

# AUTISM SPECTRUM NEWS™

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

WINTER 2009

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 1 NO. 2

## Understanding and Treating Autism Spectrum Disorders

The National Institute of Mental Health (NIMH)

Not until the middle of the twentieth century was there a name for a disorder that now appears to affect an estimated one of every five hundred children, a disorder that causes disruption in families and unfulfilled lives for many children. At the same time a German scientist, Dr. Hans Asperger, described a milder form of the disorder that became known as Asperger syndrome. Thus these two disorders were described and are today listed in the Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (fourth edition, text revision)<sup>1</sup> as two of the five pervasive developmental disorders (PDD), more often referred to today as autism spectrum disorders (ASD). All these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive, and stereotyped patterns of behavior.

The autism spectrum disorders can often be reliably detected by the age of 3 years, and in some cases as early as 18 months. Studies suggest that many children eventually may be accurately identified by the age of 1 year or even younger. The appearance of any of the warning signs of ASD is reason to have a child evaluated by a professional specializing in these disorders.



Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed “different” from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to social overtures, something is wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.

The pervasive developmental disorders, or autism spectrum disorders, range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder. This article will focus on classic autism, PDD-NOS, and Asperger syndrome, with brief descriptions of Rett syndrome and childhood disintegrative disorder.

What Are the Autism Spectrum Disorders?

The autism spectrum disorders are more common in the pediatric population than are some better known disorders such as diabetes, spinal bifida, or Down syndrome. CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network released data in 2007 that found about 1 in 150 8-year-old children in multiple areas of the United States had an ASD. Since the ADDM sites do not represent a nationally representative sample, the prevalence estimates should not be generalized to every community in the United States. Although accurate for the areas studied, rates may be higher or lower in other areas. However, these prevalence estimates can help communities project how many children may have autism for planning and identification purposes. They can also be used to provide for more appropriate interventions for children with ASDs. Results from CDC’s ADDM network showed the average ASD prevalence among states participating in the project was 6.7 per 1,000 children in 2000 (6 sites) and 6.6 per 1,000 in 2002 (14 sites), or approximately 1 in 150 children.

Most sites identified between 5.2–7.6 per 1,000 8-year-old children with ASD in 2000 and 2002. There was some variation with ASD prevalence significantly lower in 1 site (3.3 in AL) and higher in 1 site

*see Understanding on page 36*

## Autism Tissue Program Accelerates Autism Research

By **Connie Frenzel, RN, MS**  
Outreach Coordinator  
Autism Tissue Program

The Autism Tissue Program (ATP) was created to provide a centralized source of post mortem brain tissue so that scientists worldwide could study brain regions for changes that could account for autism behaviors. Due to the wonderful support we have received from donor families, precious tissue has been distributed to 87 researcher groups, contributing to a better understanding brain function in autism. Over 60 papers have been published by scientists who have accessed this resource from those with autism, donors related to

someone with autism and those who are unaffected but understand the need for ‘control’ donor brain tissue. Teri Baker, whose child Ragan died of a seizure at age 18, encourages donation saying that “knowledge is the key that will grant us the opportunity to gain prowess over our condition.”

The Autism Tissue Program is very concerned about unexpected deaths experienced by many of the donors with autism and epilepsy and in those with no history of seizures. Last year, Reid Thompson, an 11-year-old boy with autism from Thousand Oaks, California, tragically and unexpectedly died in his sleep. Even in the face of this catastrophic loss for his family, the Thompsons also courageously made the decision to donate

brain tissue to the ATP within the critical time period of less than 36 hours after Reid’s death. “Reid had autism but we don’t know exactly why his life here with us was cut short,” said Brian Thompson. The cause of his death is still unknown and Reid’s parents continue to seek answers about his untimely death, not only for their own closure, but also to help other families with autism.

New and elegant genetic studies of brain tissue are offering some insights into autism spectrum disorders. A recent publication by Professor Michel Simonneau titled “SLC25A12 Expression is Associated With Neurite Outgrowth and is Upregulated in the Prefrontal Cortex of Autistic Subjects,” was chosen as the cover article for the prestigious journal

Molecular Psychiatry. His group pursued the genetic analysis of cells in two brain regions of interest in autism, Brodmann’s area (BA) 46, an area of the cerebral cortex responsible for motor planning, organization and regulation, integration of sensory information and regulation of intellectual function and action, and the cerebellum. Specifically, they were interested in following a trail of evidence their group reported several years ago suggesting the importance of a genetic programming mechanism for the mitochondrial aspartate/glutamate carrier that functions in energy production and cell metabolism. Their first evidence for the potential involvement of this gene, called SLC25A12,

*see Autism Tissue Program on page 43*

NON PROFIT  
ORGANIZATION  
U.S. POSTAGE PAID  
WHITE PLAINS, NY  
PERMIT NO. 153

Mental Health News Education, Inc.  
16 Cascade Drive  
Effort, PA 18330

## The Autism Spectrum News Editorial Board

Joel Bregman, MD, Medical Director  
Fay J. Lindner Center for Autism and Developmental Disorders  
North Shore - Long Island Jewish Health System

Joseph D. Buxbaum, PhD, Director  
Seaver and New York Autism Center of Excellence  
Mount Sinai School of Medicine

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

Steve Freeman, Associate Executive Director  
YAI National Institute for People with Disabilities

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

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

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

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

Judith R. Omidvaran  
Parent Advocate, New York

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

John C. Pomeroy, MD, Founding Director  
Cody Center for Autism and Developmental Disabilities  
Stony Brook University Medical Center

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

Alison Tepper Singer, Executive Vice President  
Autism Speaks

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

Richard Swierat, Executive Director  
Westchester ARC

Fred Volkmar, MD, Director  
Yale Child Study Center

Carey Zuckerman, President  
Autism Society of America, Manhattan Chapter

## The Mental Health News Education, Inc. Board of Directors

### Chairman

Peter C. Campanelli, PsyD, President & CEO  
Institute for Community Living

### Vice-Chairman

Janet Z. Segal, LCSW, Executive Vice President  
Four Winds Hospital

### Secretary

Peg Moran, LMSW, Senior Vice President  
F·E·G·S Health and Human Services System

### Treasurer

Peter Beitchman, DSW, Executive Director  
The Bridge

### Members of The Board

Constance Y. Brown, MPA, Vice President, Corporate Community Relations  
Institute for Community Living

Carmen Collado, LCSW, Director of Immigrant and Latino Services  
Jewish Board of Family & Children's Services

Donald M. Fitch, MS., Executive Director  
The Center For Career Freedom

Michael B. Friedman, LMSW  
Public Policy Consultant

Mary Hanrahan, LCSW, Government Relations Specialist  
New York Presbyterian Hospital

Amy Kohn, DSW, Executive Director & CEO  
Mental Health Association of Westchester

Leo Leiderman, PsyD, Director, Latino Treatment Services  
Saint Vincent Catholic Medical Center

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

Barry B. Perlman, MD, Director of Psychiatry  
Saint Joseph's Hospital

Alison Tepper Singer, Executive Vice President  
Autism Speaks

Giselle Stolper, EdM, Executive Director  
Mental Health Association of New York City

Alan Trager, Executive Director & CEO  
Westchester Jewish Community Services

Jonas Waizer, PhD, Chief Operating Officer  
F·E·G·S Health and Human Services System

Carolyn Reinach Wolf, Esq.  
Abrams, Fensterman, Fensterman, Eisman, Greenberg, Formato & Einiger

## Autism Spectrum News™

Is a publication of Mental Health News Education, Inc, a nonprofit organization.

Mailing Address: 16 Cascade Drive, Effort, PA 18330

Phone: (570) 629-5960 E-mail: iraminot@mhnews.org Website: www.mhnews-autism.org

Mental Health News Education, Inc. does not endorse the views, products, or services contained herein.  
No part of this publication may be reproduced without permission. We are not responsible for omissions or errors.

Copyright © 2009 Mental Health News Education, Inc. All rights reserved.

# Autism Spectrum News - Table of Contents

## The Publisher's Desk

- 5 Praise From Readers Tells Us We're on The Right Track

## Autism Spectrum News Desk

- 6 NYS Governor Signs Bill to Help Children with ASD's  
 6 Cartwright New Director of YAI/NIPD Autism Center  
 7 Study Refutes Connection Between Vaccine and Autism  
 7 NIMH Terminates Chelation Study for ASD's  
 8 Common Mechanisms May Underlie Gene Mutations  
 8 Father Honors Son's Memory by Running For a Cause  
 8 Law Enforcement Receive Autism Training

## Our Cover Story: Understanding and Treating Autism Spectrum Disorders

- 1 Autism Spectrum Disorders: An NIMH Overview  
 1 Autism Tissue Program Accelerates Autism Research  
 9 Dr. Paul Offit Speaks Candidly about Childhood Vaccines  
 11 Autism Speaks Announces New Treatment Grants  
 11 Family Services Community Grants Announced  
 13 Accessing Services and Coping with a Child's Autism  
 13 Riding in Trains with Asperger's  
 14 Understanding and Treating Self-Injurious Behavior  
 15 Social Skills Therapy Groups  
 17 Interventions to Reduce Escape and Avoidant Behaviors  
 19 Building Communication Skills in Non Verbal Children  
 19 Autistic Spectrum Disorders: A Social Dilemma  
 21 Robin's Blog: A Resilient Mom's Commentary on Autism  
 22 View From the Spectrum: Autism From Around the World

- 23 The Daniel Jordan Fiddle Foundation at Work  
 25 Understanding Science and the Scientific Method  
 26 Understanding Asperger Syndrome  
 27 Dr. Roy Richard Grinker on Autism and Culture  
 29 Meeting the Needs of Students With Autism  
 30 Introducing the Editorial Board of Autism Spectrum News  
 31 Dr. Catherine Lord Answers Questions for Parents  
 31 New Program Educates Teachers About Early Intervention  
 33 Living With Autism: What Every Parent Should Know  
 34 The Importance of Suicidal Ideation and Peer Victimization  
 35 CAT-kit Helps Children with Thoughts and Feelings  
 37 Challenges for Parents of Children with Asperger's  
 41 Social Skills Training for Children with Asperger's  
 43 A Parent's Perspective on Autism Spectrum Disorders

## Autism Spectrum News Upcoming Theme and Deadline Calendar

### Spring 2009 Issue:

**"Helping Parents and Family Members Cope with ASD's"**

**Deadline: December 15, 2008**

### Summer 2009 Issue:

**"Education for Children & Adults with Autism Spectrum Disorders"**

**Deadline: March 15, 2009**

### Fall 2009 Issue:

**"Addressing the Needs of Adults on The Spectrum"**

**Deadline: June 15, 2009**

### Winter 2010 Issue:

**"Understanding the Assessment Process: What Parents Should Know"**

**Deadline: September 15, 2009**

## Autism Spectrum News Thanks Our Honored Sponsors

### *Platinum Sponsor*

Anonymous (2)

YAI National Institute for People with Disabilities

### *Gold Sponsor*

New York State Office of Mental Retardation  
and Developmental Disabilities

Seaver and New York Autism Center of Excellence  
Mount Sinai School of Medicine

Westchester County Department  
of Community Mental Health

### *Silver Sponsor*

McCarton Foundation

Services for the Underserved

### *Advisor Sponsor*

Abrams, Fensterman, Fensterman,  
Eisman, Greenberg, Formato & Einiger, LLP

### *Friend Sponsor*

Judith R. Omidvaran

## Help Support our Nonprofit Mission Become an Honored Sponsor of Mental Health News Education, Inc.

### *Benefactor: \$25,000*

Thanks to your generosity you will receive the following added benefits: A custom designed multi-page section including advertising and article space in 4 quarterly issues of Mental Health News, Salud Mental, or Autism Spectrum News. We will also ship as many copies of the newspaper as you need for distribution to clients, staff, board members, and satellite programs.

### *Platinum: \$10,000*

Thanks to your generosity you will receive the following added benefits: A full page advertisement and article space in 4 quarterly issues of Mental Health News, Salud Mental, or Autism Spectrum News. This layout is designed to give your organization a dramatic two-page spread in the newspaper. We will also ship you several bundles (50 copies per bundle) of the newspaper for distribution to clients, staff, board members and satellite programs.

### *Gold: \$5,000*

Thanks to your generosity you will receive the following added benefits: A half page advertisement and article space in 4 quarterly issues of Mental Health News, Salud Mental, or Autism Spectrum News. We will also ship you several bundles (50 copies per bundle) of the newspaper for distribution to clients, staff, board members and satellite programs.

### *Silver: \$2,500*

Thanks to your generosity you will receive the following added benefits: A quarter page advertisement in 4 quarterly issues of Mental Health News, Salud Mental, or Autism Spectrum News. We will also ship you 1 bundle (50 copies) of the newspaper for distribution to clients, staff, board members, and satellite programs.

### *Bronze: \$1,000*

Thanks to your generosity you will receive recognition on our honor roll page.

### *Advisor: \$500*

Thanks to your generosity you will receive recognition on our honor roll page.

### *Friend: \$250*

Thanks to your generosity you will receive recognition on our honor roll page.

*All of the above sponsor categories will receive special recognition on our special honor roll page in each issue of Mental Health News, Salud Mental, or Autism Spectrum News. All contributors to our nonprofit mission, regardless of the amount, will be recognized with great honor in every Spring Issue of Mental Health News, Salud Mental, and Autism Spectrum News, as a follow-up to our annual fall fundraising appeal.*

### **To Become an Honored Sponsor Please Contact**

**Ira H. Minot, LMSW, Executive Director**

**Mental Health News Education, Inc.**

**16 Cascade Drive, Effort, Pennsylvania 18330**

**E-mail: [iramintot@mhnews.org](mailto:iramintot@mhnews.org) Phone: (570) 629-5960**

## We Wish to Thank our Advertisers For Their Participation and Support

Carla Alvarez-Gould, LMSW

Future Horizons

Asperger Syndrome and High  
Functioning Autism Association

Institute for Child Development  
SUNY Binghamton

Autism On The Seas

Interactive Autism Network

Autism Speaks

Jewish Board of Family  
and Children's Services

Chapel Haven

Long Island Psychiatric

Columbia University Press

New York Institute  
of Technology

Devereux

Simons Foundation

Donna Klein & Associates

Social Skill Builder

Fay J. Lindner Center for Autism

The Daniel Jordan Fiddle Foundation

F·E·G·S Health and Human  
Services System

The JCC in Manhattan

Foundation for Educating  
Children with Autism

Westchester Jewish Community Services

## From The Publisher

### Praise From Readers Tells Us We're On the Right Track

*“One of the most informative and educational publications I have read in ages.”*

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

Soon after our recent fall premier issue of *Autism Spectrum News* reached readers, we began receiving feedback on our new publication. We had worked on its development for over two years, so you can imagine how excited we were when calls and emails praising *Autism Spectrum News* began to come in. Here's a sample of what readers told us.

“As the parents of an adolescent child on the spectrum, your new publication is a “breath of fresh air.” For years, we have been struggling to find a trustworthy source of news, research reports, and up-to-date information, about our son's illness. The internet has a tremendous amount of misinformation—much of which we found to be untested and quite dangerous. Many parents like us are desperate to find help for our children and there are many “experts” out there who are praying on us with expensive and risky therapies. The evidence-based mission of your new *Autism Spectrum News* will stand apart as a “beacon of hope” to parents. We have told all the members of our support group about it and want to thank you for this outstanding new publication!”

“I am in receipt of the premier issue of *Autism Spectrum News* and must tell you that cover to cover, it is one of the most informative and educational publications I have read in ages. Thank You! I am a parent of a daughter with an ASD, a special education advocate providing pro-bono services and support to parents, and a school board member fighting for services for our special needs population. Your publication provides reliable content in all three areas. THANKS! I would like to contribute an article for your spring issue under the topic “Helping Parents and Family Members Cope with ASD's.”

“I just returned to campus after vacation and found a copy of the premier issues of *Autism Spectrum News* in my mailbox. I read many of the articles, and they are fantastic. The Dean of our program, has authored many articles in various publications throughout the country and would be happy to write an article for your newspaper as well on a variety of topics such as transitioning from high school to post secondary school and the impact on Asperger's Syndrome on parents”



Ira H. Minot, LMSW

We are so pleased that you are finding *Autism Spectrum News* to be both helpful and informative. Your praise and support of our evidence-based mission is also very important to us, because it tells us we're on the right track. Having to turn advertisers and articles away because they don't meet our editorial policy is difficult. However, the evidence-based community has responded in a very positive way.

In this issue of *Autism Spectrum News* we have put together a broad view of many issues surrounding the understanding and treatment of ASD's. We lead off with a comprehensive discussion of the spectrum as discussed by the National Institute of Mental Health (NIMH). We have presented their discussion in its entirety (even though it is quite long) because we want our readers to be able to read and keep this important information that comes to us from this most trusted national institute.

Sharing the cover of this issue is an article about the groundbreaking research of The Autism Tissue Program. Their mission—to unlock the mysteries of spectrum disorders—is being made possible by the enormous generosity of parents that have lost a child and want their loss to benefit other families with children on the autism spectrum.

Also in the research spotlight in this issue are two important announcements in our NewsDesk section on page seven. First we learn of the Columbia University study that refutes the connection between the mumps, measles, and rubella (MMR) vaccine and autism. The Columbia team's findings further show that gastrointestinal symptoms and autism onset are both unrelated to MMR vaccine timing. This is important news for parents.

Another research related news item on page seven is the announcement from the NIMH that they have terminated their

chelation studies. Chelation is a method of cleansing toxins from the bloodstream. In the case of autism, some advocates of this reportedly dangerous treatment believe that their children have received autism triggering substances in their blood as a result of childhood vaccines. In making their announcement, NIMH stated that “there was no clear evidence for direct benefit to the children who would participate in the chelation trial and that the study presents more than a minimal risk.” Further, the announcement cited the NIMH Board's belief that the autism community would be better served by having research dollars devoted to pursuing “research on the basic pathology of autism” that will “provide deeper understanding of the causes of autism and more refined avenues for developing treatments.”

In your feedback on our premier issue you also told us that you were pleased to see that we had articles by parents and people on the spectrum. To continue this important part of our content we have several articles in this issue that we hope you will find inspirational.

You must read *Robin's Blog* on page 21. In two short vignettes, Robin Morris first discusses her feelings on the increasing need for autism awareness in communities across the nation. It's the heartfelt story of a young man with ASD who went out for a walk to get a soda and ended up being arrested and held for six hours to undergo a psychiatric evaluation by community officials unaware that the young man's “disorientation and poor eye-contact” was a sign of an autism related disorder, not drug abuse. Robin's other story is an equally compelling discussion of the difficulties parents face in finding solutions to breaking through the often rigid and repetitive behaviors that their child's illness presents.

In this issue we have another wonderful article by Dr. Stephen Shore on page 22. Stephen, a renowned author and lecturer, has taken his mission of advocating for people on the spectrum around the world and has learned how autism is recognized, perceived, and how support is provided in different communities. In his latest *View from the Spectrum* column, Stephen reports that “I have found that no matter how poor or desolate of resources a location may be, pockets of best practice can always be found. These pockets of best practice demonstrate that autism and the challenges it brings spans the globe. We have much to learn from all areas of the globe on how to match best practice to intervention—empowering people with autism to lead fulfilling and productive lives.”

We feature a wonderful article on the meaningful work being preformed by The Daniel Jordan Fiddle Foundation. In her article on page 23, Linda Walder Fiddle, Founder and Executive Director of The Daniel Jordan Fiddle Foundation

begins by reflecting that “Sometimes the flame of inspiration needs a little rekindling. In our day-to-day lives, fast paced and full, there is often no time to take a pause and reflect upon where we are and where we are going: we just go! But then, unexpectedly a moment happens, and life gives us a pause that reaffirms that the road we are traveling on is the right one or the realization that we need to find another way. If we listen to life and pay attention to these miraculous moments they can be validating.” The meaningful work of the Foundation, inspired by the memory of Linda's son Danny, is truly an inspiration to us all. Linda's work inspires me and lets me know we're on the right track with *Autism Spectrum News*.

I wish I could go on to spotlight all of the many wonderful articles (including many renowned authors) contained in this issue, but would rather you read them and let us know which ones inspired you. To be sure, they have inspired us by their participation.

Let me conclude by telling you about our exciting roundup of themes for the 2009 calendar of *Autism Spectrum News*. In our upcoming spring issue our theme will be “Helping Parents and Family Members Cope with ASD's.” Our deadline for articles and advertising for this important issue is December 15th.

Our calendar continues with our summer issue which will focus on “Education for Children & Adults with Autism Spectrum Disorders.” Next fall we will take a look at “Addressing the Needs of Adults on The Spectrum,” and next winter our theme will be “Understanding the Assessment Process: What Parents Should Know.”

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing 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](http://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 [iramintot@mhnews.org](mailto:iramintot@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  
 Autism Spectrum News Cares About You*

*Have a Wonderful Winter Season.*

# AUTISM SPECTRUM NEWS DESK

## NYS Governor Signs Bill to Help Children with Autism Spectrum Disorders

*Bill Will Update Standards and Guidelines Used to Identify Kids with ASD's*

Staff Writer  
Autism Spectrum News

**G**overnor David A. Paterson recently signed a bill that will require the Department of Health (DOH) to update the guidelines used by pediatricians to identify children with Autism Spectrum Disorders (ASD's) and refer them for appropriate services.

"This legislation will help pediatricians across the state quickly and comprehensively identify kids with ASD's, so that they can receive the support they need at an early age," said Governor Paterson. "Coupled with other efforts recently announced by the Office of Mental Retardation and Developmental Disabilities, this bill will not only ensure our children have access to appropriate services, but will help educate the public on these often overlooked disorders."

ASD's are developmental disabilities usually evident and typically diagnosed within the first years of life and often associated with mental retardation. Individuals with ASD's often have difficulty relating and responding to persons, events or objects, and engage in repetitive behaviors or exhibit preoccupation with narrow interests. The severity of these challenging behaviors varies considerably, resulting in multiple diagnoses along the autism



**Governor David A. Paterson**

spectrum. According to the federal Centers for Disease Control and Prevention, ASD's affect one in every 150 children in some communities.

The bill (A.9512-A/S6527-B) requires DOH to establish best practice protocols for early screening of children for ASD's by pediatric primary care providers. These protocols would incorporate standards and

guidelines established by the American Academy of Pediatrics and must include: (1) the routine employment of objective ASD screening tools at regular intervals during critical childhood developmental stages; (2) facilitation of a dialogue between service provider and parents for purposes of educating the parents about ASD's, using a modified checklist for ASD's in toddlers; and (3) an appropriate referral mechanism for children who, based upon results of the screening process, require further evaluation. The bill also requires DOH to make the modified checklist for ASD available to the public on its website.

New York State Health Commissioner Richard F. Daines, M.D. said, "To give children the best start, we should do everything we can to make sure that children receive intervention services as soon as possible when it appears that an ASD is present. The Department of Health is committed to updating the autism screening protocols to make sure that practitioners and families have the tools they need to help identify children with ASDs."

New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) Commissioner Diana Jones Ritter said, "OMRDD's Autism Platform will go a long way towards promoting research and education that will be translated into practical assistance for both children and adults with ASD's.

OMRDD's mission is to help individuals with developmental disabilities live richer lives. This bill will help ensure that more children are referred for important intervention services at an early age, enhancing the foundation for lifelong supports."

The Governor has vetoed two other bills related to ASDs, S.5760/A.11275 and S.8475-A/A.7942-B, which called for OMRDD to study and report on issues involving individuals for ASD's. Both bills, which would have required large expenditures of scarce state funds, were unnecessary because they were largely duplicative of the comprehensive Autism Platform recently announced by OMRDD, which encompasses several key initiatives including: (1) an increase in the number of ASD-related research at the agency's Institute for Basic Research in Developmental Disabilities (IBR), including the creation of a national autism tissue bank; (2) a newly created ASD research consortium which will facilitate the pooling of research and treatment resources between IBR and various academic research centers; (3) the establishment of an Inter-agency Task Force on Autism, which will bring together several state agencies to collaborate on the provision of appropriate services and support to individuals with ASD's; (4) an examination of the prevalence of ASD's in New York State

*see Governor's Bill on page 44*

## YAI/NIPD Network Names Dr. Charles Cartwright Director of Autism Center

*Members of Autism Advisory Council Also Named*

Staff Writer  
Autism Spectrum News

**I**n a major step toward the development of its Autism Center, the YAI/National Institute for People with Disabilities (YAI/NIPD) Network has announced the appointment of Charles Cartwright, MD as Director of the Center.

Dr. Cartwright is nationally known for his expertise in the diagnosis and treatment of children with autism spectrum disorders and is highly respected for his research in autism.

Prior to accepting the position, Dr. Cartwright served as the Director of The Autism Center of the University of Medicine and Dentistry of New Jersey-New Jersey Medical School. He is a board certified child and adolescent psychiatrist and a faculty member in the Department of Psychiatry, Child and Adolescent Division, at UMDNJ-New Jersey Medical School.

"By promoting a culture of learning within the center, we will keep in touch with cutting edge developments in the field," Dr. Cartwright said. "Our program will include the latest evidence-based approaches and treatments. It will aim to identify infants and young children on the autism spectrum as early as possible so that early intervention can be implemented, with the best chance of successful outcomes."

"We're proud to have a nationally renowned expert join our team to enhance our existing programs and services for individuals with autism," said Dr. Philip H. Levy, President of the YAI/NIPD Network. "Dr. Cartwright's arrival is a significant step toward the realization of a comprehensive, state of the art autism center."

Dr. Cartwright completed a general psychiatry residency in Cape Town, South Africa, as well as fellowships in child and adolescent psychiatry at New York University/Bellevue Hospital and autism research at the Mount Sinai School of Medicine, Seaver and New

York Center for Excellence in Autism. He was awarded the two-year National Alliance for Autism Research/Bristol-Myers Squibb Research Fellowship in Autism and Neuropharmacology.

Known for his expertise in the diagnosis and psychopharmacological management of autism spectrum disorders in children, adolescents and adults, Dr. Cartwright's research interests are in autism genetics, neuroimaging and psychopharmacology. He has a large clinical practice and lectures widely.

"Dr. Cartwright brings a wealth of expertise in early detection, diagnosis and treatment that will enhance our integrated care for children and adults on the spectrum," said Stephen E. Freeman, Associate Executive Director of YAI/NIPD.

"Given his background and knowledge, Dr. Cartwright is uniquely qualified to make our center a leading force in the area of early detection and diagnosis of children along the autism spectrum of disorders," said Dr. David Kaufman,

Medical Director of Premier HealthCare, a medical practice with doctors, dentists and specialists specifically trained to treat individuals with developmental disabilities. Premier HealthCare is a member of the YAI/NIPD Network.

The YAI/NIPD Network has been meeting the needs of individuals of all ages on the autism spectrum and their families since it was founded in 1957. The autism center will focus on:

- The evaluation and treatment of children on the spectrum
- A school-age program, which is currently under development and scheduled to open in the fall of 2009
- A life planning program to ensure that individuals and their families have access to any services they need, both within and outside of the YAI/NIPD Network

*see YAI/NIPD on page 46*

# AUTISM SPECTRUM NEWS DESK

## Columbia University Study Refutes Connection Between MMR Vaccine and Autism

*Findings Show Gastrointestinal Symptoms and Autism Onset are Both Unrelated to MMR Timing*

Staff Writer  
Autism Spectrum News

In a case-control study, the presence of measles virus RNA was no more likely in children with autism and GI disturbances than in children with only GI disturbances. Furthermore, GI symptom and autism onset were unrelated to MMR vaccine timing. Study findings are reported online in the Public Library of Science and can be found at: <http://dx.plos.org/10.1371/journal.pone.0003140>.

