaminsky and Dewey (2001) found that siblings of children with autism experienced less sibling intimacy, positive social interaction, and nurturance than did siblings of children with Down syndrome or of typically developing children. However, they also described a greater admiration for their brother or sister and fewer feelings of competition.

It can be helpful for parents to provide

developmentally appropriate information to the siblings about the nature of autism to help reduce fear and misconception and to aid understanding (Glasberg & Harris, 2003; Glasberg, 2000). It can also be helpful to teach siblings how to engage their brother or sister in simple toy play (e.g., Celiberti & Harris, 1993). This can reduce the disappointment siblings feel if they are unsuccessful in getting their sibling to attend to them or engage with them.

Older adolescents and adults sometimes report that their experiences as a sibling of a child with autism taught them a patience and tolerance they might not otherwise have learned. Martins (2007) also reported that siblings of children with autism are drawn to the helping professions and often report a sense of mission about helping others on a large scale. As parents age, typically developing siblings may have to increase their involvement with their sibling with autism and may have to cope with the death of their parents without the kind of sibling support they might wish was possible.

Summary

Families may be helped by participation in support groups, by meeting and networking with other families of children with autism, by becoming involved in advocacy efforts, and by contributing to causes and programs that improve the lives of people with autism. Coping may also be enhanced by finding activities that bring them joy and by developing good stress reduction skills. Siblings may be helped by being provided with accurate information, by teaching them skills to interact effectively with their brother or sister with autism, and by knowing other children in a similar circumstance.

There can be plenty of joy in a family that includes a child with autism, and many families report that such joy outweighs the challenges. A family that copes effectively may feel closer to one another because they have worked together to manage difficult circumstances. And families that cope well may experience the special pride and pleasure that come from meeting life's challenges with determination, grace, and optimism.



McCarton Foundation

The McCarton Foundation is dedicated to increasing the educational opportunities for children with autism and ASD and making a better life for them and their families.

Please join us for our Parent & Caregiver Workshop:

"Structuring Leisure Time"

Wednesday, March 25th, 2009

6:30 – 8:30

(Workshop will be held at The JCC in Manhattan)

For more information please contact:

Harvey Weissman - (646) 277-5422

hweissman@mccartonfoundation.org

350 East 82nd Street, New York, New York 10028

Summer Camp from page 29

changing the lives of children!

Questions to Ask the Camp Directors

- What is the camper to staff ratio? How many staff members and campers live in each bunk?
- How do you recruit and train the staff? What are your basic requirements for age and experience working with children on the spectrum?
- What are the living accommodations? Will there be enough space to accommodate my child's needs?
- What can you tell me to confirm that you really understand my child's special needs?
- What is the application process?
- Are you willing to meet me and my family?
- How will the directors and staff com-

municate with me while my child is at camp?

- Tell me about how you got involved with this camp?
- How will you help prepare my child (and me) for camp before the summer?
- Is there flexibility in the camp program to accommodate a challenging day or a need that my child has?
- How much structure and choice are built into daily activities?

Debbie and Eric are the directors of Camp Akeela, a coed, overnight summer camp in Vermont for children and teens with Asperger's and NLD. Debbie has a Master's in School Counseling and a Doctorate in Clinical Psychology; Eric has a Masters in Education from Harvard University. Akeela focuses on building a community in which campers feel great about themselves, make friends, try new things and have fun! For more information about Camp Akeela, see www.campakeela.com or call Debbie and Eric at 866-680-4744.

Rice Study from page 1

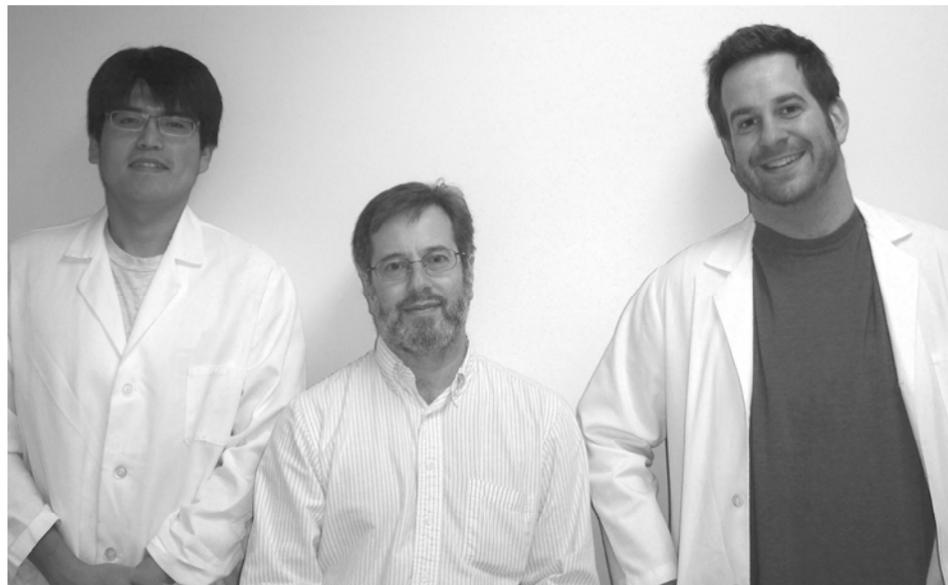
neurofibromatosis. The Department of Defense is very interested in how PI3K is regulated in the nervous system because of its role in tumor formation.”