Prior to the implementation of measles vaccines in 1963, three to four million people were newly infected each year, 400-500 died, 48,000 were hospitalized, and 1,000 developed chronic disability from measles encephalitis. From January 1 through July 2008 the Centers for Disease Control and Prevention received 131 reports of confirmed measles virus infection in the U.S., the highest number for the same time period since 1996. Of these 131 cases, 91% occurred in individuals who had not been vaccinated or had unknown vaccination status.

In 1998, a report of the presence of measles virus RNA in intestinal tissue from children with autism spectrum disorders and GI disturbances (Wakefield *et al.*) resulted in public concern over the safety of MMR vaccine. Although epidemiological investigations found no asso-



Mady Hornig, MD

ciations between MMR vaccine and autism, no subsequent studies tested for the presence of viral RNA in GI tissues of children with autism and GI disturbances or examined the temporal relationship of MMR, GI disturbances, and autism. Failure to have done so may have contributed to persistent concerns that have influenced vaccine acceptance rates, resulting in outbreaks of measles.



Ian Lipkin, MD

Scientists at Columbia University Mailman School of Public Health's Center for Infection and Immunity and researchers at the Centers for Disease Control and Prevention, Massachusetts General Hospital, and Trinity College Dublin, evaluated bowel tissues from 25 children with autism and GI disturbances and 13 children with GI disturbances alone (controls) by real-time reverse transcrip-

tion (RT)-PCR for the presence of measles virus RNA. Samples were analyzed in three laboratories blinded to diagnosis, including one wherein the original findings suggesting a link between measles virus and autism had been reported.

"Our results are inconsistent with a causal role for MMR vaccine as a trigger or exacerbator of either GI difficulties or autism," states Mady Hornig, associate professor of Epidemiology and director of translational research in the Center for Infection and Immunity in the Mailman School, and co-corresponding author of the study. "The work reported here eliminates the remaining support for the hypothesis that autism with GI complaints is related to MMR vaccine exposure. We found no relationship between the timing of MMR vaccine and the onset of either GI complaints or autism."

Analysis in all three laboratories found two biopsy samples with measles virus RNA, one from a boy in the autism/GI group and the other from a boy in the control group, showing that the presence of measles virus sequences was not associated with an autism diagnosis (autism/GI group, 4%; control, 8%).

The temporal order of onset of GI episodes and autism relative to timing of MMR vaccine administration was examined as well. If MMR is causally related

*see Columbia Study on page 45*

## NIMH Terminates Chelation Study for Autism Spectrum Disorders

By The National Institute of Mental Health (NIMH)

The protocol for a proposed National Institute of Mental Health (NIMH) chelation study for autism that has been discussed for the past two years for human subjects protections has been discontinued. NIMH has decided that resources are better directed at this time to testing other potential therapies for autism spectrum disorders, and is not pursuing the additional review required to begin the study.

The chelation study protocol was originally reviewed by an NIH Institutional Review Board regarding the risks and benefits of the treatment and was approved to go forward in June 2006. No subjects were recruited for this clinical trial. In February 2007, based on new scientific data, an NIH Institutional Review Board reassessed the risk benefit ratio of the proposed study. The Board determined that there was no clear evidence for direct



benefit to the children who would participate in the chelation trial and that the study presents more than a minimal risk. Thus, the only way that the

study could go forward would be through an additional approval process by the Department of Health and Human Services (DHHS).

Two years have elapsed since the initial protocol was reviewed for human subjects' protections. The DHHS review process can take as long as one year to complete because it includes review by a pediatric advisory board, the Food and Drug Administration and public commentary. If DHHS were to approve the study for subject recruitment, it is estimated that data collection would take at least another three years. During those four years, it is quite likely that additional research on the basic pathology of autism will provide deeper understanding of the causes of autism and more refined avenues for developing treatments. Given the time and resources required for this additional approval process, NIMH has decided to use its intramural program to test other interventions for autism and will not pursue the required DHHS review.

As a result, the Protocol 06-M-0238: "An Investigation of the Efficacy of Mercury Chelation as a Treatment for Autism Spectrum Disorder" has been terminated.

# AUTISM SPECTRUM NEWS DESK

## Common Mechanisms May Underlie Autism's Seemingly Diverse Mutations

### *Study Implicates Disruption of Genes Regulated by Early Experience*

By The National Institute of Mental Health (NIMH)

**M**any of the seemingly disparate mutations recently discovered in autism may share common underlying mechanisms, say researchers supported in part by the National Institute of Mental Health (NIMH), a part of the National Institutes of Health (NIH). The mutations may disrupt specific genes that are vital to the developing brain, and which are turned on and off by experience-triggered neuronal activity.

A research team led by Christopher Walsh, M.D., Ph.D., and Eric Morrow, M.D., Ph.D., of Harvard University, found two large sections missing on chromosomes in people with autism and traced them to likely inherited mutations in such genes regulated by neuronal activity. They report their findings in the July 11, 2008 issue of *Science*. The study was

also supported in part by the NIH's National Center for Research Resources, National Human Genome Research Institute, Eunice Kennedy Shriver National Institute of Child and Human Development, and the National Institute on Neurological Disorders and Stroke.

The study breaks new ground for complex disorders like autism, taking advantage of a shortcut to genetic discovery by sampling families in which parents are cousins. The researchers found genes and mutations associated with autism in 88 families from the Middle East, Turkey and Pakistan in which cousins married and had children with the disorder.

"The emerging picture of the genetics of autism is quite surprising. There appear to be many separate mutations involved, with each family having a different genetic cause," explained NIMH Director Thomas R. Insel, M.D. "The one unifying observation from this new report is that all of the relevant mutations could disrupt the formation of vital neural connections dur-

ing a critical period when experience is shaping the developing brain."

Earlier studies had suggested that the individually rare mutations are present in at least 10 percent of sporadic cases of autism, which is the most common form.

The researchers used a technique that pinpoints from a relatively small group of families' genes responsible for disorders that can be amplified by parenthood among relatives, which can increase transmission of recessive diseases. Evidence had hinted at such transmission in autism, and the large amount of genetic information obtainable from such families reduced the need for a much larger sample including many families with multiple affected members.

The ratio of females to males with autism - normally one female to four males - was less lopsided in such families in which parents share a common recent ancestor, suggesting a doubling of the rate of autism, due to recessive causes on non-sex-linked chromosomes. Also, autism-

linked spontaneous deletions and duplications of genetic material were relatively uncommon in these families, suggesting recessive inherited causes.

The researchers found multiple different genetic causes of autism in different individuals with little overlap between the families in which parents shared ancestry. Yet a few large inherited autism-linked deletions, likely mutations, in a minority of families stood out. The largest turned out to be in or near genes regulated, directly or indirectly, by neuronal activity.

"Autism symptoms emerge at an age when the developing brain is refining the connections between neurons in response to a child's experience," explained Walsh. "Whether or not certain important genes turn on is thus dependent on experience-triggered neural activity. Disruption of this refinement process may be a common mechanism of autism-associated mutations."

More information is available at the NIMH website, [www.nimh.nih.gov](http://www.nimh.nih.gov).

## Running For A Cause

By Brian Thompson  
Director of Program Development  
Train 4 Autism, Inc.

**I** started running about eight years ago, shortly after my son Reid was diagnosed with autism as at the time I weighed close to 290 pounds and realizing he may need long-term care, I quickly came to the conclusion I needed to make many life changing decisions. To date my wife Kristin and I have completed four marathons raising funds for autism awareness and education.

On August 2, 2007, our beautiful 11 year-old son Reid passed away unexpectedly in his sleep. Reid had autism but we still do not know exactly why his life here with us was cut short. Doctors are working with the Autism Tissue Program (part of Autism Speaks) to exam brain tissue taken from Reid in hopes of providing our family, friends, and others impacted by autism the answers we seek in a groundbreaking study called the Autism Genome Project Brain Tissue Genotyping Initiative.

Since Reid's passing I've channeled my energies to help establish Train 4 Autism (T4A), a parent-founded non-profit dedicated to raising awareness and funds for autism research and treatment through athletic events. T4A is a powerful and very unique program. It provides a system by which individuals can train for and participate in athletic events such as marathons, half marathons, 10-K's, 5-



**Brian Thompson**

K's, walks, triathlons, swimming, and/or cycling events and at the same time raise funds for the autism program of their choice. Participants create and edit their own webpage, send emails to donors, get training tips, join or create their own T4A chapters, meet professional athlete spokespersons, all while raising funds and awareness of autism. The most powerful

*see Running on page 46*

## Law Enforcement Receive Training

By Christine Reinhard  
Deputy Commissioner  
Westchester County DCMH  
of Community Mental Health

**L**aw Enforcement trainees in Westchester County, NY will soon receive an introduction to Autism as part of their training. The Westchester County Department of Public Safety is responsible for training law enforcement recruits for the municipalities in Westchester. Beginning in October, the training they already provide on people with disabilities, including Autism, will include additional information on identifying individuals who are on the Autism Spectrum as well as how to best approach them, in their unit on People with Disabilities. A separate unit on individuals with mental illness is done in collaboration with the Westchester County Department of Community Mental.

A seven-minute "roll call" DVD developed by the Chicago Police Department and Dennis Debbaut, a former police officer and parent of a son with Autism, will be the foundation for the training. It is available through Autism Speaks. The DVD was designed to be utilized with police officers as a brief training during their daily roll call. It provides an overview of the signs of Autism as well as direction on how to best approach an individual who appears to have Autism as well as what interven-

tions to avoid so as not to escalate the situation. While the Department of Public Safety has been providing information on individuals with Autism and other disabilities as part of their curriculum for about a year, the idea to add the DVD was the result of a recent meeting of the Westchester County Department of Community Mental Health Autism Advisory Committee. The Advisory Committee was convened by Westchester County Executive Andy Spano to identify areas of need in Westchester County for individuals on the Autism Spectrum and their families and make recommendations for meeting these needs. They have been meeting since April.

Many parents have expressed concerns that if their adult child with Autism should have an incident in the community, police who respond may interpret some of the behaviors they exhibit as resistance and use techniques that could be potentially harmful or exacerbate the situation. When Westchester County Public Safety Commissioner Thomas Belfiore was approached to include the DVD in his training to law enforcement he was very receptive. He too expressed concern that law enforcement officers who did not recognize the signs of Autism might misinterpret them and respond in a manner that might cause the situation to escalate. Some states, including New Jersey, have passed legislation that requires

*see Training on page 44*

## Autism's False Prophets

*Dr. Paul Offit Speaks Candidly about Childhood Vaccines with Autism Spectrum News*

Staff Writer  
Autism Spectrum News

**A**utism Spectrum News recently sat down with Dr. Paul Offit, author of the newly released book "Autism's False Prophets" and Chief of Infectious Diseases at Children's Hospital of Philadelphia (CHOP). The book examines the theory that vaccines cause autism and the cottage industry of potentially harmful therapies and false hopes that it spawned. All proceeds from sales of the book will be donated to the autism research program at CHOP.

Q: Dr. Offit, what is the main message of your new book?

A: Reasonably, some parents are concerned that vaccines might have caused or worsened their child's autism. From their point of view, their child was fine, received a series of vaccines, and then wasn't fine anymore. The main message of this book is that the medical and scientific community has responded to these concerns by performing many studies to determine whether parental fears are well-founded. The results of these studies have been clear, consistent, and reproducible. Vaccines don't cause autism.

Another reason that I wrote the book is that the persistent fears that vaccines cause



Paul A. Offit, MD

autism has done a lot of harm—harm from not getting needed vaccines, harm from potentially dangerous treatments to eliminate mercury, harm from elimination diets that deprive the body of calcium, harm from therapies as absurd as testosterone ablation and electric shock, and harm from the continued diversion of research dollars away from more promising leads.

Those who oppose vaccines in this

country have taken the autism story hostage, much to the detriment of the children whom they claim to represent.

Q: Why does the notion that vaccines cause autism persist?

A: I think that there are many reasons for this. First, some people continue to hold onto the notion that vaccines cause autism with religious zeal, unwavering in the face of contrary evidence. They have been convinced by marginal scientists or physicians who have promised cures based on the notion that vaccines are the problem. Second, many in the media have been quite irresponsible on the subject, continuing to present the notion that vaccines cause autism as a scientific controversy when it is no longer a controversy among scientists who have looked at the data. Stories carried as a controversy are far more likely to gain attention and sell advertising than those that present the issue as resolved. Third, some politicians have taken up the cause and clearly had an impact on the public's perception of the issue. Fourth, information on the Internet can be misleading, confusing the public about the quality of the science that exonerates vaccines.

It's been frustrating to watch the manner in which good science has been distorted through the opaque prisms of the media and the culture.

Q: Many parents of children with autism are concerned about the current CDC vaccine schedule. How do we know that the schedule is safe?

A: Today, young children receive vaccines to protect them against 14 different diseases. Because some vaccines require more than one dose, children can receive as many as 26 inoculations by two years of age and up to five shots at one time. The concern that too many vaccines might overwhelm a baby's immune system is understandable, but the evidence that they don't is reassuring.

Before a new vaccine can be licensed by the Food and Drug Administration (FDA), it must first be tested by something called "concomitant use studies." Concomitant use studies require new vaccines to be tested with existing vaccines. These studies are performed to make sure that the new vaccine doesn't affect the safety or effectiveness of existing vaccines given at the same time, and vice versa. Because concomitant use studies have been required for decades, many studies have been performed showing that children can be inoculated with multiple vaccines safely.

Q: Why not delay immunizations until children are older, just in case?

*see False Prophets on page 45*

"Every parent who has doubts about the wisdom of vaccinating their kids should read this book."

—Peter C. Doherty, Ph.D., *St. Jude's Children's Research Hospital, Nobel Laureate for fundamental contributions in Immunology*

"Every child has a right to be vaccinated against deadly diseases.... Offit's book sets the facts straight."

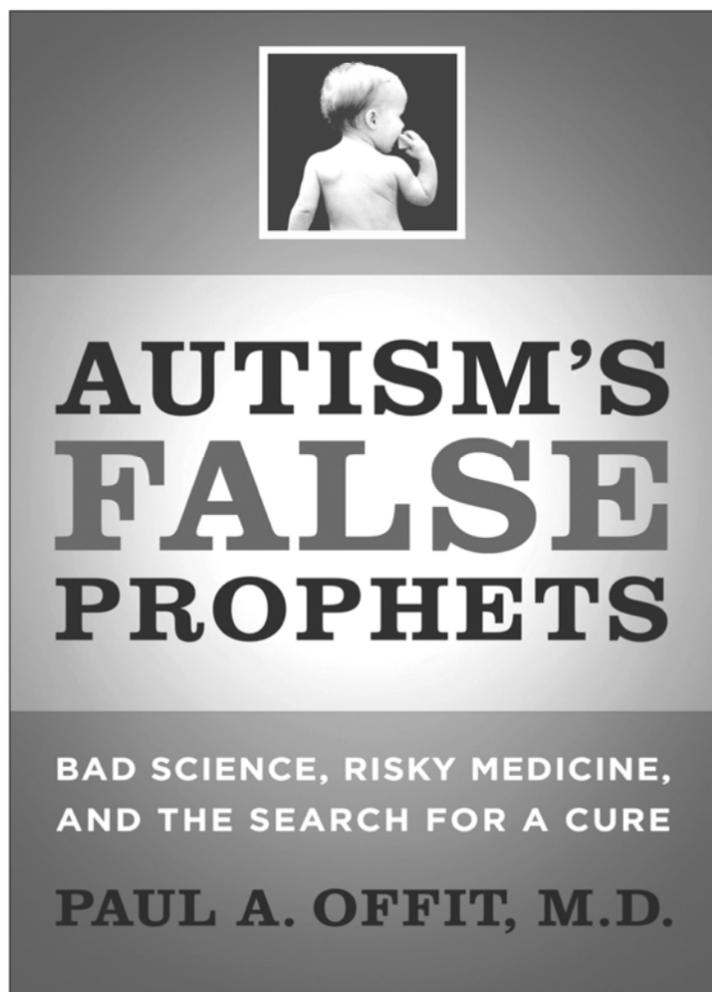
—Rosalynn Carter, *former first lady*

"[Offit shows] how easily Americans have been bamboozled into compromising the health of their own children. *Autism's False Prophets* is a must read."

—David Oshinsky, winner of the Pulitzer Prize in History for *Polio: An American Story*

"As a parent it is my job to protect my children.... This book makes it clear that vaccines save lives, and that they clearly do not cause autism."

—Amy Pisani, *mother*



C O L U M B I A

Read an excerpt at [www.cup.columbia.edu](http://www.cup.columbia.edu)

# 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](http://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](mailto: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 Nearly \$3.85 Million in New Treatment Grants

*Thirteen Research Projects Representing a Variety of Treatment Approaches Funded Over Next Three Years*

Staff Writer  
Autism Spectrum News

**A**utism Speaks, the nation's largest organization dedicated to funding and facilitating autism research, announced today that it has awarded more than \$3.8 million in grants to be paid out over the next three years to investigate a wide array of promising treatments for individuals with autism spectrum disorders (ASD). Thirteen innovative grant proposals were selected from a pool of over 120 applicants, including six proposals from Autism Speaks' first review session devoted solely to studies of complementary and alternative medicine (CAM) approaches.

The grants are intended to help address the urgent need to develop effective therapies to treat both the core and domain-specific features associated with ASD. The funding will support research focused on studying multiple treatment approaches, from biomedical to behavioral and technological, utilizing rigorous scientific trials. A key feature of many of these studies is to track multiple characteristics of participants in an attempt to discover which individuals are most likely to benefit from a specific therapy. This is vitally important given the growing awareness of the need to individualize treatments for people across the autism spectrum.



The CAM-related studies will explore the potential benefits of treatments such as vitamin B12 injections, omega-3 fatty acid supplementation, sensory-based interventions, and acupuncture. Additionally, one of the studies will address the presence of oxidative stress markers in children with autism, while researchers in another study will survey parental and clinician attitudes toward the gluten-free, casein-free (GFCF) diet in preparation for future studies of this dietary intervention.

Given its involvement in brain development, another research project will explore the possible role cholesterol plays in autism. Taking a cue from a rare cholesterol disorder in which affected individuals frequently have autistic traits, this research will determine whether cholesterol levels tend to be low in individuals with autism, and if simple dietary supplementation can affect behavior.

Several studies will address the efficacy of behavioral interventions. One

project focuses on stereotypes, such as hand-flapping and body-rocking, that can consume a significant amount of time and attention in some individuals with autism, thus competing with their ability to learn. This study aims to recognize when motivation to engage in these behaviors is low during the day, and to see if these periods can be encouraged through different methods.

Another study will evaluate the effectiveness of integrated play groups, which provide an opportunity for children with autism to interact with their typically-developing peers. This study will also teach the typically-developing children about how best to interact with a peer who has autism in an effort to promote his or her inclusion and social development.

Other treatment projects selected for funding will investigate the benefits of special technological interventions. Three projects will test computer-assisted programs designed to help teach social skills. One uses an interactive "drama book" to teach the importance of speech prosody – the nuances of rhythm, loudness, and timing of speech that convey meaning, which can be hard to grasp for a person with autism.

"Autism Speaks is committed to expanding treatment options by supporting the work of innovative researchers," said

*see Treatment Grants on page 44*

## Second Round Recipients of Family Services Community Grants Announced

*More Than \$450,000 Awarded By Autism Speaks to 21 Community Organizations Across the Country*

Staff Writer  
Autism Spectrum News

**A**utism Speaks, the nation's largest autism advocacy organization, today announced that its board of directors has approved more than \$450,000 in funding for twenty-one Family Services Community Grants, for a total of over \$1 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).

In February, Autism Speaks invited autism service providers to submit grant applications that addressed at least one of the following areas of need: Education, Recreation/Community Activities, Equipment/Supportive Technology and Young Adult/Adult Services. Autism Speaks received 370 applications from organizations in 46 states and Canada. For a list of all grant recipients, visit [www.autismspeaks.org/community/family\\_services/grants\\_june\\_2008.php](http://www.autismspeaks.org/community/family_services/grants_june_2008.php).

"These grant recipients are doing remarkable, innovative work to deliver im-

portant services to individuals with autism across the country," said Peter Bell, Autism Speaks executive vice president of programs and services. "In addition to providing financial support to these worthy programs, we are gaining and sharing valuable information about service delivery models that can and should be replicated elsewhere."

The funding for the twenty-one grants falls into the following categories: Education – nine grants totaling \$184,000; Recreation/Community Activities – eight grants totaling \$180,000; Young Adult/Adult Services – three grants totaling \$73,000; and Equipment/Supportive Technology – one grant totaling \$20,000. Geographically, the grants support six programs in the Midwest, six programs in the Northeast, five programs in the Southeast, and four programs in the Western region of the country.

The education grants feature a high degree of collaboration between organizations to provide optimal programming. In addition, several of the education grants incorporate training for families to ensure consistency across home and school for the learner with autism. Many of the proposals funded have several modules or components for on-going training, while others have a hands-on training element. One proposal will focus on offering con-

tinuing legal education courses to practicing attorneys who wish to enhance their knowledge of special education law. Additionally, they will seek to train education professionals and parents of children with autism who are unfamiliar with special education law, enabling them to better serve the needs of children with autism. Another education grant will focus on providing behavioral services to families and educators in an underserved community for a thirty-nine week period, as well as quarterly training to local school districts over a twelve month period.

In the recreation and community activities category, grant recipients will focus on summer camp, after-school social skills programs and fitness and exercise. Specific grants include a collaborative after-school program for students with moderate to mild autism to provide recreation, education and social skills training in an inclusive environment. Another proposal focuses on social skills training for 12-15 year-old learners with autism that will include peer modeling and inclusion opportunities. Concurrent parent training will increase the carryover of these skills at home.

The three programs funded in the area of young adults and adults services specifically address the transition, life skills and employment needs of young adults

and adults with autism. One grant focuses on autism-specific employment support in an underserved community. In addition to working with individuals with autism, the grant will provide training to potential employers. Another grant will focus on the transition process of secondary school students with autism and the specific goals that need to be put in place during the transition process which will result in employment opportunities when the individuals leave the educational system.

A two-tier review process, including both professional and parent reviewers, was used to assess each grant application.

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.

*see Family Services on page 44*



# 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](mailto:link@yai.org) or visit [www.yai.org](http://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.

## Guiding Families: YAI Service Coordinators Assist Families in Accessing Services and Coping with a Child's Diagnosis of Autism

By Charles Cartwright, MD  
Director, The Autism Center  
YAI/National Institute for  
People with Disabilities Network

Parents of a 2-year-old girl are very concerned that their daughter has not spoken a meaningful word or shown any interest in socializing with others. Determined to find help, they make an appointment with a speech therapist. Following a comprehensive assessment, which includes a hearing test, and a brief period of speech and language therapy that does not lead to improvement, the girl is referred to a developmental pediatrician for a second opinion.

Finally, the parents learn the news: Their daughter has an autism spectrum disorder. Her delayed speech development led them to seek help but, in retrospect, as they learn more about autism, they recall that there were a number of signs that were consistent with the diagnosis (see side bar on page 46).

This is not an uncommon event. It affects the lives of many families, given that one in 150 children are diagnosed with an autism spectrum disorder.

"The family initially thought that as soon as her speech got a boost, she'd be fine," explained Jennifer Hoffman, an Early Intervention Service Coordinator with the LifeStart program at the YAI/National Institute for People with Dis-



Charles Cartwright, MD

abilities (YAI/NIPD) Network. "But a lot of other things were going on, such as repetitive play and obsessive-compulsive tendencies. She had issues with clothing (shoelaces had to be tied a certain way) and her eye contact was very poor. But the family hadn't recognized that these were issues."

This girl's parents, who were determined to help their child, were fortunate to find Jennifer, a caring, compassionate service coordinator, with extensive ex-

perience in the early detection and diagnosis of autism, and in treatment planning and implementation. She helped guide the family at this critical stage in their journey with their child; recognized and respected their strengths and resilience; supported their determination to identify the best resources; and assisted them in navigating the early intervention system.

Jennifer partnered with the family and, together, they developed an individualized action plan that incorporated evidence-based treatments appropriate for the needs of this child. This was the beginning of a long journey for the family, in which they would work hard to face the challenges of autism and alleviate the symptoms and behaviors that affected the daughter's development. Taking these important steps maximized the child's ability to reach important goals and lead as independent a life as possible.

In the early stages of their professional relationship with Jennifer, these parents had the opportunity to voice their confusion and fear. They felt relieved to have someone help answer their many questions: "How severe is her autism?" "Will she grow out of it?" "What will her life be like?" "Will she be able to attend school with children who do not have autism?"

Parents of young children who are diagnosed with an autism spectrum disorder experience a range of feelings, among them intense sadness, fear that the child

will never develop typically, anxiety about which treatments will lead to recovery and compassion for the child coupled with a determination to help.

While trying to deal with their emotions, they must also find practical solutions. They must decide how to navigate complex service systems to get the help their child needs. They may find it necessary to spend hours on the Internet, in chat rooms, in libraries, talking to friends and families, trying to sort through the huge amount of information about cures and controversies, and how to finance the care they know their child needs. They are often left feeling overwhelmed and unsure about how to get the treatment process started.

This is where an expert service coordinator can play a vital role, offering emotional support, information, linkages to services and assisting parents in advocating for the needs and rights of their child.

"The service coordinator is the direct contact for the family as they go through the evaluation process to figure out what early intervention services their child will need," said Nancy Pellicione, M.A. Ed., Coordinator of LifeStart. "Parents rely on their service coordinator to help them understand not only the early intervention system, but how all the different therapists will work with the child and family to help the child meet developmental milestones."

see *Guiding Families* on page 46

## Riding in Trains with Asperger's

By David Morris  
An Adult with Asperger's Syndrome

Like millions of New Yorkers, I commute on the Long Island Railroad. In many ways, my trip is an easy one. My home is within walking distance of the Douglaston Station of the Port Washington line, which makes getting into Manhattan a breeze, mainly because this train has one of the most reliable schedules in the LIRR system. Furthermore, I arrive at nearly all of my Manhattan destinations by way of Penn Station, which makes going home an easy task. However, my commute is complicated by one seemingly insignificant problem in my genetic makeup — I have Asperger's syndrome.

For those who may have missed the recent spate of movies and books addressing it, Asperger's is one of the autism spectrum disorders or ASDs. Like all ASDs, the symptoms of Asperger's vary from person to person, and may include problems with sensory overload; poor social awareness involving personal habits and interactions with others; difficulty concentrating; the inability to discern speech patterns and non-verbal communication; and the inability to deal with changes in routines. Though I've probably had this disorder my whole life, I didn't become aware of it until I was 16.

So how does having Asperger's affect my commute by train? For me, the symptoms manifest themselves most when there is a change in my routine—such as when the train deviates from its printed schedule.

It used to be excruciating for me whenever I was late because of track work, or when the train had to stop mid-journey because two trains were occupying a single track. For most people, it may seem relatively insignificant whether a train arrives exactly where it should, exactly when it should; but when you have Asperger's, delays are intolerable and can lead to anxiety and outbursts. And because there is usually no one person responsible for the delays, my frustration can end up being directed toward anyone. I still remember a few years back, when my train stopped between the Auburndale and Bayside stations for nearly an hour. To cope with my aggravation, I ended up walking up and down the length of the car, snarling at anyone who approached me.

The problem of maintaining my routine becomes even more of an ordeal when I choose to dine on the train, usually at the end of the day. Even though Asperger's is not the same as obsessive compulsive disorder, I know that I have demonstrated symptoms of it in my eating rituals: I don't start eating until we pull out of Penn Station; I can't have the meal more than half finished before presenting my

ticket to the conductor; and the meal cannot be finished until I've gotten past Woodside. Oh, and the dining process must be carried out across an entire row of seats. This last part is so important that I have been known to pace the length of the train, searching for a vacant row that will support this crucial detail.

These nuisances have quickly escalated to major issues when I have occasionally forced my position on innocent passengers, to my own detriment. One night, a couple of years back, I was on my way home, having picked up my dinner at McDonald's. I had gotten on to the train, just a couple of minutes before it pulled out of Penn Station, and consequently was having trouble locating an empty row. I felt myself getting more and more fed up as I passed through one car after another. Finally, I took out my anger by yelling at a group of passengers near the corner of the train car, before sitting down. I don't remember what exactly I said, but evidently I was intimidating enough that one of the passengers spoke to a conductor. That conductor walked over to my seat and told me that he was going to have to call the police. This scared me into timidity, and I begged and pleaded with the conductor to the point where he reluctantly acquiesced and let me go.

This taught me an important lesson: Never get angry with people on the train. I do sometimes still get frustrated with secu-

rity guards, conductors and the occasional fast food vendor at Penn Station. I started to make significant progress in overcoming this issue when, two and a half years ago, I began seeing a therapist entirely for the purposes of anger management.

For years, I had been resistant to any change in my position that I was right and that my nemesis, the LIRR, was wrong. On some level, I knew how unreasonable this was, but I maintained it for a long period regardless. Like many people with Asperger's, when I reached my 20s, I began to achieve a greater understanding of how the world works, rather than only considering my own point of view. I believe that the progression of the syndrome, combined with the therapy, has enabled me to get to the point that I no longer have outbursts on the Long Island Railroad.

Of course, that doesn't mean I'm "cured" and I still follow the same routine on the train as much as possible. But I don't think of it as a dangerous place anymore. And to me, that feels like a victory.

*David Morris received his bachelor's of arts/science in 2002 from Adelphi University. He is pursuing his goal of working in journalism or publishing with the help of YAI/National Institute for People with Disabilities' Employment Initiatives Department, which is dedicated to the training and placement of people with disabilities in the workforce.*

## Understanding and Treating Self-Injurious Behavior

By J. Helen Yoo, PhD, BCBA  
Research Scientist, Department  
of Psychology, New York State  
Institute for Basic Research

Few things are more puzzling and disturbing to parents and caregivers than self-injurious behaviors (SIB) exhibited by individuals with autism. SIB is a deliberate harm to one's own body that may result in tissue damage, such as open cuts and bruises, and that may lead to inflammation and infection. It is often associated with intellectual and developmental disabilities (IDD), including autism, and can be exacerbated by co-existing psychiatric disorders such as mood disorders. The most common types of SIB are excessive scratching, head banging, and biting of the extremities, especially the wrist.

Individuals with autism spectrum disorders (ASD) often struggle with communication, social interactions, repetitive behaviors and inflexible daily routines. SIB is *not* part of these core symptoms, but can derive from deficits and excesses in these three domains. It is often a chief concern of caregivers.

Currently, two major causal theories of SIB exist in the scientific literature: environmental and biological. Because of the overlap between the two, a combination of these two models is more plausible.



J. Helen Yoo, PhD, BCBA

The environmental, or operant model, proposes that SIB is learned and maintained by environmental consequences, such as positive or negative reinforcement. The biological model proposes that SIB is a neuropathology resulting from interactions of neurotransmitter systems. SIB may also occur as a way to minimize physical pain resulting from other medical conditions.

### Environmental

*Applied Behavior Analysis:* After more than 40 years of research, applied behavior analysis (ABA) has demonstrated its profound effect on individuals with autism (Matson, 2008; Eikeseth, 2008). It is a branch of psychology which focuses on the science of behavior and uses a systematic approach to assessing and intervening (Baer et al., 1968). ABA observes what happens before (antecedents) and after (consequences) the behavior and, using a functional behavior analysis (FBA), determines the environmental factors that may be encouraging or maintaining the SIB. Essentially, SIB is seen as a nonverbal request for a preferred outcome.

In order of increasing complexity, the three types of FBA are indirect, descriptive, and experimental. *Indirect FBA* involves interviewing caregivers about the situations and settings in which SIB occurs using questionnaires and rating scales. This type of analysis is considered a first step in FBA.

*Descriptive FBA* involves observing the frequency of SIB in the natural environment (e.g., home, school) and recording what happens before and after the SIB. Indirect and descriptive FBA do not involve environmental manipulations. They seek to identify patterns and correlations rather than discover clear cause-and-effect relationships. If FBA identifies ob-

vious conditions maintaining the SIB, an intervention plan involving one or more strategies may be devised.

However, in cases where it is unclear why an individual engages in SIB despite caregiver interview and direct observation in the natural setting, *experimental FBA* may be necessary. Experimental FBA exposes the individual to situations which vary the presence and absence of attention, preferred leisure materials, and tasks (work). The frequency of SIB is then compared across these situations to delineate the reasons for the behavior. The changes in frequency or intensity of SIB under the different situations often explain why the behavior is occurring and facilitate a treatment plan. During treatment, the behavior analyst attempts to teach the individual a more appropriate way to produce the desired consequence (attention, materials, escape, and so forth).

*Common Treatment Modalities:* Engaging in SIB often results in an individual receiving desired consequences such as social attention and interaction, leisure materials, food, avoidance of non-preferred activity or work requests, or a caregiver's compliance with a previously denied request. To minimize the occurrence of SIB in these situations, minimal attention should be given to SIB. This includes giving no direct eye contact,

*see Self-Injurious on page 37*

**We help people with developmental disabilities live richer lives.**

**Learn more about our programs and services:**  
(866) 946-9733 (voice) • (866) 933-4889 (TTY)  
[www.omr.state.ny.us](http://www.omr.state.ny.us)

- High Quality Person-Centered Services • Residential Service Options
- Employment/Day Services • Family and Individual Supports

"Putting People First" is OMRDD's simple, guiding principle. And simply put, it means giving people with developmental disabilities as much individual choice and control over their lives as possible, as well as a chance to achieve four basic outcomes:

- Enjoy meaningful relationships with friends, family and others in their lives
- Experience personal health and growth
  - Live in the home of their choice
  - Fully participate in their communities

**OMRDD** NYS Office of Mental Retardation & Developmental Disabilities  
**Putting People First**

David A. Paterson  
Governor

Diana Jones Ritter  
Commissioner

## Social Skills Therapy Groups

### *Evaluating the Behavioral and Neural Impact for Children with Autism Spectrum Disorders*

By Latha Soorya, PhD  
and Ting Wang, PhD  
Seaver and New York Autism  
Center of Excellence  
Mount Sinai School of Medicine

**S**ocial dysfunction is the central, unifying feature of autism spectrum disorders (ASD) and perhaps also the most debilitating. Impairments in socialization persist in individuals with ASD regardless of age or language level and are likely to impact quality of life variables, such as employment and companionship. Improvement in social functioning is widely considered to be a crucial target for intervention. Even so, there are very few controlled studies of treatments that focus specifically on social skills. Much of the current literature describes comprehensive treatment plans and applied behavior analytic approaches geared toward increasing language and basic skills deficits found in young, primarily nonverbal children with ASD. Little is known about effective strategies for improving socialization in older, high-functioning children with ASD.

In clinical practice, several models of social skills interventions have been applied to verbally fluent children with autism that address a range of social deficits, from basic, (e.g. emotion recognition) to more complex (e.g. "theory of mind," the ability to understand the mental states of others). Models of intervention include

cognitive behavioral therapy (CBT); play therapies based in psychodynamic theories and/or the floortime model; comprehensive packages such as the Relationship Development Intervention (RDI); and eclectic approaches that draw from several theoretical orientations. In addition to variations in the model of intervention, variability in the modality and location of interventions also exist. Modalities may include traditional outpatient group therapy models, computerized programs (e.g. face or emotion training programs), individual therapy, push-in social skills in classrooms, peer-facilitated models, and board games.

Despite the availability of an array of intervention approaches, little is known about the efficacy of these approaches because few treatments targeting social skills have been manualized and subject to controlled investigations. A study currently in progress at the Seaver and New York Autism Center of Excellence by Drs. Wang and Soorya is one step towards developing the empirical support needed to advance therapeutic interventions for socialization skills in children with ASD. The study, funded by Autism Speaks, is evaluating short-term outcomes associated with two forms of commonly used social skills therapies: CBT and play therapy. Each 12-week group is focused on children 8-11 years of age with ASD and fluent verbal skills and includes a separate, concurrent therapy group for parents.

Importantly, the study utilizes manualized protocols for both CBT and play

therapy as well as a randomized, controlled design, which provides basic elements of experimental control in order to evaluate potential changes. This pilot study is assessing a broad array of potential outcomes including effects on emotional perception, changes in social behavior at home and school, and changes in brain activity during social information processing (measured by functional magnetic resonance imaging). Through the randomized methodology and manualized treatment protocols, the study seeks to provide preliminary data on the nature of potential benefits from CBT and play therapy groups and develop hypotheses regarding the neural mechanisms responsible for potential changes.

The demand for providing socialization interventions for children with ASD has led to a proliferation of clinical interventions; often with strong support from families and therapists but unfortunately with limited data to support their use. Data from this study may serve as an initial step in understanding the effects of commonly used socialization programs for high functioning children with ASD. Many other studies are also underway at the Seaver and New York Autism Center of Excellence where we are dedicated to discovering the biological causes of autism and to developing breakthrough treatments.

The Seaver Center is under the direction of Dr. Joseph Buxbaum, the G. Harold and Leila Y. Mathers Research Professor of Psychiatry, Neuroscience, Ge-

netics and Genomic Sciences at Mount Sinai School of Medicine.

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

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

*For more information about Research and Clinical Programs at the Seaver and New York Autism Center of Excellence, please contact: Jessica Kiarashi - [jessica.kiarashi@mssm.edu](mailto:jessica.kiarashi@mssm.edu), 212-241-7098.*

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



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

EMAIL [theseavercenter@mssm.edu](mailto:theseavercenter@mssm.edu)  
CALL 212-659-8287  
VISIT [www.mssm.edu/psychiatry/autism](http://www.mssm.edu/psychiatry/autism)



MOUNT SINAI  
SCHOOL OF  
MEDICINE

# The Simons Simplex Collection

*innovation, courage, connections*

*leading an  
international  
investigation  
into the  
mysteries of*

**AUTISM**



## 13 Collection Sites Across North America



## We are currently enrolling families to join our important study

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

Simons Foundation, [www.sfari.org/ssc](http://www.sfari.org/ssc)

# Interventions to Reduce Escape and Avoidant Behaviors In Individuals with Autism

By **Johanna Lantz, PhD**  
Licensed Psychologist, Developmental  
Neuropsychiatry Program, Division of  
Child and Adolescent Psychiatry,  
Columbia University Medical Center

People with autism spectrum disorders can display behaviors that present challenges to educators, parents, and other caregivers such as aggression, self-injury, disruption, property destruction, and elopement. When such problem behaviors are present, the first step is to conduct a functional behavioral assessment (FBA). The goal of the FBA is to identify factors that are maintaining a behavior by examining the antecedents and consequences for a behavior. The FBA results in a hypothesis of behavioral function. In other words, it tells us what purpose the behavior serves for the individual. Behaviors can serve one or more of the following functions:

- The person uses the behavior to gain access to attention or tangible items
- The person uses the behavior to escape or avoid aversive conditions
- The behavior is automatically reinforcing and is not mediated by social consequences.

Interventions based on function tend to be more effective than non-function based interventions. This article will identify four intervention strategies that can be used when an FBA suggests that problem behaviors serve an escape or avoidance function: extinction, antecedent manipulation, functional communication training, and positive reinforcement of compliance.

## Extinction

Extinction simply means removing reinforcement for the behavior. In the case of behaviors that serve an escape/avoidance function, this entails not allowing escape or avoidance following a problem behavior. If a person is given a timeout or is sent home from a school or work program because of maladaptive behaviors that occur in response to a demand, this inadvertently reinforces the behavior and increases the likelihood that the behavior will be repeated to obtain these same consequences. Therefore, an intervention plan should not include such procedures in the case of escape or avoidant behaviors. If possible, the person should complete the task or remain in the setting even if he or she is engaging in challenging behaviors. When extinction is used, an initial increase in behavior can be expected as the person realizes that the behavior is no longer working and he or she reacts by engaging in worse behaviors to see if they will work. This is known as an



**Johanna Lantz, PhD**

“extinction burst.” To maximize effectiveness and to minimize any extinction burst, extinction should be used with other strategies as described below.

## Antecedent Manipulation

Antecedent manipulation involves altering the qualities of the task or setting to make them more attractive to person. When the environment is made more appealing to the individual with autism, there is a lesser chance that he or she will engage in a problem behavior in order to be removed from the environment. Antecedent manipulation strategies are proactive and are meant to prevent problem behaviors from occurring. The following are antecedent manipulation strategies that can be used when an FBA suggests an escape/avoidance function:

**Noncontingent Escape:** The person is allowed out of a task or setting on a schedule rather than as a result of a problem behavior. This eliminates the connection between the maladaptive behavior and the escape consequence.

**Demand Fading with Extinction:** Demands are eliminated or significantly decreased until problem behaviors are reduced and then demands are gradually reintroduced.

**Intersperse Easy and Difficult Tasks:** Allowing the person with autism to experience success is vital to maintaining motivation.

**Avoid Repetitive Tasks:** Tasks should be mixed and varied within an instructional session rather than presenting the same task or question several times in a row.

**Examine Instructional Methods:** One study found that it was not the demand itself that produced problem behaviors; rather, it was

the type of prompting used that was aversive for the participant (Crockett & Hagopian, 2006). Therefore, it may be worthwhile to explore the contribution of instructional procedures to problem behaviors and make appropriate modifications.

**Give the Person Choices:** For example, a teacher or caregiver may make a list of different activities and allow the person with autism to choose what he or she would like to do. Ideally, the list would include some preferred activities within the choices. People with autism can spend the majority of their day responding to the demands of others. This can certainly contribute to the desire to escape and avoid tasks or settings. At least a portion of a person’s day should be spent in activities that he or she leads. Examples of intervention approaches that are more self-directed include incidental teaching and DIR/Floortime. Just because an activity is directed by the individual with autism, does not mean that problem behaviors should be allowed to occur, however. Behavior modification procedures still need to be applied.

**Incorporate the Person’s Interests:** People with autism can have restricted interests. People’s interests can be used to increase the reinforcing value of the task or setting. For example, a child who is interested in searching the Internet, may be taught to spell by typing in search terms. A student who likes Star Wars may have math word problems that include Star Wars characters.

The antecedent manipulations described above are meant to increase the reinforcing value of the environment. Concurrently decreasing the reinforcing value of the escape environment is also advisable. In situations where the individual is not able to be prompted through demands, he or she must be deprived of any other sources of reinforcement such as preferred items or activities or attention from others and the demand has to be reissued until completed. Even consequences that may be thought to be punishing for the individual may not actually be serving as a punisher relative to the task they are avoiding.

## Functional Communication Training

People with autism may engage in a problem behavior because they lack more appropriate alternative behaviors. As a result of these skill deficits, engaging in a problem behavior may offer a more efficient means to get what they want. Furthermore, teachers and caregivers may be more responsive to problem behaviors, making them more effective for the person with autism. Functional communication training (FCT) involves teaching the individual to produce communicative behaviors that serve the same function as the problem behaviors. Communication can

be verbal (language or voice output device) or nonverbal (sign language or picture exchange). Therefore, FCT is appropriate for individuals with autism at all levels of functioning. Examples of appropriate functional communication responses for behaviors that serve an escape/avoidance function include a.) asking for a break b.) requesting a change in activity c.) asking to leave the room d.) saying finished e.) telling others to wait or f.) asking others to stop. These responses need to be taught using systematic procedures where the person has frequent opportunities to practice. In addition, the responses need to be practiced with multiple people and in varied settings to promote generalization. Given that opting out of a task can be problematic for learning, once a functional communication response is reliably emitted, demand fading as described above can be added. This means that the individual is made to complete a gradually increasing number of tasks between the time they communicate the need for escape and when they are allowed to escape. Functional communication training should be used in conjunction with extinction of problem behaviors.

## Differential Positive Reinforcement of Compliance

Another intervention strategy that can be effective at reducing escape or avoidant behaviors is positive reinforcement of compliance. For example, a child who likes Barney would receive access to a Barney doll for a short period of time following the completion of a demand. This strategy may work because the reinforcer has more appeal than escaping or avoiding the task. Pairing reinforcement with a demand may also make it more attractive. If positive reinforcement is not working, a reinforcer assessment should be completed that examines a.) how valuable the reinforcer really is to the person b.) how soon after the desired behavior the reinforcer is provided (immediate reinforcement vs. delayed) and c.) the quantity of the reinforcer (more is not always better and can lead to satiation).

## Conclusion

Individuals with autism may engage in problem behaviors as a means to escape or avoid a task or setting. This can be particularly problematic in school and work programs where there are high levels of demands. Fortunately, there are strategies that can increase a person’s motivation to remain engaged in a task or setting. These include eliminating reinforcement of the behaviors by not allowing escape or avoidance, manipulating the antecedents to the behavior, teaching an alternative to the problem behavior, and reinforcing compliance. In practice, a combination of these approaches is likely to produce the best results.

# CHANGING LIVES AND NURTURING HUMAN POTENTIAL

**We Develop Innovative and Effective Solutions  
for Individuals with Autism Spectrum Disorder.**



**Connecticut** Devereux Glenholme  
81 Sabbaday Lane • Washington, CT 06793 • (860) 868 - 7377

**New Jersey** Devereux New Jersey  
286 Mantua Grove Rd. Building #4 • West Depford, NJ 08066 • (856)-599-6400

**New York** Devereux Millwood Learning Center  
14 Schuman Road • Millwood, NY 10546 • (914) 941-1991

**Pennsylvania** Devereux Kanner  
390 East Boot Rd. • WestChester, PA 19380 • (610)-431-8100



**Devereux**

For more information, please visit our website at [www.devereux.org](http://www.devereux.org)  
or contact the National Referral Office at 800-345-1292.

## THE DEVEREUX DIFFERENCE

Devereux focuses on individualized, client-centered, family-focused care based on strengths and needs, respect for goals and dreams, partnership with families, cultural sensitivity and promotion of developmental and functional skills.

Devereux follows a philosophy of Positive Approaches that promotes a sense of hopefulness by building and strengthening important social skills while adhering to a problem-solving orientation. We focus on achieving sustainable gains in high quality, cost-effective and culturally competent manner while preserving each person's values and right to self-determination.

## EDUCATIONAL PROGRAM

### Instructional Model

- Broad spectrum applied behavior analysis techniques.
- Educational focus is placed upon communication, social and independent skills which include: self care, life skills, functional academics, community recreation/play, gross and fine motor skills and vocational.
- Skills are taught in context during natural activities.
- Students participate in community inclusion activities through trips, events and service learning opportunities.
- Functional behavior assessments are the cornerstone for the development of all behavioral interventions.

Devereux has operations in  
11 states - Arizona, California,  
Colorado, Connecticut, Florida,  
Georgia, Massachusetts,  
New Jersey, New York,  
Pennsylvania and Texas.

## Building Communication Skills in Non Verbal Children with Autism Using Augmentative or Alternative Systems

By **Cindy Alterson, PhD, BCBA**  
**Jennifer Naughton Basch, MS, CCC/SLP**  
**Devereux Millwood Learning Center**

According to the National Research Council (2001), approximately one-third to one-half of children and adults with autism do not use speech functionally. When verbal speech or gestures are insufficient for an individual with autism to communicate their needs and wants, augmentative or alternative systems of communication (AAC) are developed. An augmentative system is a supplemental service when verbal speech is unintelligible, when vocabulary is not complex, or when spontaneous language is lacking. An alternative system is a primary means of communication when verbal speech is not present.

If an ACC system is recommended for an individual with autism, two common questions often follow this recommendation:

- Which AAC systems are most effective towards functional communication in people with autism?
- Which system, if any, will facilitate the development of verbal speech?

This article will define common AAC systems currently in use with individuals with autism and will briefly review the state of the literature in providing answers to the above questions.



**Cindy Alterson, PhD, BCBA**

What AAC Systems are Available?

AAC systems are generally grouped into two categories: “unaided” and “aided” systems. Unaided systems are those that don’t require any extra materials to use, such as American Sign Language (or other developed systems of sign). Aided systems are those that do require equipment or materials to implement. Examples of aided systems are picture or symbol systems (such as PECS, Bliss Syms, photographs) and vocal out-

put devices (VOCAs). VOCAs are computerized systems that use buttons, switches or touch screen technology with synthesized voice output.

All of these systems are used with individuals with autism and different instructional methodologies often have a preference for one over the other. Programs using applied verbal behavior instruction typically focus only on sign language as AAC, with the rationale (among others) that motor planning skills needed to produce the sign will facilitate production of verbal approximations. TEACCH models typically use PECS and other pictures for AAC, with the rationale that individuals with autism often need visual cues and support to understand their environment. By way of full disclosure, the authors of this article do not have a preference or theoretical bias towards any AAC system and have used all effectively.

Effectiveness of AAC Systems

The “good” news regarding effectiveness of AAC systems towards functional communication is that all types of AAC have been demonstrated to be useful as modes of communication in individuals with autism. There is a wide body of literature suggesting that AAC can be extremely effective under certain conditions. Some of these conditions include:

- An AAC is effective if the physical response effort required to produce the desired result with the AAC is less than

the effort required to produce the result by other behaviors (Horner and Day, 1991).

- A visual AAC (i.e. use of pictures/symbols) is more effective the closer the pictures/symbols resemble their real-world counterparts (this is referred to in the literature as “iconicity”) (Fuller and Stratton, 1991).

An AAC is effective only to the extent that the communication is intelligible to others and can produce the desired result (Schlosser, 2003).

The “bad” news, however, is that the research still has a long way to go in determining whether one type of system or another is more effective in meeting communication goals in individuals with autism on the whole. Very few studies have compared unaided to aided systems directly, and less have focused on only individuals with autism. The research has not at all addressed the question of “what are the characteristics of an individual that make one type of system potentially more effective than another?”

When choosing an AAC system for an individual, practical concerns such as portability, durability, and vocabulary needs and space will generally take precedence over research-based suggestions. Also, student interest in and motivation to use the system is critical to its success, regardless of how the research supports its use.

*see Communication on page 22*

## Autistic Spectrum Disorders: A Social Dilemma

**Margo Benjamin, MD**  
**Attending Psychiatrist, New York**  
**Presbyterian Westchester Division**

The general reasons why people pursue psychiatric treatment are twofold. The majority of individuals who seek treatment do so because they have identified “pain” in some form or another and they want the therapist to address the pain by validating it and working towards diminishing it. These individuals seek professional help to do this because discussing their problems casually with others in their lives has not proved helpful. Another reason people may seek psychiatric treatment is because they have had difficulties in relationships and even though this subset of individuals don’t necessarily think that the problems in their lives are related to their behavior, they are seeking to have more positive relationships. This is accomplished in part by the fact that in establishing a new relationship with another person, one is afforded the opportunity to redefine themselves by presenting the most positive aspects of themselves and/or their Ideal Self – that is the person/personality that they wish to be. In the

room with the therapist, this latter group at some point may begin to see their role in conflictual relationships and seek to make changes- either to repair damages in previously formed relationships, or to learn appropriate ways to develop new ones. Alternatively, they may develop a “good enough” therapeutic alliance with the therapist, and this new relationship becomes the one good relationship in their lives. This latter group can end up being potentially more fragile because there is always the risk of having difficulty maintaining the positive therapeutic relationship if they have not yet learned mature defenses and have difficulty accepting the good and the bad of the therapist and the therapeutic process. Alternatively, they may inappropriately use the therapeutic relationship as “evidence” that they are capable of forming good relationships, and therefore proclaim that this had not occurred in their lives previously because of a flaw in the behavior of others and therefore not their fault. This incorrect conclusion serves to protect them against viewing their own contribution to conflict ridden relationships by shifting the focus to others; which makes the therapeutic work of generalizing gains made in the treatment process to the outside world more difficult.

In many cases the autistic individual can neither identify ‘the pain’, nor see the conflicts inherent in their interactions with others. This makes it difficult to establish therapeutic goals without the input of a “significant other” in their lives. The input from a parent or spouse is important in identifying goals and establishing a system of checking how well (or not) the individual is progressing in their treatment plan. Role play is an effective therapeutic intervention with these individuals. When the therapist models positive interactions in a safe environment (such as the therapy room), it can be added to the individuals repertoire of appropriate social interactions. In the context of a good therapeutic alliance the therapist can re enact a social scene that is described to him /her, and demonstrate how one picks up on social cues and incorporates them into similar situations.

What stands out most in an individual whose way of relating to the world is within the autistic spectrum, is the inappropriate affect. This is the quality that is sensed by the other person in the first few minutes of an encounter. Although it can present in a variety of ways the “prototypical” way is that the individual with autism makes little or no attempt to

interpret another person’s emotional state. As a result, these individuals are at an extreme disadvantage in socializing with others, since this requires developing a sense of another person’s emotional state and addressing it in some way. This is one of the ways people develop a common affective history with one another, that over time helps to define the relationship. Because such an individual has such difficulty managing the first step in building a common affective history, it is a struggle for them to interact with others. In general, they are “misread” as self-centered when they direct the conversation towards themselves and have difficulty allowing others to give input to the topic of discussion. Often, if a topic of interest is brought up, the autistic individual is likely to interject with a one sided “conversation” including every detail they know about the topic. Attempts by others to interrupt and/or give input are quickly thwarted, and sometimes followed by the individual starting over from the beginning of their soliloquy to be sure they were “heard”. This can be off putting for those who have had no previous exposure to these individuals, particularly in the case

*see Social Dilemma on page 39*



## Raising Children Raises Questions We can help.



Jewish Board  
of Family and  
Children's Services

**If your child is experiencing problems in school, we can help you make sense of all the information, consider your options and reach the best decision about what to do next.**

At Learning Resource Network, highly trained professional staff offer —

- Consultation on educational and developmental concerns
- Evaluation of school options
- Review of previous evaluations
- Recommendation of resources

JBFC Learning Resource Network • (212) 632-4499

Our "Thinking Children" newsletters offer a range of helpful articles for parents and professionals. Available at [www.jbfc.org](http://www.jbfc.org).