Discovering the negative feedback loop that keeps neurons stable was key, said Stern, but not the end of the investigation. “We know that glutamate activates mGluR and PI3K, but we don’t know how,” he said.

“There are almost certainly a number of intermediates that remain to be identified, and we have several candidates we’re looking into.

“We’re finding a mechanistic link among these molecules that hadn’t been previously appreciated,” Stern said.

“Obviously the next step would be to test whether these same molecules are playing similar roles in mammalian neurons,” said Howlett, who will leave Rice in the spring to pursue postdoctoral cancer research at Vir-



Curtis Lin, Michael Stern, BS, PhD, Eric Howlett, William Lavery (absent)

ginia Commonwealth University. A native Houstonian, he earned his bache-

lor’s in biology at the University of Houston-Clear Lake.

Howlett said mGluRs had already been targeted in possible treatments for schizophrenia, epilepsy and other “excitability” diseases, so it’s not a stretch to think his research could lead to even more strategies in treating neurological ailments.

“Actually, all of the molecules involved in our model have been implicated in one way or another with neurological diseases, but no one has been able to link them together into a coherent explanation of the diseases,” he said. “Our model provides a novel framework that could really go a long way toward doing that.”

The research study was conducted by Dr. Michael Stern, Curtis Lin, Eric Howlett, and William Lavery. The research article can be found at www.plosgenetics.org/article/info%3Adoi%2F10.1371%2Fjournal.pgen.1000277. This press release has been reprinted with permission from Rice University.

School-Age Program from page 13

quickly gauge a sense of comfort and confidence in a teacher’s ability to communicate what he or she is doing in classrooms and how individualized the educational plan is for each child,” Dr. Cartwright said. “Ask teachers about the different ranges of disabilities in their students and how they tackle different behaviors.”

Be sure to ask school officials about the staff turnover rate. - “There’s nothing that drives parents more crazy than starting the year with one teacher, but going through two or three more teachers by end of year,” Dr. Cartwright said. “The teacher never had an opportunity to get to know their child or learn how their child processed information, and what worked well with their child.”

Mia advises parents to inquire about staffing levels to ensure that there’s sufficient coverage among speech and other therapists. “At many schools, if a speech pathologist is on a leave of absence, there’s a big gap in services.”

Look for a balance of support and nurturing with room to grow. Will the school challenge your child? Is there enough emphasis on cognitive, social and language development? - “If your child is not a talker yet, you need a curriculum that focuses on language all day long,” said Carol Stein-Schulman, Assistant Director of the New York League for Early Learning. “Language has to be taught and some children need hundreds of opportunities to use words. It can’t be done in a half hour.”

Are there strategies in place to increase a child’s repertoire of interests, as well as

interventions available that can reduce repetitive behaviors? - “Teachers should also recognize that there are a number of co-existing conditions or behaviors that go along with autism, such as anxiety, poor impulse control or difficulty sustaining attention,” Dr. Cartwright said. “For example, a child who experiences anxiety needs more structure. The teacher should have a knowledge base about what strategies can be used to reduce these levels of anxiety.”

Some parents have realized that many schools for children with special needs focus too much on the “special” and not enough on the “education.”

Make sure that the school’s educational curriculum suits your child. - Whether the school uses an intensive ABA model, verbal behavioral approaches or other evidence-based strategies, the curriculum should benefit your child’s academic growth, as well as his or her communication, social and psychological development. Ask the school about the data they collect and how it’s used to track a child’s progress.

Dr. Cartwright finds that many children on the spectrum respond to a developmental matching process, which identifies a child’s strengths and relative weaknesses. This enables teachers to match the most appropriate educational model -- from a highly structured intensive behavior approach to a relational approach, such as DIR®/Floortime™ Model – with the student. This technique has been incorporated in the New York League Model ©, which has been developed over 15 years in NYL’s seven preschools.

According to many families, the absence of social skills training marks a

major gap in many schools.

“Many of the children on the spectrum aren’t given the opportunity to socialize with their non-disabled peers or learn social skills,” Mia said. “Many times what you see is that many programs are in isolated areas of a school. That’s something to think about. Do you want your child in an isolated setting or in a place for integration into mainstream events.”

Ask about “specials,” adaptive physical education, art and music. These classes often provide opportunities for inclusion. Having role models is important for the development of social skills in children on the spectrum, Dr. Cartwright adds. “And their parents want their children to have the same academic and social experience that any other child would have in a school-age program.”

After touring schools and visiting with teachers, make sure you speak with parents of students who are a year or two older than your child. “Network, make those phone calls and get their advice,” Michelle says.

The YAI/NIPD Network is in the process of developing a school-age program in Manhattan for children on the autism spectrum. For more information, contact Randi Kent Mattson, Executive Assistant, at 212-273-6145.

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 with autism spectrum disorders, please contact YAI LINK at 1-866-2-YAI-LINK; TDD: 212-290-2787, link@yai.org or visit yai.org.

Carol Stein-Schulman, Assistant Director of the Education and Training Department for YAI/National Institute for People with Disabilities, a member of the YAI/NIPD Network, understands that changing school environments creates anxiety. “You’re facing something new and unknown,” she says. “Knowledge can ease your anxiety.” According to Carol, these are some questions parents should ask when looking for a school-age program for their child on the autism spectrum.

- Does your program have an individualized approach?
- What methodology or combination of approaches do you use?
- Who are the people on my child’s team? Are they Board Certified? (Remember, parents are part of the team).
- Do you provide staff training? Parent training?
- Ask to see data and program books
- How do you provide for generalization of skills?
- Do the children learn and have fun?