## Robin's Blog

### *A Resilient Mom's Commentary on Autism*



## He Took a Walk to Get a Soda and Ended Up in a Hospital For a Psych Evaluation

### *A Cry for Increased Autism Awareness*

By Robin Morris  
Patient Advocate

This is the story of M, a young man with autism. M is a handsome shy guy whose soft spoken words prompt the listener to sometimes shout, as if he doesn't understand. What's interesting is that his anxiety level presents a picture of significant disability. He has reached his 22 years, with notable trials and tribulations, nevertheless has successfully transitioned to an outplacement facility. M is more capable than he presents and lives independently while learning vocational skills while residing at a group program with supervision.

Recently, M took a walk. He later explained to his mother that he enjoys the orange soda at the local YMCA and wanted to purchase a can in the machine. The circumstances that followed are fod-



Robin Morris

der for television drama, as M's plan went severely awry.

Prior to leaving his house, M shaved.

He cut his chin. He then walked across the bridge, an overpass, on his way to the Y. He paused to watch the cars. A passing driver's 911 report to the state police spotted M by the bridge. She saw blood on his chin and thought he was about to take his life. A state trooper drove to the scene and tried to approach M. M's basic instinct was to run. After all, he was just going to get a soda. The state trooper later explained that M presented as a young adult who had just taken the drug ecstasy; he was disoriented with poor eye contact.

The officer pursued M, put him in the police vehicle, and took him to a local clinic. M was told to disrobe and put on a hospital gown. He was then transported on a gurney in an ambulance to a hospital for a psychiatric evaluation. Six hours passed. M was traumatized and mortified when he had only wanted to simply get a soda.

When M's mother talked to the state trooper, he indicated that if he had known M was autistic, he would have escorted him

back home. When M was calmer, he explained the specifics to his family. He articulated his fear and anxiety. He thought he was being arrested but didn't know why.

What is the lesson here? What can we learn? There are bracelets for diabetics who might go into shock. There are Amber Alerts to dissuade kidnappers. Autism awareness is sadly in its infancy stages, even though the news media has been consumed with its epidemic.

Perhaps we should have a registry, be pro-active for those suffering with autism. Shouldn't these citizens be protected under the law? Wearing a bracelet, wallet identification, or dog tag might work. A nationwide registration for those diagnosed would be a start. It shouldn't matter what the IQ or physical appearance presents because individuals on the spectrum react differently on a daily basis.

Educated citizens are the only answer. We can do this as a nation. It starts in Washington and becomes law.

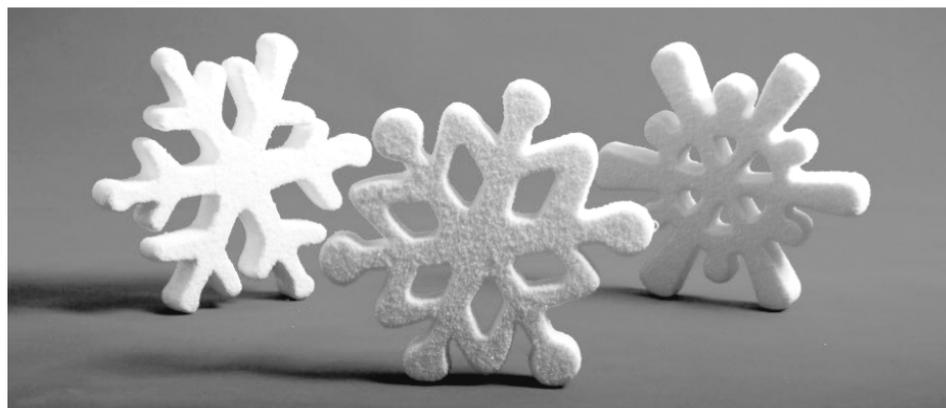
## Flexibility and Rigidity: Unwilling Partners in Tackling Autism

By Robin Morris  
Patient Advocate

Those of us who live in the autism circle would consider the notion of flexibility coupled with autism as polar opposites. After all, the rigidity factor is remarkably consistent with our children living on the spectrum. I do believe that all of us as parents of autistic children share a common goal. We are ordained experts via the school of hard knocks. However, my expertise is just that, a student of life's indelible lesson. My observations are those of experience and "living the life of autism".

Historically, human beings affected by autism are governed by levels of rigidity and inflexibility. The variables depend on areas of understanding and functioning in the spectrum of pervasive developmental disorders. I do believe that man is innately reactive and responds to conditioned reflexes, as in Pavlov's experiment. Consequently, flexibility and rigidity might be partners, albeit unwilling, in tackling autism.

If one subscribes to the behavioral modification theory, we might be convinced that if the stakes are high enough, flexibility could be induced by the dangling carrot, candy, video, train game, twirling top, or any other inflexible routine. Basically, we hold the abhorrent behavior hostage and make it work for us. Clearly Annie Sullivan was successful in developing communication with Helen Keller. She too used a behavioral model.



Initially, our disabled toddler seemed very content in his world. He did not tantrum or cry unless he was hurt. However, we never allowed him to perseverate or dwell on rigid ritualistic behavior. I remember sabotaging his obsessive design of salt, pepper, and napkins that were grouped in a line on our kitchen table. Every time he tried, I went in there and messed it up. We were operating on gut feeling and somehow fighting an unknown opponent.

When our son remained non-verbal at age 3, and the masters in the field advised us to get a sign board (as used for the hearing impaired) because he would never speak, we instinctively knew that there must be another way. I am keenly aware that there are many children who are able to communicate effectively employing the use of signing. Nevertheless, parents must trust their instincts at some juncture and this was our most significant determination thus far.

We found a speech therapist that created a model that worked for our son. Her name is Dr. Nancy Schwartz, and I must say, without exaggeration, that she changed our lives. Utilizing a type of Gestalt, she would choose a habit that our son was drawn to, in his case he was mesmerized by Disney videos. She would allow him to watch a segment and midstream, turn it off. She followed with a simple phrase: "turn it o\_?" making the 'ah' sound. Remarkably, within a week our nonverbal child was filling in the blanks with simple words like *on* and *more*.

I am not a Pollyanna who believes in miracles or that a few words made our son normal. Yet, we all must have a vision for growth, and are compelled to start somewhere. Nearly twenty years have passed and I continue to believe that a behavioral approach plays a significant piece in conquering autism. Dr. Schwartz's no nonsense approach is hardly a candidate for a popularity contest. She makes no apologies for her assault on autism, yet often induces results.

Dr. Schwartz has treated hundreds of children over the years, and clearly emphasizes that no cases are exactly alike.

She has developed a certain methodology that has gleaned positive results in recent years, specifically stressing that procuring language by creating motivation through relatedness is the essential conduit for successful interaction. Ideally, you don't want one without the other. Dr. Schwartz has enhanced her process to 'humanize' (my word) children on the spectrum. The downside of simply regurgitating words creates a robot or automaton like behavior.

I must admit, that when our boy could not speak, we did not care how he got language. Given our desperation, we were determined that we would 'hone' his social delivery in the future. The years flew by, and our son continued to escalate his level of speech, but the delay remained in social understanding. Ultimately, creating motivation through relatedness was the key.

I reiterate that every case is truly unique. Dr. Schwartz applauds our son's internal motivation. One of his brothers aptly coined the expression "snowflake", describing people affected by autism. No two snowflakes are alike. Nearly twenty years ago, we were advised that our main aspiration should be that he never plateau, an auspicious goal. Our son continues to learn.

You can reach Dr. Nancy Schwartz at (203) 544-9560. To visit Robin's blog online, go to [www.revolutionhealth.com/blogs/resilientmom](http://www.revolutionhealth.com/blogs/resilientmom), and her group site *Parents: Champions for Children of Autism*, at [www.revolutionhealth.com/groups/parents-champions-children-of-autism](http://www.revolutionhealth.com/groups/parents-champions-children-of-autism).

## View From the Spectrum: Autism From Around the World

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

Four students with Asperger Syndrome from a school in Christchurch, New Zealand have gone on to successful courses of study at colleges or universities. Another school in Beijing, PR China has developed a remarkable program emphasizing the administration of sensory integration therapy. Yet another organization in Kawagoe City, Japan houses nonverbal adults with autism, engages them in teamwork using dangerous power tools building shipping pallets, all while having them lead dignified, pleasurable, and productive lives. A newly formed parent group in Kolkata, India hosts an internationally known speaker and consultant on autism for the very first time. In South Korea, only students at the top of their class are chosen to study special education at the university level - and these educators are paid more than regular teachers.

In my travels around the world consulting and presenting on autism I sense that I have gotten somewhat of a sample of how autism is recognized, perceived, and how support is provided in different communities. Even though I have been to six out of seven continents it's also important to realize that I have only seen a small minority of countries, hence the sample I do have may be biased. However, perhaps some of my observations regarding the countries I have visited are worth exploring.

For example, I have found that no matter how poor or desolate of resources a location may be, pockets of best practice can always be found. These pockets of best practice demonstrate that autism and the challenges it brings spans the globe. We have much to learn from all areas of the globe on how to match best practice to intervention—empowering people with autism to lead fulfilling and productive lives. On the other side of the coin, challenges of identification, intervention, and support for successful transition to adulthood continue to represent significant barriers to overcome in all areas of the world.



Stephen M. Shore, EdD

### Incidence Rates

There seems to be a general increase in the incidence rate of autism in the countries I have visited. For example, a figure of greater than one percent seems regularly accepted in Northern Ireland as well as in the rest of the United Kingdom. Those of us in the United States are all too familiar with the revised figure of 1 in 150 promoted by the Center for Disease Control in Atlanta, Georgia. Other countries such as India, Japan, Australia, New Zealand, South Korea, etc. all seem to either report or accept similar figures. Of course there are many other countries I have yet to visit that may not have the resources to accurately assess the number of people on the autism spectrum within their borders so my sample is probably biased in a number of ways.

There are many competing theories about this relatively sudden increase ranging from environmental toxins interacting with genetic predispositions to greater community readiness, awareness, and a broadening of the accepted criteria for autism as discussed by Richard Grinker in his book *Unstrange Minds* and in his presentations. Others even suggest that the autistic way of being may be the next step in evolution and that those of us on the autism spectrum are perhaps "early adopters." Like with some many things,

the truth lies with additional resources and may include a number of existing theories and other possibilities we have yet to discover.

All I know is that through my grade school days I was the only person I knew of as being on the autism spectrum. Thinking back, a number of my classmates probably should have been diagnosed as having autism. However, even with including those students, it remains somewhat baffling to explain that we now have entire rooms in our public schools devoted to children on the autism spectrum. Or, the fact that within bicycling distance of my home in the Boston area, there are at least 5 private schools, exclusively for students with autism that the public schools are unable to serve.

### Similarities and Differences in the Autism Community

People on the autism spectrum face the same challenges in communication, socialization, and other areas worldwide. These similar issues present difficulties for many who are not on the autism spectrum in understanding us and vice versa as we are not understanding them. Perhaps the concept "Theory of Mind" – suggesting that people on the autism spectrum have difficulty understanding the non-autistic (neurotypical) mind – cuts both ways where persons not on the spectrum also experience difficulties understanding the autistic mind. Similarly, there is a true community between those of us with autism where we share common experiences and observations about how we interpret the world we live in. This fact calls for greater efforts of people non-autistic and autistic alike to come to greater mutual understanding.

Parents of offspring on the autism spectrum are the same as well. They share deep dedication to helping their children lead as fulfilling and productive lives worldwide. Picture Exchange Communication Systems (PECS) and other visual supports adorn their homes, schools, and other areas where people with autism are found. Just like in the United States, some parents seem overwhelmed by the situation they find themselves in whereas others are driven to develop lo-

cal, regional, national, and perhaps soon to be internationally known support groups. Classified as "high demand-high support" parents by Arnold Miller of the "Miller Method," these parents seek out the most development possible from their children on the autism spectrum and their organizations. Lisa Ackerman, executive director of Talk About Cure Autism (TACA), is such an example and has counterparts in India, Northern Ireland, Japan, and in many other countries.

The people devoted to the education of children with autism also have great similarities worldwide. As I travel about the world it seems that these star teachers and therapist have many similarities including:

- *A mission to achieve intensive interaction.* These educators intuitively understand how their charges with autism interactive and find ways to draw them out. This characteristic is found both across different methodologies as well as in different areas of the world.
- *Often they have been touched with autism in some significant way.* Perhaps a family member or close friend is on the autism spectrum. It often seems that these star educators have a touch of being on the autism spectrum themselves, which engenders a greater understanding of how their students perceive the world.
- *Continual thirst for knowledge.* These are educators scouring websites, books, and where possible attending conferences to ever increase their knowledge base on helping their students with autism lead fulfilling and productive lives.

The differences I have seen in people with deep involvement mostly pertain to language, accents, and support they receive from their government. While the difference in language and accents can be overcome, government assistance often presents a far greater challenge. For example, in Northern Ireland, students with disabilities end their education at age 16

see *Around the World* on page 44

**subscribe to Autism Spectrum News - go to [www.mhnews-autism.org](http://www.mhnews-autism.org)**

### Communication from page 19

#### Effect of AAC on Verbal Speech

If an AAC system is recommended as an augmentative system (rather than alternative), a primary concern is how that system will effect the person's acquisition and use of any verbal speech that is present. It is an occasional assumption that the AAC will be taught or used at the exclusion of verbal speech and that the child will lose whatever verbal speech is present. We have had parents who don't want their children to use AAC because they are afraid of this result. In order to pro-

gram effectively for our students' communication needs, we have had to develop a response to this fear.

In general, results in the scientific literature suggest that total communication approaches result in faster and more complete vocabulary acquisition that does speech alone (Mirenda 2003). There is a considerable body of research in which total communication was compared with speech alone and/or AAC alone to teach receptive and/or expressive vocabulary with children with autism who have limited or no functional verbal speech. Layton & Watson (1995) said that communicating with sign may

transfer to that spoken word after a child has learned approximately 200 signs and/or starts to chain together two or more signs. Bondy & Frost (1994) said that verbal speech tended to develop with PECS as an AAC after the children were able to use 30-100 symbols.

What this means, is that AAC systems may facilitate the development of verbal speech as long as the instructors expect and reinforce verbal approximations at the same time as AAC production. Although we cannot guarantee for any individual student that AAC will automatically result in improved verbal production, we can be confident that AAC will not impede the development of this. It is

important that speech pathologists, teachers, therapists, parents, and others when they teach AAC are also requiring the student to produce some verbal sound and continue to shape that towards a more understandable vocabulary. It is also critical that individuals responding to AAC or speech production are similarly required to respond positively to the students' communication attempts.

*Cindy Alterson, PhD, BCBA, is the principal and program director of the Devereux Millwood Learning Center. Jennifer Naughton Basch, MS, CCC/SLP, is a consulting speech pathologist at the Devereux Millwood Learning Center.*

## Inspiration Along the Road

### Guiding Principle Behind the Meaningful Work of The Daniel Jordan Fiddle Foundation

By Linda Walder Fiddle  
 Founder and Executive Director  
 The Daniel Jordan Fiddle Foundation

Sometimes the flame of inspiration needs a little rekindling. In our day-to-day lives, fast paced and full, there is often no time to take a pause and reflect upon where we are and where we are going: we just go! But then, unexpectedly a moment happens, and life gives us a pause that reaffirms that the road we are traveling on is the right one or the realization that we need to find another way. If we listen to life and pay attention to these miraculous moments they can be validating.

In 2002, The Daniel Jordan Fiddle Foundation awarded its first grants to programs for adolescents and adults with autism. We are the only not-for-profit 501(c) (3) organization in the United States to specifically focus our grant giving on residential, recreational, vocational, educational and family programs

that provide opportunities for adults with autism to participate in community life. Since its inception, the all volunteer-run, Daniel Jordan Fiddle Foundation has awarded grants to role model programs throughout the United States that honor the individuality of each person throughout adulthood. Our residential programs are on farmsteads, in group homes, in assisted living apartments, and on campuses in both urban and suburban settings. Our recreational programs encompass all kinds of pursuits ranging from camping, art, music, theater, swimming and horseback riding to dog training, travel, and health and wellness activities. The foundation has enabled service providers to develop transitional programs in schools and adult day programs and has provided suitable, stimulating, and sustainable opportunities for adults to work at jobs in the community. We have funded educational materials such as the first job manual for volunteer and supportive employment for adults, a DVD series on the challenges facing adults with autism, and a

manual that guides faith communities on ways that they can include individuals with autism in their congregations. The foundation is committed to creating family wellness and our grantees have included family respite adventures, family entertainment, and support of a range of symposiums including medical, legal, and financial issues that affect their lives and the lives of their adult children with autism. Because of The Daniel Jordan Fiddle Foundation's expertise in developing, identifying, supporting, and supervising exemplary programs, we have become a leading advocacy organization for adults with autism and their families on the state and national levels.

During the past six years I have been constantly amazed by the incredible individuals with autism and their families whom I have met in my travels throughout the country. There is so much strength and talent in the autism community and I feel privileged by virtue of my role as Executive Director of The Daniel Jordan Fiddle Foundation that they have

shared their lives with me. I am always guided by the vision I had for my own son Danny, in whose memory the foundation is named; I wanted him to be respected for who he was and for him to have every chance to achieve his personal best. This mission, inspired by Danny, is my life's passion and yet as in all of our lives, I sometimes need a sign of inspiration.

Such a moment happened recently. The story begins when a dear friend named Paul, who is probably one of the most articulate and knowledgeable people I know regarding theater, film and television history, mentioned to me that he wanted to take a theater course but could not find an age appropriate one for adults over 21 year old who have Asperger's Syndrome. Paul had tried taking theater classes when he was in his twenties but had not had good experiences, mostly because he felt uncomfortable in the "typical" theater groups where people did not relate to him and he felt that he could

see *Along the Road* on page 41



Adults at Project Grow, a horticulture work program in Smithtown, Long Island, is funded by The Daniel Jordan Fiddle Foundation



An adult day program located in Fair Lawn, New Jersey, where individuals practice and learn vocational skills is funded by The Daniel Jordan Fiddle Foundation

**DJF**<sup>®</sup>  
 The  
 Daniel  
 Jordan  
 Fiddle  
 Foundation

THE MISSION OF THE DANIEL JORDAN FIDDLE FOUNDATION IS TO DEVELOP AND AWARD GRANTS TO RESIDENTIAL, RECREATIONAL, VOCATIONAL, EDUCATIONAL AND FAMILY PROGRAMS THAT ENRICH THE LIVES OF ADOLESCENTS AND ADULTS WITH AUTISM. OUR EXPERTISE ENCOMPASSES DEVELOPING, IDENTIFYING, SUPPORTING AND SUPERVISING EXEMPLARY PROGRAMS THAT HONOR THE INDIVIDUALITY OF EACH PERSON WITH AUTISM.



ADDRESS:  
 P.O. Box 1149  
 Ridgewood, NJ 07451-1149

PHONE:  
 877-444-1149

WEBSITE:  
[www.djfiddlefoundation.org](http://www.djfiddlefoundation.org)

E-MAIL:  
[info@djfiddlefoundation.org](mailto:info@djfiddlefoundation.org)

## 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*

11591-6-08

## Use Science and the Scientific Method When Considering Treatments for Individuals on the Autism Spectrum

By Pat Schissel, LMSW  
President of the AHA Association  
and Adjunct Professor, Ammon School  
of Education, Adelphi University  
and Dr. Marvin J. Schissel

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

Parents of special needs children (and adult children) are a vulnerable population, too often open to easy answers and magic cures, and too often taken in by greedy salesmen and shoddy professionals. It is difficult to accept the fact that the autism spectrum is not amenable to simple answers or magic pills, even though they are alleged to help our offspring cope more easily with their worlds. Such

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

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

It is vital to study and learn what constitutes sound Science and use this knowledge to make informed decisions.

The requirements of Science are poorly understood by most people. Treatment should produce measurable skill gains; accountability is essential. It is therefore necessary to have a sound framework of understanding, based on evidence-based scientific principles, to evaluate suggested interventions. Criteria should be established to determine progress or a lack thereof. We strongly recommend that before accepting or recom-

mending treatments you become familiar with the rules of scientific method. The following terms and definitions could be a useful start to incorporate scientific thinking into your daily life.

**Scientific Method:** Drawing conclusions based on collection of unbiased data.

**Faith:** Belief despite the absence of evidence.

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

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

**Placebo:** A substance of no demonstrated therapeutic value used for the control

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

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

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

*This article was written in collaboration with Dr. Marvin J. Schissel, who is on the scientific advisory board of the American Council on Science and Health (ACSH), and has written extensively on quackery for [www.quackwatch.com](http://www.quackwatch.com).*

*see Science on page 44*

### Special Gifts

Themed Parties

Sibling Activities

Parent's Play Time

Private Group Karaoke

Private Movie Showings

Private Muster Drill Area

Professional Autism Staff

Service Animals Permitted

Priority Boarding onto Ship

Disability Access & Services

Private Group Family Parties

Autism Awareness Cruise Staff

Priority Disembarkation from Ship

Adults with Autism Social Gatherings

Pool (water sensory related) Activities

Most "Special" Needs & Requests met

Professional Medical Physicians/Nurses

Private Ship Facility Entertainment Sessions

Same Wait Staff for Breakfast, Lunch & Dinner

Private Adventure Ocean (Children's) Activities

Private Games (Sea Animal Bingo/Pictionary, ect)

Private Dining Area for Breakfast, Lunch & Dinner

Special Dietary Accommodations (incl. Gluten and Casein Free)



### Cruises for families and adults with Autism

- Group Cruises in Jan, Apr, July, Aug & Oct 2009
- Visit our website for 2010 Group Cruises
- Individual Cruise Packages available also

**NOTE:** Prices start at \$484 per person Double Occupancy (taxes & fees add'l). Ships registered in the Bahamas. For all North American reservations made on or after June 30, 2008, a fuel supplement of \$10.00 per person, per day for the first two occupants in a stateroom will apply. For additional occupants in a stateroom, a fuel supplement of \$5.00 per person, per day will apply.

For more info:

[www.AutismontheSeas.com](http://www.AutismontheSeas.com)

1-800-516-5247



"Autism on the Seas" is a division of Alumni Cruises, LLC



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

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

*Looking for information and support?*

### AHA Association can help!

Support meetings, hotline, and informational lectures  
Bi-annual conferences for professionals,  
family, and individuals on the autism spectrum  
Email listserv and member newsletter

**(516) 470-0360**

Asperger Syndrome and  
High Functioning Autism Association (AHA) Inc.  
Bethpage, New York

Website: [www.ahany.org](http://www.ahany.org) E-mail: [info@ahany.org](mailto:info@ahany.org)

*AHA Association is a Not-for-Profit Corporation*

# Understanding Asperger Syndrome

**By James B. Snyder, MD**  
**Board Certified Psychiatrist and Director**  
**Long Island Psychiatric, PLLC**  
**Roslyn, New York**

**A**sperger Syndrome (AS) is a lifelong developmental disorder at the high-functioning end of the Autistic Spectrum. In a broader sense, AS represents a very diverse group of interest-driven individuals who suffer with impairments in the development of social skills and social communication (i.e., odd speech, awkward body language, poor eye contact, etc.). AS differs from other forms of Autism in that those with AS can be highly verbal and often crave social interaction but have a difficult time forming or sustaining relationships. Central to the disorder of AS are profound social deficits including difficulty reading social cues, difficulty understanding or recognizing the feelings of others, difficulty 'reading between the lines' and a tendency to obsessively pursue narrow and unusual topics of interest. As young adults, those with AS may not be as concerned as their peers with regard to grooming habits or fashion trends, which can create even more separation and alienation in social settings.

Those with Asperger Syndrome (AS) also exhibit a strong preference for order and routine while adhering to an extremely literal interpretation of rules or commands. Individuals with AS may become easily overwhelmed and distressed when confronted with change or expectations that fall outside of their predictable routine. When anxious or overstimulated, those with AS may make inappropriate comments, perseverate on topics of their own interest and display noticeable physical mannerisms such as repetitive hand or finger flapping, rocking or pacing and other body movements. In social settings, individuals with AS are typically unaware of how their stiff body posture, serious demeanor, uniform facial expression and avoidance of eye contact may be interpreted by others as lack of interest, suspiciousness, guilt or malicious intent.

Children with Asperger Syndrome (AS) often stand out among their peers as being "different". Sadly, the culmination of social deficits, odd mannerisms and unusual interests cause many of these children to become the target of teasing and bullying during most of their school-age years. Unlike other forms of Autism, those with AS possess a strong desire to seek friendships and become painfully aware of their rejection by peers. AS children are ill-equipped with the tools to cultivate successful relationships and continually retreat to the comfort of their familiar routines and circumscribed interests. Their innate tendency to immerse themselves in predictable and preferred fixed interests further limits opportunities for social integration. With practice, many individuals with AS may be able to mimic or learn basic social communication skills. However, these skills (sometimes acquired through observing and mimicking television, cartoon or



**James B. Snyder, MD**

movie characters) are typically performed with great effort and can appear immature, inappropriate, and scripted.

People with Asperger Syndrome (AS) have a tendency to be rather literal and detail-oriented thinkers. As a result, they are often confused by jokes and have great difficulty understanding irony, sarcasm and innuendo. In addition, those with AS are sometimes considered to be "honest to a fault" which can be somewhat disadvantageous in school-age social encounters such as when a child with AS insists or perseverates on reporting another child to the teacher who breaks a minor school rule.

Many with Asperger Syndrome (AS) attempt to impose their own sense of order on a world they don't fully understand. While many possess special abilities and aptitude in their chosen areas of interest, their ability to adjust and react to unforeseen situations can be extremely limited. For those with AS, there tends to be no middle ground. Rather, their perception of events is typically black and white and frequently a source of their aggravation and frustration in vague and chaotic situations. When under distress, their tendency is to revert to their preferred activities and the comfort of their obsessive rituals and predictable routines. When a situation does not conform to their rigid system, it becomes intolerable and subsequently put off or completely avoided. In some cases, high levels of frustration and over-stimulation are followed by outbursts of anger and/or threats of aggression and violence. At school or in the workplace, task avoidance and outbursts of anger may be viewed by others as intentional defiance rather than reactions and responses related to their disorder.

Those afflicted with Asperger Syndrome (AS) often remain entrenched in their routines and create an existence that attempts to eliminate most of life's uncertainty in order to keep things from changing. Unfortunately, predictability and strict adherence to routine are not especially compatible with sustaining deeper emotional relationships where the needs

of others have to be negotiated and occasionally demand flexibility and disruption of routine. In other words, for those with AS, extraordinary adherence to routine fits well with a relatively solitary existence but is generally disadvantageous when attempting to establish and maintain successful interpersonal relationships.

For individuals who suffer with AS, the understanding of affection, friendship, and empathy have typically been taught and rehearsed, rather than naturally acquired. Many are stuck or fixed to their own agenda and have difficulty recognizing, attending to or responding to the needs and feeling of others. Those with AS have great difficulty with expressive gestures, reading body language, and responding to subtle hints and nonverbal cues. However, as adults, many have been able to model more appropriate social graces and approach an adequate level of social functioning by gradually assembling an understanding of what to expect and, what is expected of them, in social situations.

Through increased awareness, social support, therapies and educational programs, those with Asperger Syndrome (AS) can be guided and encouraged to increase their range of interests in a broader range of activities, learn to model more appropriate methods of social relatedness, attempt to break or shift from rigid routine and learn to adopt more effi-

cient coping strategies for managing real world demands and expectations. Early diagnosis and detection of common co-existing conditions such as ADHD, mood and anxiety disorders are critical components to achieving the best overall prognosis for those suffering with AS. In some cases, psychiatric medications can be helpful in alleviating coexisting problems with aggression, mood instability, impulsivity, inattention, anxiety and compulsive behaviors, which often interfere with behavioral therapies, social relatedness, academic functioning and overall progress.

In the last several years, there has been a dramatic increase in the amount of attention allocated to Autism Spectrum Disorder research and funding of resources. In addition, there has also been a surge of technological advancements in neuroimaging, genetics and neuroscience. Our recent steps forward in understanding Asperger Syndrome has helped to emphasize the critical need for early implementation of specialized, coordinated support teams, educational services, behavioral and psychiatric consultation, legal advocacy and vocational counseling. As more awareness and understanding unfolds, many now suffering with Asperger Syndrome may look forward to developing and sustaining improvements in social functioning and, with support, learn to acquire the skills necessary to lead a more independent and productive life.

Attention Deficit Hyperactivity

Obsessive Compulsive Disorder

Depression

Selective Mutism

Tic/Tourettes Syndromes

Adult ADHD

Autism/Asperger Syndrome

Anxiety Disorders



## LONG ISLAND PSYCHIATRIC, PLLC

**A Comprehensive Outpatient Center**  
**Children • Adolescents • Adults**

Long Island Psychiatric, PLLC

is an organization of professionals dedicated to therapeutic healing and communication through Psychiatry, Psychology and Creativity. We incorporate a highly trained multi-disciplinary treatment team to assist children, adolescents and adults.

### Psychiatric Services

Psychiatric Diagnostic Evaluation  
 Psychopharmacological (Medication) Management

### Psychological Services

Individual Therapy • Cognitive Behavioral Therapy  
 Stress Management • Educational Advocacy

### Group Therapy Programs

Attention Deficit Hyperactivity • PDD/Asperger Syndrome  
 Self Esteem Enhancement • Social Skills Training

**James B. Snyder, M.D.**

Executive Director, Long Island Psychiatric, PLLC  
 Board Certified Psychiatrist

2 Main Street (Suite 8), Roslyn, NY 11576

Tel: 516-626-2182 • Fax: 516-626-9367

Visit us at: [www.lipsychiatric.com](http://www.lipsychiatric.com)

## Autism and Culture: An International Perspective

### An Interview with Dr. Roy Richard Grinker

Staff Writer  
Autism Spectrum News

Recently, *Autism Spectrum News* spoke with anthropologist and author Roy Richard Grinker, PhD about his fascinating research on autism in other cultures and his thoughts about the view that there is an epidemic of autism. Dr. Grinker is Professor of Anthropology and the Human Sciences at the George Washington University and editor-in-chief of *The Anthropological Quarterly*.

Q: How did you get interested in studying autism in other cultures?

A: Because I am both an anthropologist and the father of a girl with autism, friends started asking me impossible questions. "So what's the prevalence of autism in Tahiti?" "How do the Pygmy hunter-gatherers of Africa treat autism?" Despite the growth of autism awareness in the world - there are autism societies in 92 different countries - we still know little about autism across cultures. Although most researchers expect that the onset and core symptoms of autism spectrum disorders are uniform across cultures, this is really just an assumption. We do not even have reliable estimates of autism prevalence for any country in Africa, South



Roy Richard Grinker, PhD

America, Latin America, or Asia (with the exception of Japan). I decided to travel to a range of different countries and find out what was happening there. Those trips form the basis for my book, *Unstrange Minds*.

Q: In what countries have you looked at developmental disabilities, and autism in particular?

A: I've been to India, South Africa, South Korea, and the Democratic Republic of Congo. In these countries, autism is becoming a more popular diagnosis for kids who used to have other diagnoses, like "brain disorder" or "madness." Some of this change is due to a decrease in stigma, a decrease for which Americans are, to some extent, responsible. American charities have played a big role in changing how people throughout the world think about people with language and social deficits. In South Africa, a Zulu witch doctor diagnosed a boy with autism. He had learned about autism from the Internet.

Q: You've been traveling to Korea often. What's happening there?

A: Korea is both fascinating and sad. Because Koreans understand how large a role genetics plays in autism, parents are afraid of what an autism diagnosis would mean to their families. The lineage would be tainted; the others in the family might have a hard time getting married. For who, they ask, would want to marry into a defective family? In Korea, unfortunately, most people think that "genetic" always means "familial" or "hereditary," which, of course, it doesn't (de novo mutations probably play a significant role in autism spectrum disorders). But Korean parents, especially moms, insist that the child's

developmental problems are *their* fault, that they are just bad parents. The doctor gives therapy to the mother more often than to the child, since what we would see as "autism" is diagnosed as Reactive Attachment Disorder (RAD), which is glossed in Korean as "lack of love." RAD is sometimes diagnosed in the U.S. too, but usually only when there's clear evidence of pathological caretaking.

Q: The Korean doctors believe this too?

A: Yes, the diagnosis makes sense to many Korean physicians, and they know the parents are more likely to accept it. First, parents and doctors think autism is extremely rare. Second, there's something the parent can do; she can learn how to interact with her child. Third, Koreans think genetic disorders can't be cured, but a lack of love can be changed with better parenting skills. Fourth, the diagnosis helps explain a belief in Korea that the rapid social changes, especially working moms, are having a negative effect on children's brain development. If we do see an increase in autism diagnosis, or have reliable estimates of autism prevalence that exceed local expectations, things may change for the better, just as it did in the U.S. But for the time being,

see *Autism and Culture* on page 32

LEARNING AND UNDERSTANDING

# Social Skills

GIVING CHILDREN  
THE GIFT OF BELONGING

## Develop and Practice Skills

A series of interactive computer programs using video to build social skill understanding for preschoolers through young adults.

### Targeting:

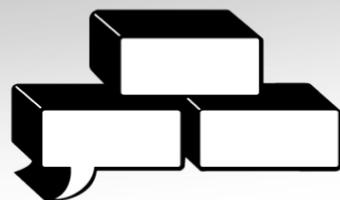
- Appropriate Social Behavior
- Interactions & Relationships
- Social Emotions
- Problem Solving

### Products Include:

- Preschool Playtime CD Vol 1 CD
- Preschool Playtime CD Vol 2 CD
- My School Day CD
- My Community CD
- School Rules! Vol 1 CD
- School Rules! Vol 2 CD

### All Programs Include:

- Multi-Level Instruction
- Customization
- Over 350 Video Clips



**Social Skill Builder**  
Quality Learning Tools

To order, view product demos or receive more information, visit our website at  
[www.socialskillbuilder.com](http://www.socialskillbuilder.com) 866-278-1452

# Institute for Child Development



To Serve • To Educate • To Understand  
 Dr. Raymond G. Romanczyk, Director  
<http://icd.binghamton.edu>

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.



State University of New York



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

- Direct service for individuals with ASD - Early Intervention, Preschool, and School Age programs as well as parent and sibling services.
- 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.

## The Institute for Child Development at Binghamton University has immediate position openings

### Outcome and Evaluation Positions:

A major long term initiative with multiple state government agencies to improve and evaluate services for individuals with ASD across the lifespan is being conducted by the Institute. Preference will be given to candidates with academic training in behavior analysis, clinical psychology, special education, speech pathology, or school psychology (other areas of specialization will be considered). BCBA status highly desirable. Applicants must have significant training/experience in autism spectrum disorders and commitment to impacting public policy through exemplary service delivery. Individuals will work with a multi disciplinary team to provide model service programs to individuals and families and participate in grant funded dissemination, capacity building, evaluation, and research projects.

Excellent benefits package. The positions are with the Research Foundation of the State of NY, an equal opportunity/affirmative action employer.  
 Submit applications to:

Raymond G. Romanczyk, Ph.D., BCBA  
 Director - Institute for Child Development  
 State University of N.Y. at Binghamton  
 Binghamton, N.Y. 13902-6000



### Direct services positions:

- Special Education Teacher
- Speech Language Pathologist
- Speech Therapist/Teacher
- Clinical Psychologist
- School Psychologist
- Behavior Analyst
- Teacher Aides

## Are you concerned about child safety and injury risk for children with ASD?

### We are, and would like your assistance.

Understanding child safety and injury risk starts with those who know children best. We are seeking parents, teachers, and other professional service providers to provide valuable information regarding safety concerns and injury risk assessment for children with ASD. This study is an anonymous, web-based survey. To help us gain insight into this important but under-researched area, please go to:

<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.



## Collaboration Across Disciplines In Meeting the Needs of Students With Autism

By Panos Rekoutis, Laura Prestia,  
Cecelia McCarton, MD, and  
Mary Jane Weiss, PhD  
The McCarton Foundation

**A**t the McCarton School in New York City, students with autism are taught in an integrated model. Professionals in Applied Behavior Analysis (ABA), Occupational Therapy, and Speech and Language Pathology work together to develop goals, provide intervention, and evaluate progress. Such a collaborative/integrated model is unique. Often when such disciplines are providing services to students with autism, they do so in an independent manner. While the collaborative model requires more planning and cooperation, it also potentially enables better service coordination and may accelerate learner progress.

In an integrated model, clinicians from each discipline bring their unique expertise and perspectives to develop a comprehensive approach to effectively address each child's challenges. Collaborative teaching is a complex paradigm which merges instruction with team-teaching. ABA teachers, speech-language pathologists (SLPs), and occupational therapists (OTs) work together to understand how each student is functioning and how to formulate and implement an appropriate and functional plan.

### ABA as the Framework

Collaboration between all the disciplines makes for maximally effective programming. The unique contributions from ABA include the development of clearly defined goals, the delineation of precise instructional strategies, the collection of objective data, and the use of data to evaluate progress and to make decisions regarding alterations in instructional objectives or methods. ABA interventionists use scientifically validated methods, and value the incorporation of methods that have been demonstrated to have efficacy. Many ABA programs do not provide services in language and OT, because these disciplines have smaller bodies of research supporting their effectiveness with learners with autism. The McCarton School employs specialists from all of these disciplines, and uses the specificity, accountability, and responsiveness of ABA instruction in all of the student's educational services and decisions.

### Contributions of Speech and Language Programming

The contributions that ABA makes to speech and language programming include operationally defining targets within all areas of the curriculum and objectively evaluating learner progress. Teachers and speech pathologists work in collaboration, employing shaping principles and taking into account varying prompt levels, such as phonemic cues or visual supports. Acquisition criteria must be reasonable and possible; this ensures success. The formulation of measurable goals facilitates the

collection of data, which are monitored on a consistent basis so that modifications (e.g. removal of mastered goals, introduction of prompts), can be made as necessary.

Speech-language pathologists provide the foundation skills for communication, which are the essential components for daily functioning across all domains. A considerable number of language goals are targeted via naturalistic teaching approaches (such as incidental teaching or natural environment training) which can target the generalization of skills learned within a more structured ABA format such as discrete trial instruction. For example, while ABA teachers may target sorting picture cards into groups of foods and furniture, SLPs may work on the same target but within more generalized contexts, such as a storybook or during snack. Additionally, SLPs may lend support to facilitating the development of basic requesting skills during manding sessions, as well as to extending the skill of manding into the natural environment.

An understanding of pragmatic skills is vital when working in a classroom setting, as pragmatic language skills augment the degree to which a student can navigate the educational environment independently. SLPs explain, model, and train ABA teachers on the various components of pragmatics and how to incorporate these goals across the school day. These skills can include appropriately greeting peers during circle time, encouraging interactions among peers during social times such as snack, improving conversational skills while talking during morning meeting, and commenting on their environment during community walks.

A significant part of the school day for young learners involves play, an area which may seem fun and effortless, but is actually complex and requires an extensive understanding of language development. SLPs work with ABA teachers to set up simple play sequences (e.g., for a garage - first get gas, next wash the car, and then go down the ramp). SLP's and ABA teachers can work together to develop goals and programs in the area of imaginative play. Goals might include using narration while expanding a play schema (dressing up as doctors, using a variety of items to perform an examination, and using context-appropriate scripts). These are also areas in which ABA research and data collection methods can inform best practice teaching approaches, allowing for very fruitful collaboration.

### Collaboration with Occupational Therapists

What occupational therapy brings to the collaboration is a perspective of human performance viewed from two different vantage points: a) sensory integration, sensory processing and regulation and b) motor learning / motor skill acquisition. Occupational therapists examine how a child receives information through different sensory systems, and how that information is processed and interpreted. Subsequently, the clinician examines how the child responds to the sensation. A sen-

sory diet is put in place that helps the child to cope more efficiently with everyday life situations, overcome sensory sensitivities and help different systems receive process and respond to stimuli in an organized, regulated and appropriate way.

This information can inform the educational interventions and approaches used. Therapists and teachers can better identify the nature of particularly appealing / motivating reinforcers, including sensory reinforcers. Sensory breaks within the overall structure of a daily sensory diet may help with maintaining the child at a level of 'optimal arousal' (a state of productive alertness) where learning and skill development can be promoted without evoking behavioral or emotional overreactions. Examples of sensory breaks can be different types of 'heavy work' (jumping on trampolines, or hippity hop balls, carrying heavy objects around rooms, running on treadmills, resistance activities, movement / exercise protocols) or intense short bursts of sensory stimulation (rotary stimulation, localized proprioceptive input, use of hand manipulatives, or visual stimulation).

Occupational therapists focus on gross and fine motor coordination skills and utilize motor learning guidelines while working on skill development. Principles regarding guidance (physical, verbal, visual modeling), feedback and variability in

practice are employed when presenting therapeutic activities across different areas of performance following a developmental progression. A variety of programs can be jointly carried out by ABA and OT staff members (gross motor imitation, fine motor imitation, ball playing, graphomotor tasks such as coloring, handwriting, cutting with scissors, ADL's - personal hygiene). Often the occupational therapist will introduce the new skills and focus on developing the necessary movement patterns. At the same time, emphasis is placed on muscle strengthening and bilateral coordination. Interventions are intense, fast paced and provide multiple opportunities for consistent practice. ABA therapists collaborate with this process by providing intensive practice that tends to accelerate skill mastery.

The occupational therapists' knowledge of kinesiology and human biomechanics can also be useful in recommending several types of adaptations in the children's classroom environment that helps enhance their performance (slant boards, seating adjustments, foot rests and back supports, inflated cushions, pencil grips, adapted scissors, modified worksheets, weighted writing mediums and utensils etc).

*see Collaboration on page 44*



*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 Look Out for Details on Our 2009 Events*

***Parent & Caregiver Workshops:  
Structuring Leisure Time  
and  
Evaluating the Effects of Alternative Treatments***

*For more information please contact:*

*Harvey Weissman*

**(646) 277-5422**

*hweissman@mccartoncenter.com*

***The McCarton Foundation  
350 East 82<sup>nd</sup> Street, New York, New York 10028***

## Introducing the Editorial Board of Autism Spectrum News

**Stephen E. Freeman, CSW**  
Associate Executive Director  
YAI/National Institute for People with  
Disabilities Network

**M**r. Stephen E. Freeman was born in New York City and attended Queens College where he obtained his B.A. in 1972. He acquired his Masters of Social Work from The Hunter College School of Social Work in 1975. Initially working as a counselor and social worker for cardiac and surgical patients at North Shore University Hospital in Manhasset and Montefiore Hospital and Medical Center in the Bronx, Mr. Freeman joined YAI in 1977. Beginning as a residential supervisor, Mr. Freeman was made a director in the residential system by 1979. He quickly rose in the ranks to become Director of Resource Management and then Director of Residential Facilities by 1982. Promoted once again to Director of Clinical Services in 1986, Mr. Freeman was named Assistant Executive Director of YAI in 1987. Mr. Freeman oversees all operations of the Department of Day Services, Clinical & Family Services (including both the Article 16 and Article 28 Clinics), and the New York League for Early Learning. In addition, he is an adjunct professor at The Hunter College School of Social Work since 1991, is a faculty advisor at Boricua College, and has had myriad articles on various aspects



**Stephen E. Freeman, CSW**

of developmental disabilities published over the last 25 years. He is a member of the National Association of Social Workers, the American Association for Mental Deficiency, the NYS Association of Day Treatment Providers, the NYS Advisory Committee on Day Services for Mentally Retarded and has served on the Executive Board of the NYC Association for Community Residence Administrators. In 1997, his twentieth year with YAI, Mr. Freeman was again promoted to the position of Associate Executive Director.



**Joel D. Bregman, MD, Medical Director**  
**Fay J. Lindner Center for Autism**  
**and Developmental Disorders**  
**North Shore - Long Island Jewish**  
**Health System**

**J**oel D. Bregman, MD is Medical Director of the Fay J. Lindner Center for Autism and Developmental Disorders, North Shore-Long Island Jewish Health System (NSLIJHS). Dr. Bregman specializes in neurodevelopmental disorders (including autism spectrum conditions), focusing on clinical care, research, and educational/treatment programming. He received his medical degree from Yale University School of Medicine, and completed residency and fellowship training general, child, and adolescent psychiatry at the University of Pittsburgh and the Yale Child Study Center and pediatric training at Stanford University and the University of Pennsylvania. Dr. Bregman has been a faculty member at the Child Study Center of Yale University, Emory University, and the University of Connecticut. He actively participated in the development of academically-based Autism Centers at Emory University and North Shore-LIJ Health System. During the coming months, he will be devoting a majority of his time to clinical research projects at the Feinstein Institute for Medical Research



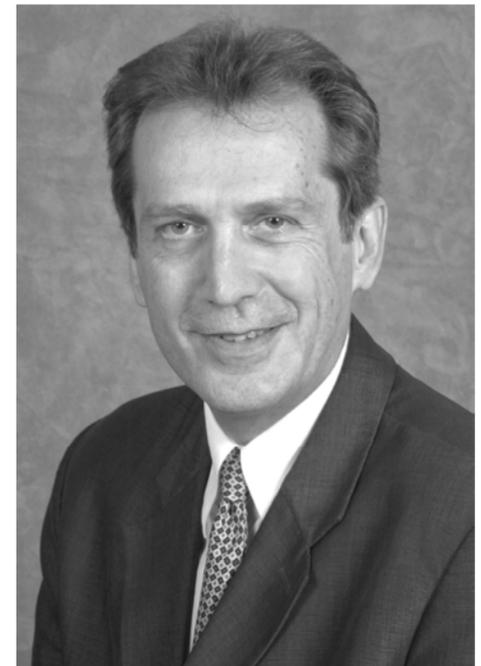
**Joel D. Bregman, MD**

of NSLIJHS as Director of Clinical Research in Autism. Current areas of investigation include psychopharmacology, genetics, and neuroimaging in autism spectrum disorders. Other research interests have included behavioral genetics and neuropsychiatric disorders among those with intellectual disability.

**John C. Pomeroy, MD**  
Founding Director, Cody Center for  
Autism and Developmental Disabilities  
Stony Brook University Medical Center

**D**r. Pomeroy is Associate Professor of Pediatrics and Psychiatry and Founding Director of the Matt & Debra Cody Center for Autism and Developmental Disorders at Stony Brook University Medical Center. Dr. Pomeroy completed medical and adult psychiatry training in the UK and then specialized in child and adolescent psychiatry at the University of Iowa. After a brief time at Cornell Medical Center he moved to Stony Brook where he was the first faculty member of the division of child psychiatry in a new medical center. In addition to developing consultation services to the Pediatrics Department and directing the Child Psychiatry Outpatient Department, Dr. Pomeroy maintained clinical and research interests in the field of Autism and the Pervasive Developmental Disorders. Dr. Pomeroy's interest in the broader diagnostic concept of Autism dated back to projects he began as a resident at the University of Iowa. In 1984 the manuscript related to this work received the J. Franklin Robinson Award from the American Academy of Child and Adolescent Psychiatry. He has since been an author on over 70 articles, abstracts and book chapters, with a particular emphasis on two fields of interest – diagnostic sub-typing of (what has become known as) the autism spectrum and the diagnosis and treatment of emotional/behavioral disorders in individuals with cognitive or developmental disabilities.

In addition to research interests, Dr. Pomeroy has developed a broad range of clinical and training programs. During the 1990's Dr. Pomeroy received funding from New York State to develop a continuum of psychiatric care for dually diagnosed (MH/MR) individuals on Long Island and for a fellowship-training program for child and adult psychiatrists to specialize in the diagnosis and treatment of individuals with dual diagnosis. More recently, with initial funding from the New York State Developmental Disabilities Planning Council, Dr. Pomeroy was a principal collaborator in the formation of the Downstate Center of Excellence for Dual Diagnosis, which is a consortium of



**John C. Pomeroy, MD**

about 30 agencies created to enhance staff training and clinical expertise in the recognition and management of mental disorders in persons with mental retardation or developmental disability. In addition he has continued to develop services for children and adults with Autism Spectrum Disorders at Stony Brook and advocate for the local development of school programs and improved clinical services.

Dr. Pomeroy has led a rapid expansion of clinical and community services for Autism and Developmental Disabilities at Stony Brook, which capitalized on the long history of clinical and research activity in this field at Stony Brook. In 1997 he was given the opportunity to form a Division of Developmental Disabilities within the psychiatry department at Stony Brook in collaboration with Lynda Geller, PhD. In 1998, Matt and Debra Cody provided funding to open the Stony Brook Resource Center for Autism and Developmental Disabilities. In April, 2001, with major philanthropic and university support the Matt and Debra Cody Center for Autism and Developmental Disabilities was created and Dr. Pomeroy became the founding director with the goal for the center to be a major regional clinical/research/training center. The Cody Center is a division of the Department of Pediatrics in the Health Science Center at Stony Brook University.

*Autism Spectrum News - Spring Issue*  
*“Helping Parents and Family Members Cope with ASD’s”*

*Deadline: December 15, 2008*

*We Invite You to Contact Us*

*About Your Interest in Submitting an Article*

*And Advertising Your Vital Programs and Services*

*Call (570) 629-5960 Email: [iramnot@mhnews.org](mailto:iramnot@mhnews.org)*

## Renowned Autism Expert Answers Questions for Parents

By Catherine Lord, PhD  
Interim Director, Asperger Institute  
NYU Child Study Center

**W**hy should parents bring their child with autism to the NYU Child Study Center? The NYU Child Study Center is one of the nation's premier centers for treatment of child and adolescent psychiatric and learning disorders including autism. The Autism Spectrum Disorders (ASD) Service at the NYU Child Study Center is dedicated to the evaluation and treatment of children and adolescents with Autism Spectrum Disorders and Pervasive Developmental Disorders. Our unique team approach allows for tailored and individualized recommendations. Our services specialize in the comprehensive evaluation and early identification of social difficulties in children as young as 18 months. Autism Spectrum Disorders (ASDs) affects 1 in 150 children. These are developmental disorders that hinder a child's ability to socially interact, communicate and play. Research tells us that early identification, parent-training, and intensive educational intervention can greatly improve children's



Catherine Lord, PhD

lives, giving them the best chance to achieve their full potential.

What are the signs of autism that parents should look for?

There are several indications that may

help identify children and infants who may be at risk for autism: lack of a social smile, poor social interactions, preference for aloneness, lack of appropriate gestures such as pointing and showing objects, minimal or nonexistent imaginative play and the need for sameness. In addition, delays in language development should never be neglected. Any of these concerns should prompt a parent to request an evaluation.

Why does it seem like more children are being diagnosed with autism today than in the past—is it an epidemic?

Many scientists feel strongly that there isn't an increase in prevalence — that what is reported as more cases, predominantly in school systems, can be attributed to better identification and a broader definition of autism. However, there are clearly more kids and adults identified with ASD; these are not just people who are a little bit unusual, but children and adults who need services. From that point of view, the larger numbers are very real, and we need information about them.

Is there anything parents can do to help prevent children from developing autism?

In most cases we do not know what causes autism. We do know that there is a strong genetic component and that psychological factors are not a cause. A small number of cases have an underlying medical disorder such as tuberous sclerosis or Fragile X. There have been some excellent studies that clearly indicate autism is not caused by vaccinations such as the measles, mumps and rubella (MMR) vaccine or by thimerosal (a mercury preservative) that has been used in the past as a preservative in vaccinations. There is also no evidence that other environmental issues such as food allergies can cause or trigger the onset of autism.

What can parents and teachers do to help children with autism succeed in school?

It is important to identify children with autism as early as possible and provide them with a specialized education program. There are special schools and programs within the public education sector. One of the most important aims of these programs for young children is to help increase interest in other people. Next is an emphasis on learning language, and finally the use of functional assessments and treatments of behaviors.

## Autism Speaks, The CDC, and The Ad Council Launch New Program To Educate Teachers About the Importance of Early Intervention for Autism

Staff Writer  
Autism Spectrum News

**A**utism Speaks, in partnership with the Ad Council, and the Centers for Disease Control and Prevention (CDC) announced today the launch of a new, groundbreaking educational tool kit, *Talking to Parents About Autism*, designed to promote early intervention and encourage educators to speak to a child's parents if they suspect a developmental delay. This is the first program to provide teachers with tools to prepare to begin this critical dialogue.

The new kit includes a *Talking to Parents About Autism* training DVD that features information and advice about how educators can best broach the topic of a potential developmental delay. Also included in the tool kit is an *Early Childhood Milestone Map*, which can be printed and distributed to parents so that they can more easily track their child's progress against the typical, age-specific developmental milestones. The entire kit, available in both English and Spanish, is available at [www.autismspeaks.org](http://www.autismspeaks.org).

According to the CDC, autism is one of a group of disorders known as autism spectrum disorders (ASDs). ASDs are developmental disabilities that cause substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, and reacting

to different sensations. The thinking and learning abilities of people with ASDs can vary—from gifted to severely challenged. An ASD begins before the age of 3 and lasts throughout a person's life. ASDs occur in all racial, ethnic, and socioeconomic groups and are four times more likely to occur in boys than in girls. CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released data in 2007 that found between 1 in 100 and 1 in 300 with an average of 1 in 150 8-year-old children in multiple areas of the United States had an ASD.

Program Helps Educators Speak to Parents About Child Development Issues

Research has shown that early detection and intervention can make a significant difference in the life of a child with autism. In fact, with appropriate early intervention services, from ages 3-5, between 20% and 50% of children diagnosed with autism will be able to attend mainstream kindergarten. Educators, who interact with and observe children on a daily basis, are in the ideal position to know if a child's development seems delayed.

"It is critical that teachers feel comfortable approaching parents and speaking frankly about any concerns they have about their young students," said Alison Singer, Executive Vice President of Autism Speaks. "This important new tool will facilitate those conversations and ensure that kids who may have a developmental delay get the services they need as early as possible."

"It's important for all those who interact with children, on a regular basis to talk with parents when they are concerned about a child's development. It may be a difficult conversation, but it could make an immeasurable difference for a child who needs services at an early age to reach their full potential," says Edwin Trevathan, M.D., MPH, CDC's Director of the National Center on Birth Defects and Developmental Disabilities.

The Ad Council and Autism Speaks initially launched an autism awareness campaign in 2006 in an effort to raise awareness about the developmental disorder and to urge parents to learn the signs of autism. The campaign has thus far generated more than \$147 million in donated print, broadcast and online media and is credited with raising awareness of autism by more than 43%. The campaign was recently awarded a prestigious bronze Effie award as a testament to its success in building awareness.