To Help You Make a Decision:

- Take into account all your hard work and data.
- Listen to your instincts as a parent and an advocate.
- Consider the needs of other family members.

Provide Autism Spectrum News to Your Clients or Staff - See our Group Subscription on Page 43

A Heroed Generation from page 33

this is not something that can ever be completely avoided. Yet being aware of certain things like noise level, the size of a venue, or how much walking is involved can help in planning and may eliminate a few potential problems.

Along with planning and positive behavioral intervention, it is crucial to be in communication with medical experts. This includes exploring the possibility of medication to help intervene with significant behavioral issues. Parents should be very comfortable with consulting with a psychia-

trist and getting a clear indication of the risks, side effects and potential benefits of a medication being recommended.

By building this network, developing an open line of communication with the professionals in their child’s life, and realizing that it is okay to

change things, it is hoped that these parents can relax. It is hoped they can realize that their decades of caring and advocacy have produced great results and, perhaps most importantly, that they can have peace of mind as both they and their children grow older.

My Son Was Autistic from page 23

“Sometimes parents want me to say their child is normal,” after improving so that they no longer meet the specific criteria for a diagnosis of autism, said Fred R. Volkmar, director of the Child Study Center at the Yale School of Medicine and one of the world’s leading autism experts. “If by that you mean no detectable social troubles or oddities, that is uncommon,” he said. “It happens, but usually there are some problems that persist, even if they are minor.”

Those problems, Fein said, include other learning disabilities and psychiatric conditions, most often attention-deficit hyperactivity disorder. Social phobias may also persist. A child with a social phobia is capable of making friends but avoids big parties and being the center of attention.

A Mother’s Journey from page 19

and achievement of their lives. We must place our precious children in the hands of their teachers and professionals, and by parents and professionals collaborating toward common goals held for our children, we work together to find the whole-life teachable moments our children need.

There are many experts whose dedication to the field of autism has raised awareness and improved treatment and education for our children. Their expertise has furthered understanding of autism in the recent decade and continues to do so. Some experts have paved the way, and others are just beginning their career and will continue developing the field, continue to benefit our own children throughout their lives. These experts research, they lecture, they write literature, they publish their studies, they work for non-profits, and they volunteer their time on committees and organizations. These are our heroes, those whose life-work has improved our children’s and our families’ lives.

Excellent Doctor from page 30

parent of an adult child, you must be aware of the HIPAA Privacy Rule. By law, the doctor cannot disclose information about your adult child without their permission. However, a savvy practitioner can convey vital information to you without breaking the privacy and trust of the patient (You should be aware of the doctor’s approach from your initial visit).

Be respectful of the doctor’s time - Don’t be late. If you have a question or need a letter, bring it up at the beginning of the session.

Keep good records - Create a medication/

CEO from page 7

colleagues and staff whose values personify the best that our nation has to offer.” Founded in 1957, the YAI/NIPD Network is among the nation’s largest

A Catch-All Diagnosis

My son was 2 years old when a behavioral evaluation labeled him autistic. The report said: “Neurological examination revealed a self-directed, language-delayed boy who had pacing behavior. Imaginative play was infrequently seen . . . The results for Leo using the CARS [Childhood Autism Rating Scale] were consistent with a diagnosis of autism.”

Leo had the three cardinal traits of autism: poor social interaction, lack of verbal and nonverbal communication, and funny mannerisms, more clinically described as odd and repetitive behavior and fixed interests. Three months later, he received a diagnosis from the Yale Child Study Center of PDD-NOS, or “pervasive developmental disorder -- not otherwise specified.” It’s a catch-all diagnosis on the autism spectrum for people who are less likely than others to have intellectual impairment.

Sometimes what can be the most touching is seeing strangers interact with our children; strangers who see evidence of the individual’s challenges, and then reach out and interact in a way that facilitates or perhaps just demonstrates their respect. It might be the teenage clerk at McDonalds patiently, perhaps timidly asking questions of an individual with autism who is attempting to order food, or perhaps it’s the shopper at Barnes and Noble smiling appreciably at an individual with autism reading a Disney story aloud to nobody in particular. Seeing strangers appreciate our loved ones with autism, helping them, charmed by them, accepting them, and interacting with them shows us a sample of pure and sweet goodness in people.

Finally, and perhaps most significantly, it’s the other parents of special needs children who touch us. We see another special parent, and we connect. We understand. A young daughter of a stranger demonstrates behavioral difficulties at a

intervention record with dates, interventions, doses, and results. Record if stopped and why.

Communicate - If you make changes to your medication, let the doctor know what you did and why and the result.

Provide feedback - Send a complimentary letter when you are pleased.

When it’s Just Not Working

If you decide after a reasonable amount of time, that things are just not working for you or your child, you may want to revisit some of the questions you initially asked,

providers of services for people with developmental and intellectual disabilities, including autism, Down Syndrome, and Cerebral Palsy.

“While our nation and our field are now confronting a challenging economic

Words popped out of Leo’s mouth every now and then, and he repeated phrases from “Thomas the Tank Engine” videos without any context. It was a challenge for him to express a basic need, such as “more juice.” He ignored group activities and never broke out in a big smile to share an accomplishment. Under stress, he traced the floral design on our rug or paced as if he were trying to figure something out. At the beach, he pitched his forehead into the sand, scooping up wet handfuls to dribble them on either side of his temples. In the grocery store, he’d burst out crying for no apparent reason.