"We are so pleased to continue our partnership with Autism Speaks on this critical issue," said Peggy Conlon, President & CEO of The Advertising Council. "I am confident that this program will help all the wonderful teachers in our schools initiate discussions with parents of children they suspect may have autism."

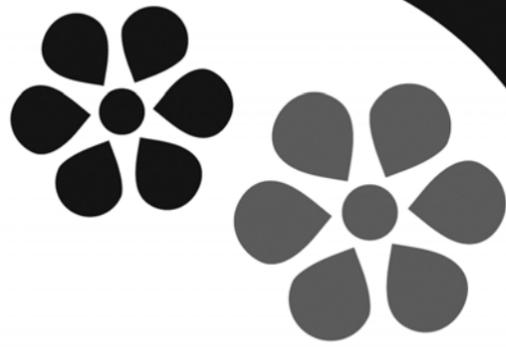
Autism Speaks and the Ad Council are co-executive producers of the new DVD. JMH Education served as producer. Funding support was provided in part by the CDC's "Learn the Signs. Act Early." campaign ([www.cdc.gov/actearly.com](http://www.cdc.gov/actearly.com)).

The "Talking to Parents About Autism" DVD and toolkit is designed to address a need we identified in early childhood educators. Many preschool teachers told us that they knew the signs of autism, and often saw early warning signs of kids at risk for developmental disabilities, but were reluctant to have the uncomfortable conversation with parents. This new DVD provides step by step advice for preschool teachers regarding how to talk to parents about autism.

Research shows that the reluctance of teachers to broach this topic with parents can lead to a delay in screening and diagnosis of six months or longer, during the critical preschool period. Our goal with this project is to enable children to be diagnosed earlier, so that early intervention services can begin as soon as possible and children can maximize their potential.

I know this project has huge potential to truly change the lives of families facing autism.

Alison Singer  
Executive Vice President  
Autism Speaks



## 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.

### KULAM: TOGETHER

#### Children, Family and Community

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

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

### TRANSITIONS

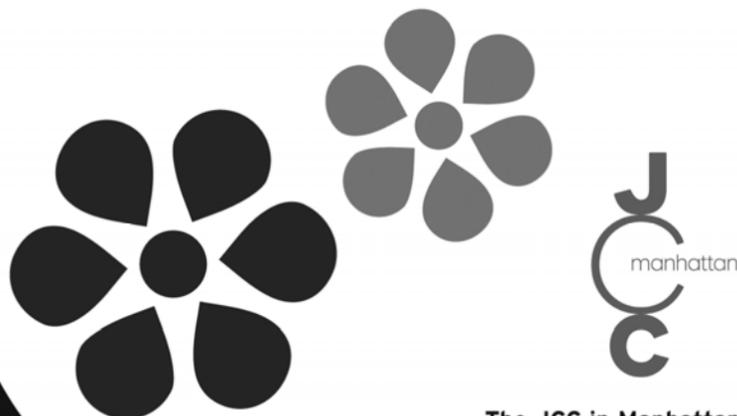
Transitions is a social program for 16-21-year-olds with a variety of special needs, including those on the high functioning end of the autism spectrum and those with varied communication and learning differences. On Sundays during the academic year, young people meet to participate in fun and social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

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

### PARENTING + MORE

Programs include support groups for parents, adult siblings and grandparents, a disability film program, panels and workshops with noted professionals which are appropriate for both parents and educators.

**For more information visit  
[jccmanhattan.org/specialneeds](http://jccmanhattan.org/specialneeds)  
or call 646.505.5729.**



**The JCC in Manhattan**  
The Samuel Priest Rose Building  
334 Amsterdam Ave at 76th St  
a beneficiary of UJA-Federation

### Autism and Culture from page 27

“Reactive Attachment Disorder” is a common diagnosis for kids you or I would think have autism.

**Q:** Can you explain what you mean by “better”? Higher prevalence can be a good thing?

**A:** Higher prevalence can mean that more people are getting identified. It doesn't always mean there's more of a disease. Prostate cancer rates, for instance, soared after the first blood test for the prostate specific antigen was developed in the late 1970s. Before that time, doctors could only screen for prostate cancer by doing a biopsy of the prostate, and so they usually screened only those people who already had symptoms. With more diagnoses came treatment of early stage cancers that never would have been diagnosed before. The cases entered into the pool of people with the disease, and so we saw higher prevalence rates but not necessarily a true increase in incidence. The same is true with autism. More kinds of cases are today called “autism,” more mild cases are called “autism,” and it's diagnosed earlier than ever. This has had a positive impact because of increased awareness, and increased intervention at very early ages.

**Q:** Is this why you challenge the view that there is an epidemic of autism?

**A:** I challenge the idea of an epidemic because there are no data to support a claim of an epidemic. Epidemics are not necessarily defined by higher prevalence rates. Take Fetal Alcohol Syndrome, for example, which increased dramatically during the 1970s and looked like an epidemic. That's because FAS didn't exist before that time. It didn't exist because the classification had not been established, and once it was established, physicians started making the diagnosis more and more. But FAS wasn't really new. No one could possibly argue that pregnant women started drinking only in the mid-1970s.

**Q:** Then how are epidemics defined?

**A:** By higher incidence rates. Prevalence is the proportion of cases in a certain population at a certain time. But incidence is the rate of new cases over time. And the fact is that we do not know the incidence of autism, and the fact that we don't know is understandable. To determine incidence you need to determine disease onset, and the emergence of ASD in early childhood is insidious. Of the few studies that have examined incidence, the date of first diagnosis is usually used as a proxy for onset of the disorder and that's a serious limitation, especially since age of diagnosis varies so much.

**Q:** What do we know about the reasons for the changes in prevalence?

**A:** We may not have data to suggest a rise in incidence, but there are data that suggest there are many factors behind the changing prevalence, all acting together. Prevalence was affected by more aggressive epidemiological studies using better screening and diagnostic tools; the criteria broadened to include a whole spectrum of autism; studies began to count as “autism” cases that, in the past, would

have been excluded, namely, autistic symptoms caused by an identifiable medical cause. Diagnosis was affected by the broadening of the criteria, earlier diagnosis, later diagnosis (teens and adults), diagnostic substitution (in which autism replaces a previous diagnosis), and the addition of an autism code in 1992 in the American public schools, which led to many more autism classifications.

**Q:** You've interviewed a lot of doctors. Is there any disagreement among them about what is and is not an ASD?

**A:** It's important to remember that the criteria and diagnostic guidelines for autism are made by consensus of experts, not by a laboratory test. Autism is whatever scientists decide it is at a particular moment in medical history. Having said that, the biggest disagreement I've seen is between researchers and clinicians. Researchers are pretty strict, but clinicians do what's best for the child, even if it means making a diagnosis a researcher would disagree with. Judith Rapoport, Chief of Child Psychiatry at the National Institute of Mental Health (NIMH), told me she'd “call a kid a zebra” if it got him the services he needed and deserved.

**Q:** How has autism awareness had an impact on your daughter Isabel?

**A:** Autism awareness has made so much difference for Isabel, and I'm sure for other kids. When Isabel was younger, I'd get so nervous calling a dance or music instructor for Isabel, or a summer camp, because people thought of autism not as a spectrum but as a single thing. The classic image was of someone completely unreachable and nonverbal. I knew they'd respond by saying, “Autism. . . well, we don't really have the ability to deal with that here.” These days, I still get nervous, but not as much. Recently, I contacted a volunteer coordinator at a zoo to find out if Isabel could participate. When I said she was autistic, the coordinator, “That's ok. We should meet and figure something out.” I was stunned. This would not have happened 10 or 15 years ago. So she ended up working at the zoo, and I think she did better at her job than a non-autistic person would have!

**Q:** What did she do?

**A:** She was in charge of making sure the 5 year old campers didn't get lost on their tours around the zoo. I was skeptical of her ability to do this, but Isabel loves collections. She has Thomas the Tank Engine trains, American Girls dolls, Pokemon, Disney characters. Nothing ever gets lost from those collections, and she treated the kids in the same way. They were probably never safer.

**Q:** So what is next for you?

**A:** Right now, I'm finishing up the data collection in South Korea for my study of autism prevalence. The work is funded by Autism Speaks and my co-investigators are Young-Shin Kim (Yale), Yun-Joo Koh (Korean Institute of Child Social Development), Eric Fombonne (McGill), and Bennett Leventhal (Illinois). I hope we will report our finds of autism

*see Autism and Culture on page 45*

# Living With Autism: What Every Parent Should Know

**By Bernice Polinsky**  
**Parent of an Adult on the Spectrum**

One of the first things parents should consider doing is to join a support group. By meeting and talking with other individuals whose loved ones have autism, you will receive support, information and gain networking opportunities that can help you and your family. You may learn from others how to organize your records, navigate the system, cope with and solve problems. Encourage your family members to join a support group. This is a great opportunity to connect with others and realize that you are not alone. Learning from others who have “been there” can also save you valuable time, as you’re not forced to reinvent the wheel.

*Learn as Much as You Can.* You and your loved one with autism know best what you need. Ask for help when you are unsure. Get a second opinion if you are not happy and comfortable with the professionals in your life. When possible attend conferences and workshops. Stick with scientific/evidence-based information. It will be the safest in the long run and you won’t spend money unnecessarily on methods that won’t work, and in some cases could be harmful. Join an e-list such as [www.ahaNY.org](http://www.ahaNY.org) or [Autism\\_NY\\_News@yahoo.com](mailto:Autism_NY_News@yahoo.com).



**Bernice Polinsky**

*Advocate: Be a Squeaky Wheel.* Know your rights: you are your child’s best advocate. Learn as much as you can about special education law, ADA, civil rights law, 504, etc. (see our suggested resources at the end of this article). Remember: If you don’t know your rights, then you don’t have any. Find a good service coordinator or education consultant (depending on age and services) to help you navigate the system. Don’t give up when the system seems to be giving you a hard time.

*Keep Organized Medical and Educational Records.* When you apply for services, it is much easier if you have the documents required to show that the developmental disability is a long-standing problem that affected the person before age 22. If your loved one with autism is taking any medication, keep a list of what he or she is taking and log how he or she is responding. This is important information to share with doctors and it is useful for the individual’s medical history for other service providers in the future.

*Plan For the Future.* Be sure to plan early to meet the future needs of your family member. Being realistic is very important. Seek the services of a professional who has experience with special needs planning. If your family member is receiving services, involve your other family members to be sure they are knowledgeable and informed. Transitioning to adulthood, particularly, is a complex, multi-faceted process. There are excellent workshops and websites for transition and it’s important to understand the process inside and out, including SSI, guardianship, OMRDD services, college and vocational programs.

*Take Care of Yourself.* This will be a long road and you must take care of yourself in order to take care of others. Take advantage of respite care when you can. Reach out to family and friends, and don’t be afraid to ask for help. If you don’t have

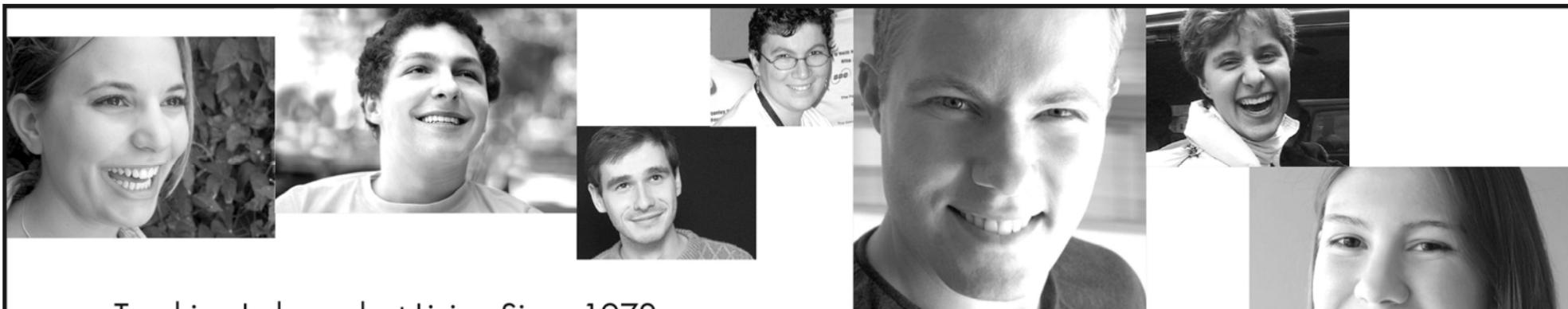
anyone to reach out to, think about counseling for yourself to get the support you need.

*Help Your Family Members Feel Good About Themselves.* Emphasize the positives in your family member with autism and focus on strengths. Give your loved one with autism as much information as he or she can understand about the diagnosis as early as possible. Insight into themselves and a high self-esteem are valuable to enable them to advocate for themselves and be the best that they can be.

*As the mother of an adult on the autism spectrum and an effective parent advocate, Bernice Polinsky has learned a lot on her journey to access services and supports to enhance the quality of life for her entire family. Bernice, whose son receives services through the YAI/NIPD Network, graciously shared these tips to help other families find information, support and greater peace of mind. Bernice is a board member of AHA, is involved with adult issues, and is editor of AHA’s newsletter: On the Spectrum.*

*Thank you to YAI/NIPD for permission to use this article, published in the first issue of their newsletter, Autism Matters, also found on [www.yai.org](http://www.yai.org). This article was also published in the Fall 2008 issue of On the Spectrum.*

*For additional information please visit us at [www.ahaNY.org](http://www.ahaNY.org) and also Wrights Law at [wrightslaw.com](http://wrightslaw.com). Send your Helpful Hints to: [newsletter@ahaNY.org](mailto:newsletter@ahaNY.org)*



Teaching Independent Living Since 1972

# CHAPELHAVEN

Providing an array of individualized support services for adults on the autism spectrum and those with cognitive disabilities, enabling them to lead independent and productive lives.

- TRANSITIONAL INDEPENDENT LIVING PROGRAM
- ASPERGER’S SYNDROME ADULT TRANSITION PROGRAM
- CHAPEL HAVEN WEST NEAR THE UNIVERSITY OF ARIZONA

CONNECTICUT CAMPUSES: New Haven, Connecticut

ARIZONA CAMPUS: Near the University of Arizona, Tucson, Arizona

FOR INFORMATION, CONTACT: Admissions 203.397.1714, [www.chapelhaven.org](http://www.chapelhaven.org)

## Suicidal Ideation and Peer Victimization An Important Assessment Criteria

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

Earlier studies (Ghaziuddin, Weidmer-Mikhal & Ghaziuddin, 1998; Gillberg & Billstedt, 2000; Tantam, 2000) have explored the comorbid clinical disorders in children and adolescents with Asperger's Syndrome (AS), but only a recent study has explored suicidal ideation among adolescents with AS (Shtayermman, 2006). Adolescents and young adults diagnosed with AS may be at higher risk for committing suicide than the neurotypical adolescent due to their difficulty with social communication and the social demands of adolescence. Some of the social demands during adolescence include dealing with increasing autonomy, finding peer groups to identify with, and forming intimate relationship with peers for the first time (Green, Gilchrist, Burton & Cox, 2000). Adolescents and young adults diagnosed with AS may find the social demands and transitions of adolescence more challenging because of their lack of social reciprocity in addition to their awareness that their peers thrive from the new social opportunities (Tantam, 2000).

Risk factors for suicide may be organized within a framework that distinguishes between proximal and distal exposures, and researchers believe this combination of factors constitutes sufficient conditions leading to suicide (Lubin, Glasser, Boyko & Barell, 2001). Proximal risk factors are more closely related temporally to the suicidal event and may act as precipitators. These proximal risk factors may include stressful life events, such as sudden illness or bereavement, and the availability of a method for committing suicide (Lubin, Glasser, Boyko & Barell, 2001; Moscicki, 1995). Distal risk factors increase vulnerability to proximal risk factors and include psychopathology, personal characteristics, substance abuse and familial risk factors. Peer victimization is a proximal risk factor for suicidal ideation (Bond, Carlin, Thomas, Rubin & Patton, 2001; Cleary, 2000). Individuals who were victimized by their peers were more vulnerable to developing psychological symptoms of depression and anxiety (Bond, Carlin, Thomas, Rubin & Patton, 2001; Juvonen, Graham & Schuster, 2003). Studies conducted in the U.S. and in other countries have found the prevalence of suicidal ideation among adolescents who were victimized in school to be 23% to 26%



**Oren Shtayermman, PhD, MSW**

(Cleary, 2000; Kim, Koh & Leventhal, 2005).

Individuals with a diagnosis of AS were found to have a prevalence of suicidal ideation—within the range of levels of suicidal ideation reported in previous studies conducted using community samples of adolescents and adults (Alison, Roeger, Martin & Keeves, 2000; Barrios, Everett, Simon & Brener, 2000; Cleary, 2000; Shtayermman, 2006). In addition, a high proportion of adolescents and young adults diagnosed with AS presented with scores above the cutoff point on the overt victimization and relational victimization scales suggesting that these adolescents and young adults experienced high levels of victimization. Mental health professionals who are working with adolescents and young adults diagnosed with AS should incorporate the assessment of suicidal ideation as well as peer victimization into their practice. Thorough assessment of risk factors for suicidal ideation would provide a solid assessment of levels of suicidal ideation and would allow the development of a more comprehensive treatment plan for the adolescent or young adult with AS. It would also alert mental health professionals to which adolescent or young adult with AS is in an immediate danger to themselves.

*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.*

**Donna Klein & Associates, Inc.**  
Pediatric Occupational and Physical Therapy Services

*Specializing in Autism Spectrum Disorders*  
EI, CPSE, and CSE services available.  
Private services available in your home or  
in our state of the art clinic.

690 North Broadway Ste 6L2  
White Plains, N.Y. 10603  
(914) 686-3116 x 104



### Vocational Independence Program



- 3-Year post-secondary program for students with special needs
- Located in Central Islip at New York Institute of Technology
- Focuses on academics, independent living, social development and career development
- Strong student-to-staff ratio
- Small classes

For more information call 631.348.335 or visit [www.nyit.edu](http://www.nyit.edu)



**The Foundation for Educating  
Children with Autism**

**(914) 941-FECA**

[www.fecainc.org](http://www.fecainc.org)

P.O. Box 813

Mount Kisco, NY 10549

*Ensuring that children with autism  
reach their full potential.*

*The Foundation for Educating Children with Autism, FECA is a non-profit organization located in Westchester County, New York. FECA is dedicated to providing the appropriate educational opportunities for children with autism based on applied behavior analysis, (ABA); through the development of schools, inclusion and vocational programs, consumer advocacy and community outreach.*

### WJCS Autism Family Center



*Support Community  
Social Skills Groups  
Family Programs  
Professional Consultation  
Networking & Resources*

Located at  
**845 North Broadway – White Plains, NY**

For more information, contact  
**914-761-0600, X 228 or [kmacaluso@wjcs.com](mailto:kmacaluso@wjcs.com)**



A non-sectarian program offered by Westchester Jewish Community Services  
with funding from UJA-Federation  
[www.wjcs.com](http://www.wjcs.com)

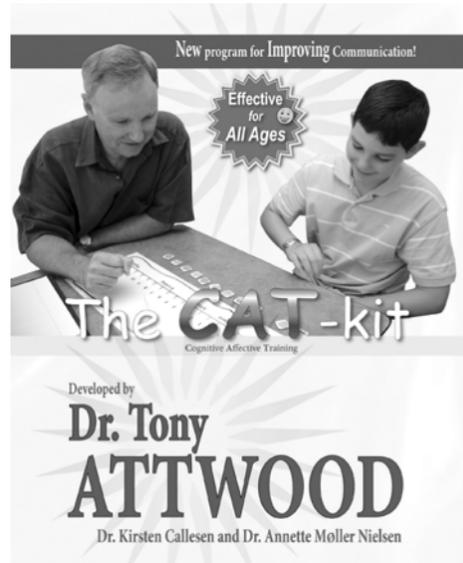
# CAT-kit Helps Children Relate Thoughts and Feelings To Actions and Social Interaction

By Lyn Dunsavage Young  
Future Horizons, Inc.

The CAT-kit is the newest and, many say, one of the most effective tools to help children and young adults with autism and Asperger's syndrome to become aware of how their thoughts, feelings and actions all interact, and to share their insights with others.

It is based on Cognitive-behavioral therapy (CBT) – one of the most widely used, extensively researched (Grave & Blissett, 2004), evidence-based therapies (Gambrill, 2004; Thyer, 2000,2001; Thyer & Kazi, 2004) for adults.

“The aim of CBT with children is to help the child identify possible cognitive deficits and distortions, to reality test them, and then to learn new thinking skills, or to help the child challenge his or her irrational thoughts and beliefs and replace them with more rational ones,” states Professor Tammie Ronen, Head of the Bob Shapell School of Social Work at Tel Aviv University. “The CAT-kit serves as a prime and promising example of a process aimed at molding these methods to suit children. . . .“It does not merely focus on understanding; it addresses also skills acquisition, training and practice. Step by step, this program teaches children the most important



**Dr. Tony Attwood converses with a student using the CAT-kit tools**

functions and needs related to emotions, to social relationships, and to better coping.”

Called CAT-kit -- because it is a Cognitive Affective Training-kit -- the program allows children to identify, express, understand, accept and control emotions through visual and concrete designed elements while conversing with an adult. The program is infused with the CBT tools to teach children new ways of think-

ing and feeling, so they can better cope and adapt to social relationships.

The CAT-kit has a game-like design that entices children to use its components. It is comprised of eight durable laminated charts, graphics, timetables, and behavior palettes with 90 Velcro-affixed “emotion words” and “emotion faces.” They offer multitudinous ways (described in a booklet) that adults can learn how to work or – perhaps, better-to-say – “play” with children to draw out their definitions and reactions to events, people, environments, and time.

The CAT-kit is the product of a multi-years’ collaboration among Drs. Kirsten Callesen, Annette Moller Nielsen, and Tony Attwood.

Dr. Attwood is a clinical psychologist from Brisbane, Australia and also adjunct professor at Griffith University, Queensland. With over thirty years in the field of Asperger’s Syndrome and high-functioning autism, Dr. Attwood is a prolific author of scientific papers and books on the subjects. Over 300,000 of his book *Asperger’s Syndrome: A Guide for Parents and Professionals* have been sold, which has also been translated into twenty languages. His DVD *Asperger’s Diagnostic and Assessment*, in which he conducts unrehearsed interviews of a child and his parents and explains his assessment and diagnosis, has become a classic for medical professionals.

Dr Callesen and Dr. Moller Nielsen are both clinical psychologists In Denmark. Dr. Callesen is also Director of the Asperger’s Resource Centre in Denmark, has over ten years in the field and consults with numerous school districts and the City of Copenhagen, in which she has been conducting a program (Pioneer Groups) for parents of children with autism.

Dr. Moller Nielsen currently runs her own private practice, AutismeMidt, but she also is actively involved with the Centre for Autism in Copenhagen, where she is responsible for planning courses, parent counseling, psychological assessments of children, adolescents, and adults.

“Until recently, therapists, parents, and teachers were handicapped in their attempt to help children because, once they defined the behaviors or problems that created the stress, they often expected children to be able to change their emotions but did not have a mechanism to teach them how to do so,” explains Ronen. The capacity to identify, express, understand, accept and control emotions cannot be taken for granted, and children should learn to acquire each of these skills,” states Ronen.

The CAT-kit gives them the way to make that happen.

Available through Future Horizons ([www.fhautism.com](http://www.fhautism.com)) or by calling 800.489.0727, the CAT-kit costs \$199.95.

# AUTISM CONFERENCES!

## OUTSTANDING PRESENTERS!



**Dr. Tony Attwood**  
*World Leading Authority on Asperger's Syndrome*



**Dr. Temple Grandin**  
*World Leading Autism Author*



**Dr. Jed Baker**  
*Recently Featured on ABC Nightline!*

Philadelphia, PA	November 3	Los Angeles, CA	December 5	<b>CEU Credits Offered!</b>
Cambridge, MA	November 5	Nashville, TN	February 27	
Kansas City, KS	November 6 & 7	Riverside, CA	March 5	
St.Louis, MO	November 14	Albuquerque, NM	March 13	
Honolulu, HI	November 21			

**Limited Room. Register Early!**

FOR MORE INFORMATION: **800.489.0727** [WWW.FHAUTISM.COM](http://WWW.FHAUTISM.COM)

### Understanding from page 1

(10.6 in NJ). Prevalence was stable from 2000 to 2002 in 4 of the 6 sites that participated in both surveillance years, but increased slightly in GA and significantly in WV, indicating the need for ongoing monitoring of prevalence over time. This wide range of prevalence points to a need for earlier and more accurate screening for the symptoms of ASD.

The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Pediatricians, family physicians, daycare providers, teachers, and parents may initially dismiss signs of ASD, optimistically thinking the child is just a little slow and will “catch up.” Although early intervention has a dramatic impact on reducing symptoms and increasing a child’s ability to grow and learn new skills, it is estimated that *only 50% of children are diagnosed before kindergarten.*

All children with ASD demonstrate deficits in 1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently. For instance, a child may have little trouble learning to read but exhibit extremely poor social interaction. Each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of ASD.

Children with ASD do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems in communication and social skills become more noticeable as the child lags further behind other children the same age. Some other children start off well enough. Oftentimes between 12 and 36 months old, the differences in the way they react to people and other unusual behaviors become apparent. Some parents report the change as being sudden, and that their children start to reject people, act strangely, and lose language and social skills they had previously acquired. In other cases, there is a “plateau,” or leveling, of progress so that the difference between the child with autism and other children the same age becomes more noticeable.

ASD is defined by a certain set of behaviors that can range from the very mild to the severe. The following possible indicators of ASD were identified on the Public Health Training Network Webcast, *Autism Among Us.*

#### Possible Indicators of Autism Spectrum Disorders

- Does not babble, point, or make meaningful gestures by 1 year of age
- Does not speak one word by 16 months
- Does not combine two words by 2 years
- Does not respond to name
- Loses language or social skills

#### Some Other Indicators

- Poor eye contact
- Doesn’t seem to know how to play with toys

- Excessively lines up toys or other objects
- Is attached to one particular toy or object
- Doesn’t smile
- At times seems to be hearing impaired

#### Social Symptoms

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile.

In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents’ displays of anger or affection in a typical way. Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to “read.” To parents, it may seem as if their child is not attached at all. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with ASD also are slower in learning to interpret what others are thinking and feeling. Subtle social cues - whether a smile, a wink, or a grimace - may have little meaning. To a child who misses these cues, “Come here” always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering.

To compound the problem, people with ASD have difficulty seeing things from another person’s perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people’s actions.

Although not universal, it is common for people with ASD also to have difficulty regulating their emotions. This can take the form of “immature” behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with ASD might also be disruptive and physically aggressive at times, making social relationships still more difficult. They have a tendency to “lose control,” particularly when they’re in a strange or overwhelming environment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms.

#### Communication Difficulties

By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and

when offered something distasteful, makes it clear that the answer is “no.”

Some children diagnosed with ASD remain mute throughout their lives. Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age 5 to 9. Some children may learn to use communication systems such as pictures or sign language.

Those who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. Some ASD children parrot what they hear, a condition called *echolalia*. Although many children with no ASD go through a stage where they repeat what they hear, it normally passes by the time they are.

Some children only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The “give and take” of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment. Another difficulty is often the inability to understand body language, tone of voice, or “phrases of speech.” They might interpret a sarcastic expression such as “Oh, that’s just great” as meaning it really IS great.

While it can be hard to understand what ASD children are saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what they are saying. Also, their tone of voice fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common. Some children with relatively good language skills speak like little adults, failing to pick up on the “kid-speak” that is common in their peers.

Without meaningful gestures or the language to ask for things, people with ASD are at a loss to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, ASD children do whatever they can to get through to others. As people with ASD grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result they may become anxious or depressed.

#### Repetitive Behaviors

Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more subtle. Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes. Some suddenly freeze in position.

As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. ASD children need, and demand, absolute consistency in their environment. A slight change in any

### Rare Autism Spectrum Disorders

#### Rett Syndrome

Rett syndrome is relatively rare, affecting almost exclusively females, one out of 10,000 to 15,000. After a period of normal development, sometime between 6 and 18 months, autism-like symptoms begin to appear. The little girl’s mental and social development regresses—she no longer responds to her parents and pulls away from any social contact. If she has been talking, she stops; she cannot control her feet; she wrings her hands. Some of the problems associated with Rett syndrome can be treated. Physical, occupational, and speech therapy can help with problems of coordination, movement, and speech. Scientists sponsored by the National Institute of Child Health and Human Development have discovered that a mutation in the sequence of a single gene can cause Rett syndrome. This discovery may help doctors slow or stop the progress of the syndrome. It may also lead to methods of screening for Rett syndrome, thus enabling doctors to start treating these children much sooner, and improving the quality of life these children experience. (Rett syndrome. NIH Publication No. 01-4960. Rockville, MD: National Institute of Child Health and Human Development, 2001)

#### Childhood Disintegrative Disorder

Very few children who have an autism spectrum disorder (ASD) diagnosis meet the criteria for childhood disintegrative disorder (CDD). An estimate based on four surveys of ASD found fewer than 2 children per 100,000 with ASD could be classified as having CDD. This suggests that CDD is a very rare form of ASD. It has a strong male preponderance (Frombonne E. Prevalence of childhood disintegrative disorder. *Autism*, 2002). Symptoms may appear by age 2, but the average age of onset is between 3 and 4 years. Until this time, the child has age-appropriate skills in communication and social relationships. The long period of normal development before regression helps differentiate CDD from Rett syndrome.

The loss of such skills as vocabulary are more dramatic in CDD than they are in classical autism. The diagnosis requires extensive and pronounced losses involving motor, language, and social skills (Volkmar RM and Rutter M. *Childhood disintegrative disorder: Results of the DSM-IV autism field trial.* *Journal of the American Academy of Child and Adolescent Psychiatry*, 1995). CDD is also accompanied by loss of bowel and bladder control and oftentimes seizures and a very low IQ.

## Research in Parenting a Child with Asperger Syndrome Identifies Challenges and Coping Strategies

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

The numbers of children affected by Asperger Syndrome (AS) in the United States is almost twice that of the number of children who exhibit classic autism. Despite these numbers, there is little empirically guided information about how best to serve families of a child with AS. Most federally funded studies of AS to date have focused upon diagnostic criterion and early detection, genetic factors and psychopharmacological interventions. Although social and family based behavioral interventions have been demonstrated to be highly effective in improving the social, behavioral, and mental health outcomes of children with disabilities, there is little research in this area.

Dr. Ernst VanBergeijk, Associate Dean of the Vocational Independence Program at the New York Institute of Technology and a Research affiliate of the Yale Child Study Center has studied the perceptions, coping strategies, and family functioning of parents of children with AS, and how existing support systems impact their family functioning. Based on focus group discussions with a sample of twenty-eight



Ernst O. VanBergeijk, PhD, MSW

parents of children with AS drawn from community-based organizations, Dr. VanBergeijk has found that parental coping and family organization are strongly linked to positive mental health outcomes of children ranging in age from 8-21 years of age.

VanBergeijk and his team applied state of the art coding procedures to the tran-

scription of the discussions and were able to identify the common substantive themes across the experiences of the parents. The most common themes the parents expressed in discussing their lives with a child who has AS were: (1) Isolation; (2) Ostracism; (3) Being blamed for their child's behavior; (4) A need to be hyper-vigilant in correcting/anticipating their child's behavior so as not to incur negative consequences from others; (5) Having to fight battles on multiple fronts in order to secure educational, medical, and social services and in dealing with their own extended families; (6) Sacrifice; (7) Worries about their child's safety and practical skills both in the present and in the future; and (8) Delightful surprises.

Josie, mother of Pete, a 7 year old boy with AS provided a quote that typified passages that were coded as a theme of isolation: "The things that bring me the most joy - talking to my friends on the phone, seeing them, going to the movies, and being around people that I love are the things he hates the most." Rita, mother of Eric, a 15 yr. old with AS and Cerebral Palsy described her son's isolation that impacted him and her as well: "The NT kid is invited to the birthday parties, the sleepovers, the Boy Scouts, the sports... As they get older they know these things. They understand. Why? Why? What's

wrong with me? He actually flat out said 'Why am I disabled?' There's a whole lot of pain there - Not just what he's experiencing, but you're experiencing it too." Parents described having to defend their child's feelings and rights against a number of different constituencies. One parent described it as thus: "It's a kicking, screaming battle. You are always fighting with someone... It's the biggest nightmare in the world if you have a child with Asperger's, because the child is a bright child..." The combination of the child's average to superior intellectual ability and severe social deficits often left the focus group members feeling confused as parents.

Despite the perception of life with a child who has Asperger Syndrome as challenging, the tone of the focus groups was quite light hearted. The use of humor was one of the most frequently used and cited coping mechanisms that the parents employed. The transcripts of the discussions were punctuated with laughter. The parents of these children are quite resilient and resourceful in their use of coping strategies. Aside from humor, the participants in the focus groups employed a variety of coping strategies including: (1) Taking turns with their spouse in caring for the child with AS; (2) Spending time with friends & NT kids; (3) Having a new

see Parenting on page 46

### Self-Injurious from page 14

reprimands, or verbal reasoning and assurance. Attempts to redirect the behavior may inadvertently increase SIB if the SIB is maintained by social attention. Instead, social interactions should be given in the absence of SIB. That is, positive interaction should occur when the individual engages in any other behavior. Ignoring SIB may initially increase the SIB, but will ultimately decrease the likelihood that the individual will engage in SIB to gain attention. Another way to minimize SIB in such cases is to make available more leisure items, attention, or opportunities for other preferences so that the individual does not need to engage in SIB to acquire them.

Redirection to another activity and time-out may also worsen the situation if the desired consequence of the SIB is to avoid a particular task. To minimize escape-maintained SIB, task difficulty can be altered, breaks from the task can be given more often, or the individual can be taught to ask for help or a break.

Teaching alternative ways to communicate is one of the most effective methods for decreasing SIB and maintaining treatment gains (Durand & Carr, 1985) if the reason for the SIB can be identified. However, functional communication training must allow the individual to reach the same desired outcome as the SIB. The mode of functional communication must fit the communication needs and abilities of the individual (e.g., pictures, micro-switches, hand signs), and the functional communica-

tion program must be incorporated into all aspects of the individual's daily activities. Over time, the individual learns that functional communication is a much easier and efficient way to get what he or she wants.

When the reason for SIB cannot be identified, the SIB is often said to be maintained by automatic or sensory reinforcement via the "pleasurable" sensations it creates. Providing equivalent, alternate sensory stimulation (such as a massage) or blocking the sensory stimulation (with protective devices) to undo the reinforcing properties of the SIB may be effective. In many cases, drug therapy is considered.

Although the Federal Drug Administration (FDA, 2006) has recently approved Risperdal for treatment of irritability associated with autism (i.e., tantrums, aggression, and SIB), there is no single, well-established medication for treatment of SIB. Rather, pharmacotherapy of SIB often involves the use of medications developed for other psychiatric disorders in a trial-and-error fashion (called 'off-label use'). Because there is no existing practice guideline or a simple litmus test to indicate which medication will work best for whom, identifying the right medication for each individual relies heavily on the treating clinician's expertise and clinical experience.

Current research findings point to the interactions of multiple neurotransmitter systems associated with SIB. Among these, medications acting on the dopamine, opiate, and serotonin systems have been studied most extensively.

**Dopamine:** Dopamine is a major regulator of motor behavior, emotions, and rein-

forcement systems. Dopaminergic treatment of SIB is primarily based on the effects of medications that either increase (agonists, such as stimulants) or decrease (antagonists, such as antipsychotics) dopamine functioning. Stimulant medications (e.g., Ritalin) developed for attention-deficit hyperactivity disorder (ADHD) have been effective in reducing SIB in a small number of individuals.

Antipsychotic medications used for treating schizophrenia are the most widely studied drugs in autism. Early attempts with thioridazine and haloperidol indicated that they nonselectively targeted all behaviors, including SIB, mainly through sedation. Such global behavioral suppression, however, was also accompanied by unacceptable levels of involuntary repetitive movement (extrapyramidal symptoms or EPS) in a significant number of individuals. Newer antipsychotic drugs (including Risperdal) are more selective for treating SIB with fewer side effects (RUPP, 2002; 2005; Zarcone et al., 2001). Ironically, there is no convincing evidence of primary involvement of the dopamine system in autism.

**Opioids:** The opiate system is a mysterious part of the brain which is best known for mediating pain. The opiate model contends that individuals engaging in SIB have unusually high tolerance for pain (hyperanalgesia) due to elevated levels of endogenous opiates (Sandman & Touchette, 2002). In fact, researchers have found that 80% of SIB occurred on only 5% of the body area, and during SIB, those same areas produced pain relief (not pain) and led to an increase in endogenous opioids (Symon & Thomp-

son, 1997). Consequently, SIB produces a feeling of euphoria that requires successively higher amounts to attain the same level of sensation. Tolerance is built with repeated opiate self-administration, followed by increased physical dependence, and compulsive, euphoria-seeking SIB.

In this situation, attempts to prevent SIB by eliminating the sensory stimulation it causes may not be successful as the individual will seek to avoid the adverse withdrawal symptoms by engaging in SIB. While studies report improvements with naltrexone in a small number of individuals with autism, several clinical trials so far indicate mixed results (Campbell et al., 1993; Willemsen-Swinkels et al., 1995; 1996).

**Serotonin:** Serotonin is a major regulator of mood, sleep, and appetite. The logic of using selective serotonin reuptake inhibitors (SSRIs) is based on the similarity of repetitive SIB to obsessive compulsive behaviors and symptoms of affective mood disorders, both of which are successfully treated with SSRIs (Aman et al., 1999). Moreover, many years of research indicate elevated levels of serotonin in the bloodstream of individuals with autism (Schain & Freedman, 1961), providing further support for SSRIs to potentially reverse some of the symptoms of serotonin dysregulation in autism. Still, controlled clinical trials show mixed results (Remington et al., 2001; Niederhofer et al., 2003).

### Summary

Dynamic interactions between and within environmental and biological mechanisms make SIB complex and

see Self-Injurious on page 45

### Understanding from page 36

routine - in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route - can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics.

#### Problems that May Accompany ASD

**Sensory problems** - When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty, the child's experiences of the world can be confusing. Many ASD children are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin almost unbearable. Some sounds - a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline - will cause these children to cover their ears and scream.

In ASD, the brain seems unable to balance the senses appropriately. Some ASD children are oblivious to extreme cold or pain. An ASD child may fall and break an arm, yet never cry. Another may bash his head against a wall and not wince, but a light touch may make the child scream with alarm.

**Mental retardation** - Many children with ASD have some degree of mental impairment. When tested, some areas of ability may be normal, while others may be especially weak. For example, a child with ASD may do well on the parts of the test that measure visual skills but earn low scores on the language subtests.

**Seizures** - One in four children with ASD develops seizures, often starting either in early childhood or adolescence. Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a "blackout"), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An EEG (electroencephalogram - recording of the electric currents developed in the brain by means of electrodes applied to the scalp) can help confirm the seizure's presence.

In most cases, seizures can be controlled by a number of medicines called "anticonvulsants." The dosage of the medication is adjusted carefully so that the least possible amount of medication will be used to be effective.

**Fragile X Syndrome** - This disorder is the most common inherited form of mental retardation. It was so named because one part of the X chromosome has a defective piece that appears pinched and fragile when under a microscope. Fragile X syndrome affects about two to five percent of people with ASD. It is important to have a child with ASD checked for Fragile X, especially if the parents are considering having another child.

A distinction can be made between a father's and mother's ability to pass along to a daughter or son the altered gene on the X chromosome that is linked to fragile X syndrome. Because both males (XY)

and females (XX) have at least one X chromosome, both can pass on the mutated gene to their children.

A father with the altered gene for Fragile X on his X chromosome will only pass that gene on to his daughters. He passes a Y chromosome on to his sons, which doesn't transmit the condition. Therefore, if the father has the altered gene on his X chromosome, but the mother's X chromosomes are normal, all of the couple's daughters would have the altered gene for Fragile X, while none of their sons would have the mutated gene.

Because mothers pass on only X chromosomes to their children, if the mother has the altered gene for Fragile X, she can pass that gene to either her sons or her daughters. If the mother has the mutated gene on one X chromosome and has one normal X chromosome, and the father has no genetic mutations, all the children have a 50-50 chance of inheriting the mutated gene.

The odds noted here apply to each child the parents have. In terms of prevalence, the latest statistics are consistent in showing that 5% of people with autism are affected by fragile X and 10% to 15% of those with fragile X show autistic traits.

**Tuberous Sclerosis** - Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs. It has a consistently strong association with ASD. One to 4 percent of people with ASD also have tuberous sclerosis.

#### The Diagnosis of Autism Spectrum Disorders

Although there are many concerns about labeling a young child with an ASD, the earlier the diagnosis of ASD is made, the earlier needed interventions can begin. Evidence over the last 15 years indicates that intensive early intervention in *optimal educational settings for at least 2 years during the preschool years* results in improved outcomes in most young children with ASD.

In evaluating a child, clinicians rely on behavioral characteristics to make a diagnosis. Some of the characteristic behaviors of ASD may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialization, or restricted behavior must be present before the age of 3. The diagnosis requires a two-stage process. The first stage involves developmental screening during "well child" check-ups; the second stage entails a comprehensive evaluation by a multidisciplinary team.

#### Screening

A "well child" check-up should include a developmental screening test. If your child's pediatrician does not routinely check your child with such a test, ask that it be done. Your own observations and concerns about your child's development will be essential in helping to screen your child. Reviewing family videotapes, photos, and baby albums can help parents remember when each behavior was first noticed and when the child reached certain developmental milestones.

Several screening instruments have been developed to quickly gather information about a child's social and communicative development within medical set-

tings. Among them are the Checklist of Autism in Toddlers (CHAT), the modified Checklist for Autism in Toddlers (M-CHAT), the Screening Tool for Autism in Two-Year-Olds (STAT), and the Social Communication Questionnaire (SCQ) (for children 4 years of age and older).

Some screening instruments rely solely on parent responses to a questionnaire, and some rely on a combination of parent report and observation. Key items on these instruments that appear to 13 differentiate children with autism from other groups before the age of 2 include pointing and pretend play. Screening instruments do not provide individual diagnosis but serve to assess the need for referral for possible diagnosis of ASD. These screening methods may not identify children with mild ASD, such as those with high-functioning autism or Asperger syndrome.

During the last few years, screening instruments have been devised to screen for Asperger syndrome and higher functioning autism. The Autism Spectrum Screening Questionnaire (ASSQ), the Australian Scale for Asperger's Syndrome, and the most recent, the Childhood Asperger Syndrome Test (CAST), are some of the instruments that are reliable for identification of school-age children with Asperger syndrome or higher functioning autism. These tools concentrate on social and behavioral impairments in children without significant language delay.

If, following the screening process or during a routine "well child" check-up, your child's doctor sees any of the possible indicators of ASD, further evaluation is indicated.

#### Comprehensive Diagnostic Evaluation

The second stage of diagnosis must be comprehensive in order to accurately rule in or rule out an ASD or other developmental problem. This evaluation may be done by a multidisciplinary team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASD.

Because ASD's are complex disorders and may involve other neurological or genetic problems, a comprehensive evaluation should entail neurologic and genetic assessment, along with in-depth cognitive and language testing. In addition, measures developed specifically for diagnosing autism are often used. These include the Autism Diagnosis Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS-G). The ADI-R is a structured interview that contains over 100 items and is conducted with a caregiver. It consists of four main factors - the child's communication, social interaction, repetitive behaviors, and age-of-onset symptoms. The ADOS-G is an observational measure used to "press" for socio-communicative behaviors that are often delayed, abnormal, or absent in children with ASD.

Still another instrument often used by professionals is the Childhood Autism Rating Scale (CARS). It aids in evaluating the child's body movements, adaptation to change, listening response, verbal communication, and relationship to people. It is suitable for use with children over 2 years of age. The examiner observes the child and also obtains relevant information from the parents. The child's behavior is rated on a scale based on deviation from the typical behavior of chil-

dren of the same age.

Two other tests that should be used to assess any child with a developmental delay are a formal audiologic hearing evaluation and a lead screening. Although some hearing loss can co-occur with ASD, some children with ASD may be incorrectly thought to have such a loss. In addition, if the child has suffered from an ear infection, transient hearing loss can occur. Lead screening is essential for children who remain for a long period of time in the oral-motor stage in which they put any and everything into their mouths. Children with an autistic disorder usually have elevated blood lead levels.

Customarily, an expert diagnostic team has the responsibility of thoroughly evaluating the child, assessing the child's unique strengths and weaknesses, and determining a formal diagnosis. The team will then meet with the parents to explain the results of the evaluation.

Although parents may have been aware that something was not "quite right" with their child, when the diagnosis is given, it is a devastating blow. At such a time, it is hard to stay focused on asking questions. But while members of the evaluation team are together is the best opportunity the parents will have to ask questions and get recommendations on what further steps they should take for their child. Learning as much as possible at this meeting is very important, but it is helpful to leave this meeting with the name or names of professionals who can be contacted if the parents have further questions.

#### Available Aids

When your child has been evaluated and diagnosed with an autism spectrum disorder, you may feel inadequate to help your child develop to the fullest extent of his or her ability. As you begin to look at treatment options and at the types of aid available for a child with a disability, you will find out that there is help for you. It is going to be difficult to learn and remember everything you need to know about the resources that will be most helpful. *Write down everything.* If you keep a notebook, you will have a foolproof method of recalling information. Keep a record of the doctors' reports and the evaluation your child has been given so that his or her eligibility for special programs will be documented. Learn everything you can about special programs for your child; the more you know, the more effectively you can advocate.

For every child eligible for special programs, each state guarantees special education and related services. The Individuals with Disabilities Education Act (IDEA) is a Federally mandated program that assures a free and appropriate public education for children with diagnosed learning deficits. Usually children are placed in public schools and the school district pays for all necessary services. These will include, as needed, services by a speech therapist, occupational therapist, school psychologist, social worker, school nurse, or aide.

By law, the public schools must prepare and carry out a set of instruction goals, or specific skills, for every child in a special education program. The list of skills is known as the child's Individualized Education Program (IEP). The IEP is

see *Understanding on page 40*

# Join Us

Tuesday, December 2, 2008

## “Leading A Full Productive Life”

### One Day Conference

Featuring Emerging Best Practices,  
Creative Resources and Negotiating Services  
for Individuals with a Dual Diagnosis of  
Mental Illness and a Developmental Disability.



**Tuesday, December 2, 2008**

8:30 AM – 4:30 PM

The McGraw Hill Building • 1221 Avenue of the Americas • New York City

**Conference Fee: \$50**

**Featured speakers include:**

**Michael F. Hogan, Ph.D.** Commissioner, NYS OMH

**Diana Jones Ritter,** Commissioner, NYS OMRDD

**Julie Gentile, M.D.** Associate Professor, Wright State University, Dayton, Ohio; Systems Change: The Ohio Approach

**This conference is sponsored by:**

Downstate Center of Excellence in Dual Diagnosis

F·E·G·S Health and Human Services System

Lifespire

New York City Department of Health and Mental Hygiene

New York State Office of Mental Health

New York State Office of Mental Retardation and Developmental Disabilities

Services for the UnderServed, Inc.

YAI-National Institute for People with Disabilities

**To register or sponsorship opportunities call:**

**212-366-8059**

**email: tmeade@fegs.org**

**F·E·G·S**  
HEALTH AND HUMAN SERVICES SYSTEM  
A beneficiary of UJA Federation  
of New York

#### *Social Dilemma from page 19*

of youngsters in the age range of 4-12, who tend to adhere to a set of rules about forming relationships that they have learned from parents, siblings and peers. Often times autistic individuals turn to an older, more mature set of individuals.

PDD spectrum individuals can appear to have a personality disorder such as narcissism or antisocial personality disorder. But there are differences that one can tease out with closer inspection. Initial attempts to interact with such individuals can end up being sporadic, and disconnected. Like in the movie 50 first dates, which portrayed a young woman who could not recall events that took place the previous day, a person with an autistic perspective has difficulty recalling the details of an affective relationship. Over time, with focused work, significant gains can be made in this area.

In order to assist autistic spectrum individuals with socialization, the details of social interaction that the average person interprets without much thought

(facial expression, choice of words, tone, rate, volume and prosody) have to be teased out and understood as individual components of the exchange prior to being understood in the context of a conversation. The skills involved in modulating the above components of speech are best learned and practiced in a safe environment. In addition to the problem of not being able to interpret others affective tone, persons with autistic spectrum disorders have difficulty modulating and expressing their own internal affective state. Emotions tend to be expressed in an exaggerated fashion. Hence, an angry exchange can rapidly become explosive; a fearful affect may be experienced and expressed as a panic state. The opposite can also occur, where an individual appears to have an inappropriate flat affect in a situation where one would expect a heightened reaction.

*Dr. Benjamin is also Assistant Professor of Psychiatry at Weill Cornell Medical College*

### 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 help families to understand the complex issues in assisting their adult child impaired with Asperger's Syndrome/High Functioning Autism. We also have speakers at many of our meetings that address various topics of importance.

**For further information contact the facilitators:**

**Bonnie Kaplan - email: Parenttalk@gmail.com**

**Judith Omidvaran - email: Judyomid@aol.com**

*A unique perspective & methodology for the variety of concerns, joys & issues facing our children & their families, by a mother who knows.*

**Carla Alvarez-Gould, LCSW, MSW, EIS**

50 Homewood Avenue  
North Haven, CT. 06473

Phone: (203) 907-7085

Fax: (203) 745-3085

buddies@bestweb.net

### Understanding from page 38

an agreement between the school and the family on the child's goals. When your child's IEP is developed, you will be asked to attend the meeting. There will be several people at this meeting, including a special education teacher, a representative of the public schools who is knowledgeable about the program, other individuals invited by the school or by you (you may want to bring a relative, a child care provider, or a supportive close friend who knows your child well). Parents play an important part in creating the program, as they know their child and his or her needs best. Once your child's IEP is developed, a meeting is scheduled once a year to review your child's progress and to make any alterations to reflect his or her changing needs.

If your child is under 3 years of age and has special needs, he or she should be eligible for an early intervention program; this program is available in every state. Each state decides which agency will be the lead agency in the early intervention program. The early intervention services are provided by workers qualified to care for toddlers with disabilities and are usually in the child's home or a place familiar to the child. The services provided are written into an Individualized Family Service Plan (IFSP) that is reviewed at least once every 6 months. The plan will describe services that will be provided to the child, but will also describe services for parents to help them in daily activities with their child and for siblings to help them adjust to having a brother or sister with ASD.

### Treatment Options

There is no single best treatment package for all children with ASD. One point that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialized programs.

Before you make decisions on your child's treatment, you will want to gather information about the various options available. Learn as much as you can, look at all the options, and make your decision on your child's treatment based on your child's needs. You may want to visit public schools in your area to see the type of program they offer to special needs children.

Guidelines used by the Autism Society of America include the following questions parents can ask about potential treatments:

- Will the treatment result in harm to my child?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into my child's current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored.

The National Institute of Mental Health suggests a list of questions parents can ask when planning for their child:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones.

An effective treatment program will build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior. Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

As soon as a child's disability has been identified, instruction should begin. Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a child care center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. Included are behavioral methods, communication, occupational and physical therapy along with social play interventions. Often the day will begin with a physical activity to help develop coordi-

nation and body awareness; children string beads, piece puzzles together, paint, and participate in other motor skills activities. At snack time the teacher encourages social interaction and models how to use language to ask for more juice. The children learn by doing. Working with the children are students, behavioral therapists, and parents who have received extensive training. In teaching the children, positive reinforcement is used.

Children older than 3 years usually have school-based, individualized, special education. The child may be in a segregated class with other autistic children or in an integrated class with children without disabilities for at least part of the day. Different localities may use differing methods but all should provide a structure that will help the children learn social skills and, functional communication. In these programs, teachers often involve the parents, giving useful advice in how to help their child use the skills or behaviors learned at school when they are at home.

In elementary school, the child should receive help in any skill area that is delayed and, at the same time, be encouraged to grow in his or her areas of strength. Ideally, the curriculum should be adapted to the individual child's needs. Many schools today have an inclusion program in which the child is in a regular classroom for most of the day, with special instruction for a part of the day. This instruction should include such skills as learning how to act in social situations and in making friends. Although higher-functioning children may be able to handle academic work, they too need help to organize tasks and avoid distractions.

During middle and high school years, instruction will begin to address such practical matters as work, community living, and recreational activities. This should include work experience, using public transportation, and learning skills that will be important in community living.

All through your child's school years, you will want to be an active participant in his or her education program. Collaboration between parents and educators is essential in evaluating your child's progress.

### The Adolescent Years

Adolescence is a time of stress and confusion; and it is no less so for teenagers with autism. Like all children, they need help in dealing with their budding sexuality. While some behaviors improve during the teenage years, some get worse. Increased autistic or aggressive behavior may be one way some teens express their newfound tension and confusion.

The teenage years are also a time when children become more socially sensitive. At the age that most teenagers are concerned with acne, popularity, grades, and dates, teens with autism may become painfully aware that they are different from their peers. They may notice that they lack friends. And unlike their schoolmates, they aren't dating or planning for a career. For some, the sadness that comes with such realization motivates them to learn new behaviors and acquire better social skills.

### Dietary and Other Interventions

In an effort to do everything possible to help their children, many parents continually seek new treatments. Some treatments are developed by reputable therapists or by parents of a child with ASD. Although an unproven treatment may help one child, it may not prove beneficial to another. To be accepted as a proven treatment, the treatment should undergo clinical trials, preferably randomized, double-blind trials, that would allow for a comparison between treatment and no treatment. Following are some of the interventions that have been reported to have been helpful to some children but whose efficacy or safety has not been proven.

Dietary interventions are based on the idea that 1) food allergies cause symptoms of autism, and 2) an insufficiency of a specific vitamin or mineral may cause some autistic symptoms. If parents decide to try for a given period of time a special diet, they should be sure that the child's nutritional status is measured carefully.