Spooked Into Action

Leo’s diagnosis also had a profound impact on me. It spooked me into action.

The science of early human development tells us that the brain has breathtaking plasticity during the first three years

parent-and-child gymnastics class, and we tell the struggling mom that things do get easier. That’s enough said, that struggling mom feels connected, saying “thank you for your comforting words” at the next gymnastics class. Or we know a mom whose physically handicapped son had recent surgery and we remember to send a note asking how he’s recovering and how she’s managing. Regardless of whether the challenge is autism or another disability or illness, raising a child with special needs is a very challenging role. We may not all share the same hardships and joys, but we all share the same goal of providing the best quality of life for our children, and wishing for the optimal outcome. We all share the burden of personal hardships. We share comfort and pain even when no words are spoken. We know, we love, we cope, we parent.

This is what our children with autism enable in us, the chance to see what people are capable of. It’s in looking for the goodness in ourselves, in our children, and in all people, it’s through appreciating the

i.e., “Is there anything that doesn’t fit? Is there anything else it could be? Could it be more than one thing?” Provide feedback by telling your doctor what you need. Ask what you can do. Ask for help in finding another doctor if you believe that is best for you.

Don’t be afraid to change doctors. You learn from each relationship, and change is one step closer to success.

Summary

Finding a good doctor can be a challenge. Changing the emphasis from simply finding a “good doctor” to developing a positive doctor-patient working relationship can alter your search, and hopefully

environment, I am sustained by the courage of the people we serve, the perseverance of families, our staff’s commitment to excellence, the support of our friends and donors, the guidance of our Board of Trustees, and our partnerships with the

of life. I was in a race against time to set him on a developmental path that would lead to independent living. The urgency to help him was almost primal.

I abandoned my writing career to manage an early intervention program that Yale and Leo’s special education teachers recommended. At its height, Leo’s program consisted of up to 35 hours a week of seven different therapies, and I was always on the lookout for anything else that might help him.

We settled on those with the most scientifically proven strengths. They included an approach to behavior modification that didn’t include repetitive instruction, a form of play therapy, social skills groups, occupational therapy and speech therapy. We tried but stopped several alternative therapies: music therapy and auditory integration therapy, which supposedly re-teaches the ear to listen, and

see My Son Was Autistic on page 42

efforts that we all make, that we find our own strength. That’s how we come to cope.

Where can you learn more about effectively parenting children with autism? Science-based treatment such as applied behavior analysis (ABA) can help you teach your child most effectively and shape his behaviors. There are a variety of websites one can visit for more information:

- The Parent-Professional Partnership Special Interest Group of the Association of Behavior Analysts International (ABAI), at www.pppsig.org/
- The Autism Special Interest Group of the Association of ABAI, at dddc.rutgers.edu/autismsig/
- ASAT Association for Science in Autism Treatment, at www.asatonline.org
- BACB Behavior Analysts Certification Board (find BCBA’s in your local area at www.bacb.com)

provide a satisfactory long-term result.

This article was inspired by a lecture given by Peter Della Bella, MD, at the AHA Association 2008 Spring Conference at Adelphi University. The title of his talk was “How to Make Your Physician Work for You.” I am grateful for his thoughtful insights, and trust this article is faithful to his intent.

Mary K. Meyer is chapter coordinator of the Adult Issues North Chapter for ASPEN. She is also a founding member of the Asperger’s Coalition - a six member organization that is dedicated to improving the lives of adults with Asperger’s Syndrome. Mary also serves on the NJ Governor’s Task Force on the Needs of Adults with Autism.

corporate sector and government,” Philip Levy said. “I am confident that, by working together, we will achieve our goal of ensuring that people with disabilities will continue to thrive and attain their rightful place in society.”

Investigational Drug Study for Children with Autistic Disorder



Does your child seem overly irritable or aggressive (towards either self and/or others)?

Does your child throw tantrums or have quick changes in mood?

Is your child between 5 and 17 years of age?

If so, your child may be eligible to participate in a research study being conducted at the Fay J. Lindner Center for Autism and Developmental Disorders, a member of the North Shore-LIJ Health System. The purpose of this study is to evaluate the effectiveness of the study drug on irritability and related behaviors associated with Autistic Disorder in children and adolescents.

Participation in this study involves:

- A diagnostic assessment
- Monitoring visits with the study psychiatrist and research staff
- Study drug or placebo (a substance containing no medication) for 6 weeks, with the possibility of a 26-week extension trial where all participants will receive the study drug.

If your child qualifies, all of the above is provided at no charge, including all aspects of the evaluation, study visits and study drug.

For more information about the project, contact the study coordinator,
Linda Spritzer, at **(516) 802-8608** or e-mail at **lspritze@nshs.edu**.

This study is being conducted at
4300 HEMPSTEAD TURNPIKE, BETHPAGE, NY 11714

**North
Shore LIJ** *Fay J. Lindner
Center for Autism*

North Shore-Long Island Jewish Health System

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Authorities from page 9

view, the officer learns from the parents that this subject is very sensitive to light, sudden movements and loud noises. Additionally, the officer learns that the subject takes an anti-psychotic medication and anti-seizure medication which causes the subject to suffer from many cardiac related side-effects. Furthermore, the officer is informed that the subject's mother has an incredibly connected relationship with her son. He often listens to her directions and seeks her comfort in stressful times. The officer explains the fact that he must take her son into custody and requests her help to minimize the physical and emotional impact on her son. The mother agrees and approaches her son to request that he sit on the porch and talk with her. Within five additional minutes, the son is no longer yelling or pacing. Five minutes thereafter he is in custody and off to the police station. Most likely still emotionally hurt with possible physical impact but the potential for profound damage has been greatly reduced.

The Police and Other First Responders Are Not the Only Guilty Parties

Prosecutorial responses to the individual with an ASD can be as generic and problematic as the responses of law enforcement to this issue. Invariably, prosecutors (District Attorneys) throughout the United States will claim that the mission of their office is to achieve justice and protect the public safety. Yet, there are scant mechanisms in place to effectively deal with a defendant suffering from an ASD. Most likely the ASD defendant will be treated either as an individual with a major mental illness (formally diagnosed per the DSM-IV) or treated as a typical criminal defendant. Both approaches are rife with problems. Many individuals with ASD have high intellectual functioning yet completely lack the ability to emotion-

ally and physically withstand the process of a criminal trial. Therefore, they are neither unfit for trial under traditional definitions of mental fitness nor are they able to effectively assist in their own defense.

The very concept of criminal culpability presents a very troubling dilemma. Most crimes are defined as having two parts, the mental state (intent – generally) and the act itself. It is entirely unclear if many individuals with an ASD can truly formulate the intent to commit many crimes. Occasionally, an individual with an ASD may physically lash out as a means of achieving a goal that cannot be obtained due to any number of emotional or expressive barriers. For example, if an individual with an ASD hits a healthcare aide in the arm at her clinic because her therapist was replaced and she cannot vent this frustration properly, did she truly intend to commit assault? This young lady is not mentally ill and is quite intelligent, therefore she will not meet criteria for lacking the ability to stand trial or criminal responsibility due to mental illness, commonly referred to as the insanity defense. What is left is to stand trial or make a plea bargain. She cannot work effectively with her attorney because even the thought of discussing this event causes her to become silent. Making matters worse, prosecutors are not trained to understand ASD and will typically view the ASD defendant as far more dangerous or troubled than she is in reality. The result? Quite possibly a period of incarceration or alternate monetary punishment, (along with a criminal record), that bears no relationship to most traditional theories of justice or punishment.

Higher Education and the Work Place: Imperfect Progress

Educators and employers should be given praise for their advances in establishing educational and employment opportunities to individuals on the Au-

tism spectrum. However, generally, much more work needs to be done. When it comes to the issue of disciplinary action and responding to situations where individuals with ASD are involved, the collective response is quite draconian. Often, academics and/or employers will offer academic admission and employment opportunities to an individual with ASD without these academic or workplace administrators having had proper education and training regarding the disorders or their impact on people. As a result, responses to a situation when an individual with an ASD acts inappropriately are usually swift and severe. Fear of the disorder and the unknown typically leads these entities to act to protect the institution without regard to the challenged individual. This attitude usually leads to unjust probations, suspensions, or terminations.

What is the Solution?

"It isn't that they can't see the solution. It's that they can't see the problem" (G.K. Chesterton). The solution to most systemic problems begins with education and changing people's attitudes. The kind of change needed to address these issues involves not only educating people about Autism spectrum disorders but changing attitudes in relation to theories of justice, responsibility and punishment and removing the stigma attached to living with a disorder on the Autism spectrum. People, government and private institutions all need to work collectively to achieve a level of fundamental fairness that will afford an individual with an ASD a set of rights that most of us usually take for granted. I would like to continue the dialogue on this issue and would appreciate hearing from you. If you have a comment on this topic or any other topic dealing with Autism and the law please feel free to e-mail me at dstern@abramslaw.com or call (516) 592-5857.

A Girl's Eye View from page 23

What Can Professionals and Educators Do to Support Clients and Families of Girls with ASDs?

- Listen carefully to and validate parents' concerns. Correctly identifying girls with ASDs can be very challenging and many families will have received confusing and conflicting information about their daughter, leaving them feeling frustrated and often disillusioned.
- Encourage diagnostic clarification and consider that the symptoms of females with ASDs may differ from those of males. Refer girls for further assessment even if they come close to but do not meet strict cut-offs on screening tests in all areas.
- Become well-versed in what is currently known about females with ASDs and develop an understanding of typical sex differences in behaviour and development; start with Koenig and Tsatsanis' chapter on girls with Pervasive Developmental Disorders in the Handbook of Behavioural and Emotional Problems in Girls (2005).

- Work to bring girls with ASDs and their families together. It can go a very long way for families and their daughters to experience a sense of validation and connection: you are not alone.

- Assist families in accessing resources about females with ASDs. Though there are few that specifically address issues facing girls, they do exist, including online articles and books (parents and women and teenage girls with ASDs have written autobiographical accounts).
- Investigate whether there are programs for girls with ASDs in your community. Some clinics offer social skills groups specifically for girls (see Fay J. Lindner Center for Autism, The Gray Center for Social Learning and Understanding).
- Encourage families of females with ASDs to participate in ongoing research.

Dr. Shana Nichols, PhD, is Clinical Director and Researcher at the Fay J. Lindner Center for Autism. Dr. Nichols is author of the new book, "Girls Growing Up on the Autism Spectrum" (Jessica Kingsley).

Travel Training from page 32

sounds. One way to deal with overwhelming smells is to have the individual carry a handkerchief that has been sprayed with a fragrance that the individual finds soothing.

Parents should consider enlisting assistance in travel training when it appears that their efforts are not producing the desired results. Under the Individuals with Disabilities Education Act (IDEA) students have an Individualized Education Program (IEP). Travel training goals can be written into the IEP. A young child's IEP goals can include pedestrian skills. Once the child reaches age 14 his or her transition plan can include learning how to use mass transit. A second source of assistance for the school-aged child is summer programs. Some summer programs explicitly train students on the autism spectrum to use mass transit. When an individual reaches post-secondary age parents can enlist the assistance of private post-secondary programs and social service agencies as well as state offices of developmental disabilities and vocational rehabilitative services to provide travel training services.

FOOTNOTES

1. New York City Assembly - Committee on Public Safety – Briefing Paper and Report of the Governmental Affairs and Human Services Divisions - Robert Newman, Legislative Director - "Examining the Roles of the NYPD and the Department of Health and Mental Hygiene in Responding to Calls to the Police Involving Emotionally Disturbed People."

2. The Surgeon General estimated that 2.6 percent of the U.S. population has a severe and persistent mental illness. [U.S. Department of Health and Human Services. *Mental health: A report of the Surgeon General* (1999).] Therefore, there were 7 million people with severe and persistent mental illnesses in the United States in 1998. [Bureau of Justice Statistics (2001). U.S. Census Bureau. Monthly estimates of the United States population. Available at <http://www.census.gov/population/estimates/nation/intfile1-1.txt>. (Visited May 4, 2001).] People with mental illnesses committed at least eight of the 61 police homicides that occurred in 1998 (13 percent) at a rate of 11 per 10 million. [Treatment Advocacy Center. Preventable tragedies database. Available at [/ep.asp](http://www.treatmentadvocacycenter.org/ep.asp). (Visited June 26, 2003).] Fifty-three police homicides were committed by the rest of the population of 263 million, at a rate of two per 10 million. [Brown, Jodi M., and Patrick A. Langan. *Policing and homicide, 1976-98: Justifiable homicide by police, police officers murdered by felons*.] Thus, people with mental illnesses committed police homicides at a rate 5.5 times greater than the general population.

3. Brown, Jodi M., and Patrick A. Langan. *Policing and homicide, 1976-98: Justifiable homicide by police, police officers murdered by felons*. Bureau of Justice Statistics (2001).

Before enrolling an individual with autism in a travel training program, the parent should ask for a copy of the curriculum. The National Dissemination Center for Children with Disabilities (www.NICHCY.org) website has an excellent document entitled *Travel Training for Youth with Disabilities* (1996) which outlines best practices of travel training programs. It is a useful document to help in writing IEP goals and evaluating a travel training program. Mastery of travel training skills not only increases a person on the autism spectrum's confidence and employability, but also reduces the burden on the family of always having to drive or escort the person. Systematic travel training helps insure safe and successful independent travel.

Dr. Ernst VanBergeijk is the Associate Dean and Executive Director of New York Institute of Technology's Vocational Independence Program. He is also a research associate at the Yale Child Study Center's Developmental Disabilities Clinic and is assigned to the autism unit. The publication of this article was made possible by a grant from the National Institute of Health, LRP grant (Number, L30HD053966-01).

Institute for Child Development



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The Institute promotes the welfare of children who are challenged by developmental, learning, and emotional disorders, through its service, training, advocacy, and research programs. Intensive treatment and educational services are provided by the Children's Units. Our guiding philosophy is to employ intensive, time-limited, child-centered, empirically validated educational and clinical procedures. Children who manifest developmental, learning, or emotional disorders impact not only upon themselves, but also on families and communities. This challenge must be met by a reciprocal intensity, quality, and precision of services. We firmly believe that providing a caring, warm, supportive environment that respects the dignity of individuals and celebrates their unique qualities and potential is the minimum starting point for services. Our hallmark is the use of empirically validated research that appears in peer reviewed professional journals. We utilize highly sophisticated assessment and evaluation technology to amplify the clinical skill and expertise of our staff.



The Institute is currently involved in the following applied activities in ASD:

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- Undergraduate training in ASD
- Graduate training in ASD
- Training and technical support through the Center for Autism Spectrum Disorders
- Development of community living options for individuals with ASD, funded through the NYS Office of Mental Retardation and Developmental Disabilities
- Support to all counties in NY for Early Intervention child and family outcomes evaluation, funded by NYS Department of Health.

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<http://icd.binghamton.edu> and click on the link for the *Child Safety Survey*.

This research project has been approved by the Binghamton University Human Subjects Research Review Committee.



My Son Was Autistic from page 38

neurofeedback, which supposedly retrains the brain to focus more.

It was an incredible juggling act as I struggled to prioritize treatments that experts recommended. I also fretted about ignoring Leo's older brother while engaging in battles with the D.C. school system and my health insurer over payment for his special education and therapies and monitoring his progress to adjust the program as he progressed. I led this life for four years, while my husband paid the family bills.

Seven years after the initial diagnosis, Leo has achieved significant gains in areas thought to be unattainable by even high-functioning children with autism spectrum disorders.

He attends a regular school and is socially engaged, articulate, creative and performing at grade level with a tutor for reading and handwriting. He understands and can express complex and abstract thoughts. He can empathize. And he has friends he cares about and who care about him.

I won't say that all the traits that led to Leo's diagnosis have disappeared. But the ones that remain are not unique to children with autism spectrum disorders.

For all his achievements, he is a spirited little boy with hair-trigger emotions that can overtake him when he cannot bend the world to his will. His behavior is sometimes compulsive. In Freudian terms, he is all id.

As for me, I became the socially iso-

lated person I worked so hard to keep Leo from becoming. My social network disintegrated in the years that I immersed myself in Leo's recovery.

The Jury is Still Out

Fein and her team in Hartford will either validate my belief that Leo has moved off the autism spectrum or tell me he is still on it. We're waiting to hear.

Their testing over two days was comprehensive. An examiner evaluated Leo's IQ, language and social skills, and his behavior and interests. She asked him questions such as "What is footwear?" and "What does 'find fault' mean?" Leo said, footwear "is something you put on your feet to keep them from getting dirty." He said "find fault" is a "way of saying that you are not the person who, for example, broke your mom's favorite vase."

To test his reasoning skills, he had to solve mathematical games such as the Tower of Hanoi puzzle, moving a stack of disks from one rod to another without putting a larger disk on top of a smaller one.

The brain scans that I found so mesmerizing were intended to give researchers more understanding about how his brain behaves by showing which regions lighted up when he responded to certain statements. Some were designed to evoke a visual image ("The letter 'J' looks like an umbrella handle"); others either stated, or misstated, facts ("Elephants can breathe underwater").

IEP Meetings from page 25

a Parent IEP Attachment" by Judy Bonnell, www.wrightslaw.com).

Make sure you have all the information you need to make informed decisions. If possible, get a rough draft of the proposed IEP. Let staff know it's nearly impossible to digest all the information in the meeting without advance preparation. If the district typically does not furnish reports ahead of time, request in writing that you receive copies of reports for review so that you can participate as a full member of the CSE. You have a right to all information that the rest of the team will have. Also put in writing any additional people you want at the meeting (e.g., the gym teacher if adaptive PE is being discussed, etc.).

Advance information should also include the proposed goals from each provider. If the needs are complex in certain areas, a separate goal review meeting with the provider may be warranted. If you're frustrated with lack of progress, check the goals: are they clearly stated and measurable, and is the method of measurement indicated? It also helps to put time into communicating with providers when things have gone right throughout the school year.

During The Meeting: Interpersonal

This is often an emotionally fraught time, so it helps to approach the professionals at the meeting as if you are on the same side - with the common goal of helping your child. Before and during the meeting, take time for some deep breaths, and center yourself. Give yourself the time you need to digest the information before making a decision; there is no law stating how long a CSE should last. Honestly state your concerns and ideas in a candid, non-confrontational way. Be ready to let go of some of the minor details in order to

focus on the bigger picture for your child's success. Be flexible where it is warranted and don't budge when you absolutely know what your child's needs are and can prove it.

Make sure that you're really listening: you may gain valuable insights from other members of the committee, and it helps to understand the group's dynamic. Agree to whatever you can agree to; ask that unresolved issues be tabled for a future date. At least then there will be a new IEP that includes the things you think will help your child and those things can be implemented without a wait. You may have to agree to disagree. Sometimes it's worth agreeing to the recommendation to see if it works. But ask for measures that will ensure that, if the recommendation does not work, the Committee will reconvene soon to adjust the IEP. You can ask that a date to reconvene be written into the notes on the IEP. But decide now how progress will be determined.

Bring someone with you: if the mother typically goes alone, remember that we're not in a post-feminist world, and sometimes "the man with the tie" can give your side more authority. And as with important medical appointments, it helps to have another set of ears and someone to take notes - it's hard to do so when you're involved in the discussion. You can also rehearse before the meeting to simulate key arguments or concerns. You can ask your child's doctor to be present in person or by telephone. Their influential title and lack of emotional investment may make your argument for the needs of your child more persuasive. Pay attention to your own presentation: this is a professional meeting, so act and dress accordingly.

You may be listened to more seriously if you check your frustration or anxiety at the door. The same "takes 20 positives to neutralize a negative and 100 to reverse it" rule that works for teachers will likely work

I answered hours of questions focused on Leo's ability to make and keep friends. I said Leo had friends, even a best friend, and asked for play dates without prodding from me. That's key: While many children with autism spectrum disorders have friends, according to Catherine Lord, director of the University of Michigan Autism and Communication Disorders Center, they don't seek out peer relationships. "Having an aunt or a music teacher as a friend doesn't count," she said.

Hope for Parents

Researchers today credit earlier diagnosis and treatment for creating more positive outcomes like my son's, but early intervention isn't the whole story.

In 1980, when autism was added to the Diagnostic and Statistical Manual of Mental Health Disorders (DSM), the bible for psychiatric disorders, the diagnosis focused on mental retardation. Studies showed that up to two-thirds required residential care or hospitalization in adulthood. About 2 percent achieved moderate to high levels of independence and had some friends but worked menial jobs in factories and office buildings.

In 1994, the fourth revision of the DSM broadened the criteria for autism to include individuals who were more cognitively able. Since then, not surprisingly, studies have shown rosier outcomes for more children.

In 2007, Wendy Stone, a professor of

pediatrics and psychology at Vanderbilt University, compared her own study of a group of children age 2 to 4 who had been given an autism diagnosis with the results of similar studies. Children received various types and amounts of intervention. But the number of therapy hours they received did not predict their outcome. What did? Age at diagnosis, symptom severity and cognitive skills.

"I don't know that the children 'recovered,' though they did improve . . . to the extent that they no longer met the diagnostic criteria," Stone said. "Almost all continued to have some form of developmental disorder."

"I think the most hopeful message we need to give parents," said Geraldine Dawson, chief science officer of the non-profit group Autism Speaks, "is that all children with autism are capable of learning and developing new skills with the help of early intervention."

And that's just what my now affectionate and fun-loving son, Leo, has done, whatever the results of the Hartford testing ultimately show.

Jayne Lytel is Executive Director of the Early Intervention Network: Enabling Families to Act Early Against Autism. Jayne is the author of her new book "Act Early Against Autism: Give Your Child a Fighting Chance From the Start" (Perigee). To learn more about Jayne and her new book, visit her website at www.jaynelytel.com.

on teachers. But along with being professional towards the teachers comes the responsibility to be true to your child's needs by sticking to your guns on the essentials. Know when enough is enough.

During The Meeting: Getting What's Needed

Make sure that you have your organized binder with you at the meeting: if any questions arise, you will have the information at your fingertips. If you are requesting new services, particularly OT or PT, have a doctor's prescription ready.

If you don't understand what the testing means, ask until you do. Ideally, do this prior to the meeting, but if not, ask during the meeting until you understand. Have everyone identify themselves and their title/position; take notes. In some circumstances, it may be prudent to record the meeting; you will most likely need prior approval from the district.

The name of the game is not how much you can get on your child's IEP but whether the supports really support him or her and enable progress. It will do your child no good, for example, to enforce the "daily speech therapy" provisions of the Part 200.13 if your child's real communication issues have much more to do with social skills deficits than with frank speech issues. Sometimes it's better to have the Committee come up with a creative solution than to invoke the letter of the law.

Don't say that what you want is the "best" for your child. Couch your requests in language from IDEA: that you want an "appropriate" public education that meets the "unique" needs of your child and "prepares" the child for further education, employment and independent living. A school district is not legally obligated to provide the "best" education.

If it becomes clear during the meeting that you will need additional documentation or information before making a decision, request to adjourn the meeting. You do not have to sign off on anything.

After The Meeting

You may want to write a letter to the CSE Chair thanking the Committee members for their time and effort. In that letter, summarize what was agreed to and anything that was denied (over your objections). Ask that the Chair to respond in writing if there is a misunderstanding. Keep that letter in your file. Keep in mind that you can always call another CSE at any time if the decisions made at this meeting don't seem to be working. And remember, if it was not written down, it didn't happen.

Attending support groups is a critically important way to network and get input from other parents who have "been there, done that." The support group facilitators have done a terrific job of guiding you through this complex process. We realize that there is a lot of information to absorb. Support group meetings are about bringing your notebook, not just your tissues. Facilitators have shared similar experiences, can empathize with your emotional responses, and will help you brainstorm solutions to your specific issues.

This article was written with recommendations from AHA Association's support group facilitators Sue Bachemin, Donna Benkert, Mike Buffa, Joan Hourihane, Sue Kinsey, Amy Perri, and Joan Trojak and was edited by Emily Raphael. This article was published in the Winter 2009 issue of AHA Association's newsletter On the Spectrum. For more information please contact the Asperger Syndrome and High Functioning Autism Association (AHA), Inc. at (516) 470-0360 or visit their website www.ahaNY.org.

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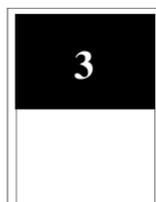
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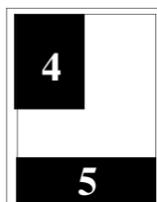
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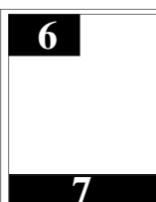
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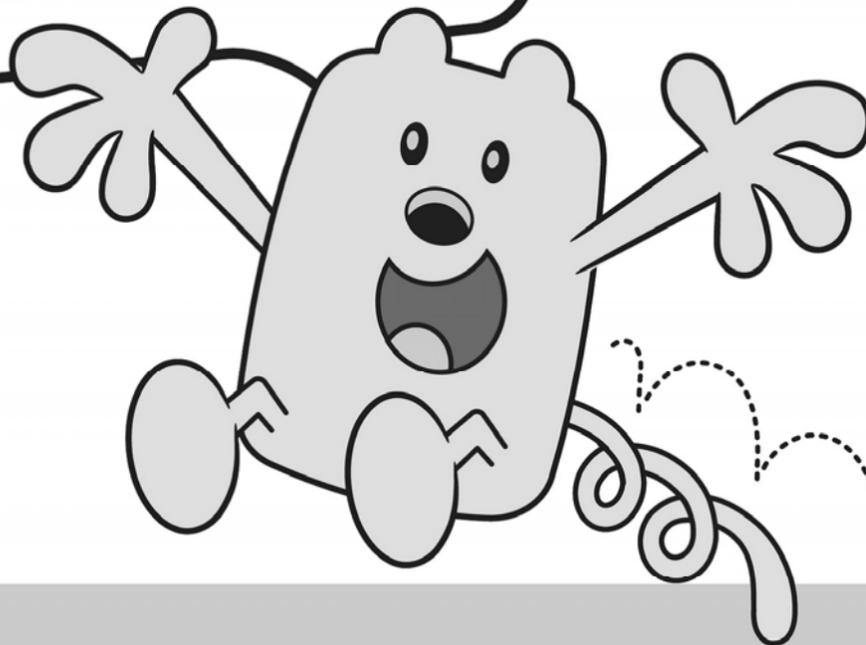


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www.WorldAutismAwarenessDay.org



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