A diet that some parents have found was helpful to their autistic child is a gluten-free, casein-free diet. Gluten is a casein-like substance that is found in the seeds of various cereal plants - wheat, oat, rye, and barley. Casein is the principal protein in milk. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is difficult.

A supplement that some parents feel is beneficial for an autistic child is Vitamin B6, taken with magnesium (which makes the vitamin effective). The result of research studies is mixed; some children respond positively, some negatively, some not at all or very little.

In the search for treatment for autism, there has been discussion in the last few years about the use of secretin, a substance approved by the Food and Drug Administration (FDA) for a single dose normally given to aid in diagnosis of a gastrointestinal problem. Anecdotal reports have shown improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. Several clinical trials conducted in the last few years have found no significant improvements in symptoms between patients who received secretin and those who received a placebo.

### Medications Used in Treatment

Medications are often used to treat behavioral problems, such as aggression, self-injurious behavior, and severe tantrums that keep the person with ASD from functioning more effectively at home or school. The medications used are those that have been developed to treat similar symptoms in other disorders. Many of these medications are prescribed "off-label." Olanzapine (Zyprexa) and other antipsychotic medications are used "off-label" for the treatment of aggression and other serious behavioral disturbances in children, including children with autism. Off-label means a doctor will prescribe a medication to treat a disorder or in an age group that is not included among those approved by the FDA. Further research needs to be done to ensure not only the efficacy but the safety of psychotropic agents used in the treatment of children and adolescents.

see *Understanding on page 42*

# Social Skills Training for Children with Asperger's Disorder

**By Jo Hariton, PhD**  
**Clinical Psychologist and Coordinator,**  
**Social Skills Program for Children and**  
**Adolescents, New York Presbyterian**  
**Hospital Westchester Division**

Since the Social Skills Program for Children and Adolescents began at New York Presbyterian Hospital, Westchester Division in 1995, there has been a steady increase in the number of children and adolescents referred who have Asperger's Disorder. Considered a high functioning autistic spectrum disorder, it is characterized by serious social difficulties and circumscribed interests however, there are no clinically significant delays in language or cognitive development.

These children and adolescents with significant impairment in social functioning can benefit enormously from social skills group therapy, which is the focus of the Social Skills Program at New York Presbyterian. They learn friendship skills in the group and then can practice the skills with others who have similar problems. The program serves children from preschool through high school.

Although some schools in the community have also developed social skills groups, the need for services of this kind for children on the spectrum far exceeds the number of groups available. New York Presbyterian has filled a "niche" in this area. In fact, many of these children supplement the services they already receive in their schools with specialized help from this program.

Children who have a need for help in the development of social skills are not limited to those with Asperger's, and in fact the Social Skills Program benefits those who may have other diagnoses as well, such as anxiety disorders, learning disabilities, mood disorders, or ADHD. A common denominator for all of the children is a wish to do better with their peers.

It is a mistake to believe that the children with Asperger's do not have an interest in making friends. As Coordinator of the program I find that many of these chil-



**Jo Hariton, PhD**

dren are often lonely, and shy away from reaching out to their peers, in part because of past experiences that have left them feeling rejected and isolated. Sometimes they have not had the opportunity to meet others like themselves who may have similar interests. By learning ways to communicate better and pick up the nuances of social cues they become better able to feel that they belong.

The Social Skills Program has 12 groups during the school year which are run at after school times. There are generally 12 sessions in each group cycle. Most of the families utilizing the program continue to send their children for repeated cycles of the program. Since social skills are seen as the primary area of need for those with Asperger's Disorder, it is not unusual for families to continue to attend the program for several years. Families and children want support and receive it in this program.

We are now receiving referrals for the summer session. This is an abbreviated cycle of 7 sessions which are held in the morning, so as to not interfere with day camp schedules. The summer cycle begins in July and runs through mid-August.

The Social Skills Program is held in

the Child and Adolescent Outpatient Department of New York Presbyterian Hospital in White Plains. All children who attend have a child psychiatric evaluation session first. This allows the team to understand the developmental needs of the child and to carefully match the child with an appropriate group. The fact that this is a Behavioral Health outpatient department enables the children who attend to benefit from the special expertise of a team approach within a child psychiatric setting. Other services such as medication management, individual or family therapy, can be utilized as needed. Given that it is often difficult to find such specialized programs in the community, the Social Skills Program will work with outside mental health providers who may follow these children individually and want this additional resource.

Two and sometimes even three group leaders generally lead our groups. These group leaders are generally social workers or psychologists, with co-leaders who are Child Psychiatry Residents, Postdoctoral Fellows in Psychology or Psychology Externs. The fact that it is a teaching hospital enables the program to have the luxury to draw from staff of different disciplines and to have an abundance of staff interested in leading these groups and in training others to do so. The combined Columbia - Cornell Child Psychiatry Training Program sends its Child Residents for four-month rotations through the Social Skills Program.

I provide ongoing consultation for all of the groups, and hold a group therapy seminar for clinicians within the program. By leading three groups myself, I am always directly involved, and often the person to make the match between the child and the group. Since children with Asperger's Disorder can sometimes become overwhelmed in large groups, I might sometimes suggest a "mini-group" as an ideal way to help them learn the communication and relationship building skills that can increase their confidence and self esteem. Sometimes the group is a duo therapy of two similarly matched children. This can help prepare the children

for joining a larger group at a later date. Since the number of children and adolescents who are referred has expanded, the opportunity exists to make a well-suited match.

Even in the larger groups with 6-8 children, it is sometimes suggested to break the group in mini-groups for a brief period. Sometimes the larger group is too overwhelming for the child to be able to learn a skill and to practice it. A small group experience to practice first makes clinical sense.

Typical skills worked on these groups include Communication Skills, Interpersonal Perspective Taking, Problem Solving, Feelings Identification, Self Awareness, Increasing Frustration Tolerance, Good Sportsmanship, and the ability to be Flexible and able to Compromise.

Each group of children takes on its own personality and it is the job of the group leaders to pick the skills that need the most practice for any particular group. For children with Asperger's Disorder, picking up social cues and ascertaining the nuances of interpersonal communication is often difficult, and thus more time is generally spent on these skills. Role playing, stopping the action in the group to examine what has transpired, and understanding one's impact upon other members of the group, is often practiced and reinforced.

It can be tremendously reassuring for individuals with Asperger's Disorder to find others who face similar issues. Often these children have been isolated or rejected by their peers. Sometimes they can become stuck in roles at their own schools, which leads to avoidance in social situations. This can lead to further unhappiness, depression, and anxiety. The benefits of decreasing loneliness and increasing the prospects of friendship cannot be underestimated! By attending a program like this, renewed optimism and a wish to try again with their peers can be the outcome.

*For those wishing to refer to the Social Skill Group Therapy Program, please contact Dr. Jo Hariton at (914) 997-5957.*

## Direct the Autism Community to Your Vital Programs and Services - Advertise in Autism Spectrum News

### Along the Road on page 23

not express himself comfortably and fully. At 34 years old, he wanted to be among like-minded peers who face similar challenges in their own lives and who love the theater as much as he does. I decided to contact a local equity theater company called The Garage Theater located near where Paul lives in Bergen County, New Jersey. Michael Bias, the theater company's director was engaged with the idea of starting a theater program for adults over age 21 with an autism spectrum disorder, and Paul and I were thrilled. I then contacted Madeleine Goldfarb, Director of Outreach for the Autism Center of New Jersey Medical School—a true impresario of autism programming—who I knew had expertise in running theater programs for individuals with autism and had success-

fully done so at Montclair State University. Thus the team was established and this pioneering theater program for adults 21 and older was launched. Paul guided every aspect of the program's development so that it not only addresses his own interests in the theater but also provides the participants with the chance to make new friends.

I had mentioned the theater program to the mom of a young man I know named Steven who had looked out for my son Danny as kind of a mentor and big brother when they were in school together. Steven has grown into such a terrific person and is a talented musician and poet who also loves the theater. I thought Steven might be interested in this newly formed theater group and indeed he was.

The first meeting of the group of 15 men and women arrived and I went to welcome the participants and their fami-

lies. When Steven arrived with his dad my heart lifted. I hadn't seen him in several years and he had matured from the caring, adorable 11 year old I remembered into a handsome and articulate man of 21 who still possessed the same endearing, angelic quality that drew him to be Danny's protector and friend. Then Paul arrived, filled with enthusiasm and pride for the program he inspired and created. Standing on the sideline, watching the group, the thought came to me to introduce these two men whom I adored. Truly, I never saw anything like it; it was as if lightning had struck. Steven and Paul immediately started up a conversation that lasted for over an hour, as if they had always been best friends.

As I drove home that afternoon my face was soaked with tears of joy. Because of Danny and The Daniel Jordan

Fiddle Foundation, the opportunity for me to meet Paul and develop the theater program arose. And now, even more importantly, through this program, I could give Steven the gift of friendship that he had given to Danny so many years ago. There could be no better affirmation that I am traveling on the road that is my destiny.

*Linda Walder Fiddle is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation. She is a member of the New Jersey Adults with Autism Task Force, a member of the board of trustees of COSAC, the Autism Center of NJMS and the recipient of numerous community service awards including the Ann Klein Advocate Award that she will receive on October 23, 2008 from the Community Health Law Project. For more information on The Daniel Jordan Fiddle Foundation visit [www.djfiddlefoundation.org](http://www.djfiddlefoundation.org).*

### Understanding from page 40

A child with ASD may not respond in the same way to medications as typically developing children. It is important that parents work with a doctor who has experience with children with autism. A child should be monitored closely while taking a medication. The doctor will prescribe the lowest dose possible to be effective. Ask the doctor about any side effects the medication may have and keep a record of how your child responds to the medication. It will be helpful to read the "patient insert" that comes with your child's medication. Some people keep the patient inserts in a small notebook to be used as a reference. This is most useful when several medications are prescribed.

**Anxiety and depression** - The selective serotonin reuptake inhibitors (SSRI's) are the medications most often prescribed for symptoms of anxiety, depression, and/or obsessive-compulsive disorder (OCD). Other medications are used to address symptoms or other disorders in children with autism. Fluoxetine (Prozac) and sertraline (Zoloft) are approved by the FDA for children age 7 and older with obsessive-compulsive disorder. Fluoxetine is also approved for children age 8 and older for the treatment of depression. Three that have been approved for OCD are fluvoxamine (Luvox®), age 8 and older; sertraline (Zoloft®), age 6 and older; and clomipramine (Anafranil®), age 10 and older. Treatment with these medications can be associated with decreased frequency of repetitive, ritualistic behavior and improvements in eye contact and social contacts.

Fluoxetine and sertraline are antidepressants known as selective serotonin reuptake inhibitors (SSRIs). Despite the relative safety and popularity of SSRIs and other antidepressants, some studies have suggested that they may have unintentional effects on some people, especially adolescents and young adults. In 2004, after a thorough review of data, the Food and Drug Administration (FDA) adopted a "black box" warning label on all antidepressant medications to alert the public about the potential increased risk of suicidal thinking or attempts in children and adolescents taking antidepressants. In 2007, the agency extended the warning to include young adults up to age 25. A "black box" warning is the most serious type of warning on prescription drug labeling. The warning emphasizes that children, adolescents and young adults taking antidepressants should be closely monitored, especially during the initial weeks of treatment, for any worsening depression, suicidal thinking or behavior, or any unusual changes in behavior such as sleeplessness, agitation, or withdrawal from normal social situations. The FDA is studying and analyzing data to better understand how to use the SSRI's safely, effectively, and at the lowest dose possible.

**Behavioral Problems** - Antipsychotic medications have been used to treat severe behavioral problems. These medications work by reducing the activity in the brain of the neurotransmitter dopamine. Among the older, typical antipsychotics, such as haloperidol (Haldol®), thioridazine, fluphenazine, and chlorpromazine, haloperidol was found in more than one study to be more effective than a placebo in treating serious behavioral problems. However, haloperidol, while helpful for

reducing symptoms of aggression, can also have adverse side effects, such as sedation, muscle stiffness, and abnormal movements.

Placebo-controlled studies of the newer "atypical" antipsychotics are being conducted on children with autism. The first such study, conducted by the NIMH-supported Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, was on risperidone (Risperdal®). Results of the 8-week study were reported in 2002 and showed that risperidone was effective and well tolerated for the treatment of severe behavioral problems in children with autism. The most common side effects were increased appetite, weight gain and sedation. Further long-term studies are needed to determine any long-term side effects. Other atypical antipsychotics that have been studied recently with encouraging results are olanzapine (Zyprexa®) and ziprasidone (Geodon®). Ziprasidone has not been associated with significant weight gain. On October 6, 2006 the U.S. Food and Drug Administration (FDA) approved risperidone (generic name) or Risperdal (brand name) for the symptomatic treatment of irritability in autistic children and adolescents ages 5 to 16. The approval is the first for the use of a drug to treat behaviors associated with autism in children. These behaviors are included under the general heading of irritability, and include aggression, deliberate self-injury and temper tantrums.

**Seizures** - Seizures are found in one in four persons with ASD, most often in those who have low IQ or are mute. They are treated with one or more of the anti-convulsants. These include such medications as carbamazepine (Tegretol®), lamotrigine (Lamictal®), topiramate (Topamax®), and valproic acid (Depakote®). The level of the medication in the blood should be monitored carefully and adjusted so that the least amount possible is used to be effective. Although medication usually reduces the number of seizures, it cannot always eliminate them.

**Inattention and Hyperactivity** - Stimulant medications such as methylphenidate (Ritalin®), used safely and effectively in persons with attention deficit hyperactivity disorder, have also been prescribed for children with autism. These medications may decrease impulsivity and hyperactivity in some children, especially those higher functioning children.

Several other medications have been used to treat ASD symptoms; among them are other antidepressants, naltrexone, lithium, and some of the benzodiazepines such as diazepam (Valium®) and lorazepam (Ativan®). The safety and efficacy of these medications in children with autism has not been proven. Since people may respond differently to different medications, your child's unique history and behavior will help your doctor decide which medication might be most beneficial.

#### Adults with Autism Spectrum Disorder

Some adults with ASD, especially those with high-functioning autism or with Asperger syndrome, are able to work successfully in mainstream jobs. Nevertheless, communication and social problems often cause difficulties in many areas of life. They will continue to need encouragement and moral support in their struggle for an independent life.

Many others with ASD are capable of

employment in sheltered workshops under the supervision of managers trained in working with persons with disabilities. A nurturing environment at home, at school, and later in job training and at work, helps persons with ASD continue to learn and to develop throughout their lives.

The public schools' responsibility for providing services ends when the person with ASD reaches the age of 22. The family is then faced with the challenge of finding living arrangements and employment to match the particular needs of their adult child, as well as the programs and facilities that can provide support services to achieve these goals. Long before your child finishes school, you will want to search for the best programs and facilities for your young adult. If you know other parents of ASD adults, ask them about the services available in your community. If your community has little to offer, serve as an advocate for your child and work toward the goal of improved employment services. Research the resources listed in the back of this brochure to learn as much as possible about the help your child is eligible to receive as an adult.

#### Living Arrangements for the Adult with an Autism Spectrum Disorder

**Independent Living** - Some adults with ASD are able to live entirely on their own. Others can live semi-independently in their own home or apartment if they have assistance with solving major problems, such as personal finances or dealing with the government agencies that provide services to persons with disabilities. This assistance can be provided by family, a professional agency, or another type of provider.

**Living at Home** - Government funds are available for families that choose to have their adult child with ASD live at home. These programs include Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid waivers, and others. Information about these programs is available from the Social Security Administration (SSA). An appointment with a local SSA office is a good first step to take in understanding the programs for which the young adult is eligible.

**Foster Homes and Skill-Development Homes** - Some families open their homes to provide long-term care to unrelated adults with disabilities. If the home teaches self-care and housekeeping skills and arranges leisure activities, it is called a "skill-development" home.

**Supervised Group Living** - Persons with disabilities frequently live in group homes or apartments staffed by professionals who help the individuals with basic needs. These often include meal preparation, housekeeping, and personal care needs. Higher functioning persons may be able to live in a home or apartment where staff only visits a few times a week. These persons generally prepare their own meals, go to work, and conduct other daily activities on their own.

**Institutions** - Although the trend in recent decades has been to avoid placing persons with disabilities into long-term-care institutions, this alternative is still available for persons with ASD who need intensive, constant supervision. Unlike many of the institutions years ago, today's facilities view residents as individuals with human needs and offer opportunities for recreation and simple but meaningful work.

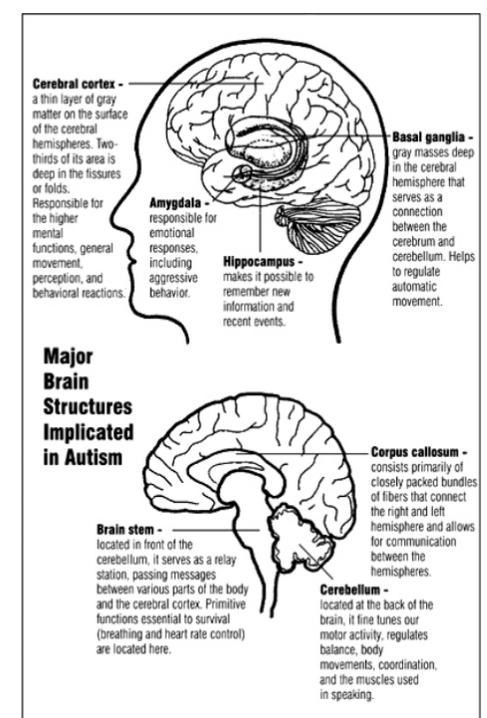
#### Research into Causes and Treatment of Autism Spectrum Disorders

Research into the causes, the diagnosis, and the treatment of autism spectrum disorders has advanced in tandem. With new well-researched standardized diagnostic tools, ASD can be diagnosed at an early age. And with early diagnosis, the treatments found to be beneficial in recent years can be used to help the child with ASD develop to his or her greatest potential.

In the past few years, there has been public interest in a theory that suggested a link between the use of thimerosal, a mercury-based preservative used in the measles-mumps-rubella (MMR) vaccine, and autism. Although mercury is no longer found in childhood vaccines in the United States, some parents still have concerns about vaccinations. Many well-done, large-scale studies have now been done that have failed to show a link between thimerosal and autism. The Institute of Medicine (IOM) conducted a thorough review on the issue of a link between thimerosal (a mercury based preservative that is no longer used in vaccinations) and autism. The final report from IOM, Immunization Safety Review: Vaccines and Autism, released in May 2004, stated that the committee did not find a link. Until 1999, vaccines given to infants to protect them against diphtheria, tetanus, pertussis, *Haemophilus influenzae* type b (Hib), and Hepatitis B contained thimerosal as a preservative. Today, with the exception of some flu vaccines, none of the vaccines used in the U.S. to protect preschool aged children against 12 infectious diseases contain thimerosal as a preservative. The MMR vaccine does not and never did contain thimerosal. Varicella (chickenpox), inactivated polio (IPV), and pneumococcal conjugate vaccines have also never contained thimerosal. A U.S. study looking at environmental factors including exposure to mercury, lead and other heavy metals is ongoing.

#### Research on the Biologic Basis of ASD

Because of its relative inaccessibility, scientists have only recently been able to study the brain systematically. But with the emergence of new brain imaging tools -



## A Parent's Perspective on Autism Spectrum Disorders

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

**H**ow do I help my child? I remember the first time I sat in the psychiatrist's office to discuss my son, Andrew, then 7 years old and in the second grade. We had been referred to Dr. J as a specialist in Attention Deficit Disorder, the popular diagnosis of the time. Dr. J diagnosed Andrew with ADHD, and treatment began with stimulant medication.

Andrew improved with meds and Dr. J's parenting coaching, yet I still felt there was "something else" going on that we had not identified. We then took Andrew to a neuropsychologist who provided three full days of testing. She was the first to introduce us to Asperger's Syndrome. As I read the few pages on Asperger's, I felt we finally had a more complete picture of our son.

Andrew is now 21 years old, and we still struggle with his Asperger's characteristics. Looking back, I can offer the following insights for parents on understanding and treating their child's AS disorder:

*It's Not Just the Child But the Parents Who Can Benefit From Treatment.* My husband and I attended a parent group, met with our psychiatrist, and went to seminars (Tony Attwood, PhD and Ami Klin, MD were especially informative) to



Betsy Ern, MA

learn how to effectively interact with our AS son. We also met regularly with a therapist to discuss ongoing challenges and develop strategies for evolving situations. We needed a team of professionals to get us through!

*Write Up Your Child's Family History.* You will be asked for this time and again; it's easier to have it ready than to recreate it for everyone who asks. Details surrounding your pregnancy and birth experience, developmental milestones, and especially communication behaviors will be asked.

*Practice Describing Your Child in Plain English.* You will be asked "what's your child like?" Professionals will want to know how he gets along with friends, performs at school, behaves at home, what he likes to do, what doesn't seem right to you, and what he is especially good at and not so good at.

*You Are Your Child's Best Advocate.* Don't leave your child's best interests up to the teacher, the school psychologist, administrators, or even the doctor. You know your child best; a good doctor will listen to your insights and observations. Teachers and administrators have many students under their umbrella, so it's up to you to keep your child on their screen.

*Treatment Should Include the Home Environment, Not Just School.* Your child's ability to function at home is important to the family's emotional health as well as his own. The meds shouldn't stop working once school is out, and how siblings, caregivers, and all family members interact with your child matters greatly. Family members will need to be educated on how an AS disorder affects your child.

*Learn All About How Special Education Services Are Provided in Your District.* Then navigate the system with positive diligence. We got support by asking for help, while we saw others get nowhere making demands. I also found that showing gratitude (and bearing baked goods) went a long way to building positive relationships with school personnel.

*Make It as Easy as Possible for Your Child's Teachers to Effectively Interact With Your Child.* If you see a paragraph in an article that is particularly relevant to your child, copy the article and highlight the paragraph. If a teacher isn't interested in informally implementing suggestions, bring your information to the special education meetings and get important data included in your child's IEP (Individualized Education Plan) or whatever that document is called in your district.

*Expect to Continue Learning and Keep an Open Mind.* A friend presented me with an article about food allergies and autism. I didn't have any faith in managing Andrew's problems with diet, but reading the article, had to agree that it sounded like it was describing Andrew. We weaned him off dairy products, and after he was a bear for a few days, he appeared to feel much better. Andrew couldn't notice feeling any differently on his meds but reported feeling "happier" without the dairy products. Any win is a big help!

*Face The Fact That You're In It For The Long Run.* I remember feeling dismayed when Andrew's medications had to be reevaluated a few short months after he began taking them. I came to realize that managing medications is an ongoing activity, as is dealing with an AS disorder in general. It becomes part of your life and as you embrace the challenge, solutions will come to you.

**Provide Autism Spectrum News to Your Clients or Staff - See our Group Subscription on Page 47**

### Autism Tissue Program from page 1

in autism came from a study they had performed, using DNA obtained from blood samples from a subset of subjects from Autism Speaks' Autism Genetic Resource Exchange (AGRE). The authors had previously shown that the SLC25A12 gene on chromosome 2 is important in neurodevelopment. This gene 'turns on' early in human fetal neuronal tissues which then impacts the region of prefrontal cortex associated with early exaggerated postnatal growth in children with autism.

#### Brain Tissue Provides Key to Face Processing Differences in Autism

The intense examination of post mortem tissue can also yield findings that may explain the social and behavioral differences seen in people with autism. A recent publication in the journal *Brain* by investigators in New York and the Netherlands describes a significant anatomical difference in the face processing area of brain donors with autism compared to non-affected donors. A key feature of normal social functioning in humans is the processing of faces, which allows people to identify individuals and enables them with the capacity to understand the mental state of others. Recent functional magnetic resonance imaging studies have demonstrated that people with autism could perform face perception tasks. However, the

fusiform gyrus (FG) and other cortical regions supporting face processing in controls are less active in people with autism.

Examination of post mortem tissue showed anatomical differences in those with autism in the same area, the fusiform gyrus, as was previously implicated in imaging studies. For the last five years, Imke van Kooten, Ph.D., and her colleagues at the University of Maastricht in the Netherlands and here in the U.S. have made painstaking measurements of neurons in post mortem brain sections. Neurons in the primary visual cortex connect to neurons in the fusiform gyrus, effectively sending visual information to the region specialized for face processing. Analysis of neurons in the layers of these two areas showed that, compared to controls, patients with autism showed significant reductions in neuron density, total neuron numbers, and mean neuron cell volume in the fusiform gyrus. The authors suggest that the reduced neuronal size and total neuron number in the fusiform gyrus might contribute to impaired face processing in autism. Since individuals with autism can indeed 'see' faces, but may see them differently, most likely by utilization of unique neural circuitry, the research team plans further study of other additional cortical areas implicated in visual processing.

This continued research will be part of the Brain Atlas Project, a larger study to map the brain that is supported by Autism



Connie Frenzel, RN, MS

Speaks' Autism Tissue Program. This project, begun in 2002, is a joint effort of co-PIs Christoph Schmitz, Ph.D., Patrick Hof, Ph.D., and Jerzy Wegiel, Ph.D., at the NY Institute for Basic Research in Staten Island.

The ATP participates in a nationwide campaign to understand and treat a whole spectrum of pervasive developmental disorders. The studies described above are just a sample of the many research studies

utilizing post mortem tissue. There is a real need for continued donations and we encourage everyone, with or without autism, to consider giving the 'gift of hope' and signing up as a brain donor.

For more information on the ATP and to register online, please visit the program at [www.autismtissueprogram.org](http://www.autismtissueprogram.org) or call (877) 333-0999 and ask for information. The ATP is deeply grateful to the many families who have given the gift of hope to advance research into the causes and treatments for autism.

*Connie Frenzel, RN, MS, is the Outreach Coordinator for the Autism Tissue Program which is funded by Autism Speaks and the National Institutes of Health. She is responsible for outreach to the professional and lay community on issues pertinent to brain research. A graduate of San Jose State University and Stanford University, she is the founder of the Parents Helping Parents PDD/Autism group in the San Francisco Bay area. A strong advocate for the autism spectrum community, she continues to volunteer with numerous national and statewide parent advocacy groups and is a member of the Developmental Disabilities Nursing Association. You may contact her at (877) 333-0999 or email her at [csfrenzel@gmail.com](mailto:csfrenzel@gmail.com).*

**Around the World from page 22**

whereas regular education students finished their compulsory school days at age 18 or 19. Given that autism is a developmental delay, meaning it takes longer to learn, it would only make sense that children on the autism spectrum should be allowed to remain in school longer than their regular education peers like they do in the United States and some other countries. As I write this article, I will be meeting with an official of the government of Northern Ireland later today to bring up this very point.

Of course, services and support in the United States is not a panacea either. As mentioned in the introduction, unlike in South Korea where special educators earn higher salaries and receive additional needed support from the government to do their jobs than their regular education counterparts, these dedicated professionals in the United States are often paid less and receive fewer supports than regular education teachers. As suggested above, there is much to learn from all people of the world in supporting people on the autism spectrum.

**Science from page 25**

He has authored three books guiding consumers to scientific and ethical dentistry.

Through AHA Association's support

**Training from page 8**

Autism awareness to be part of the training curriculum for law enforcement officers and other emergency responders.

**Family Services from page 11**

**Clarity** – The extent of the proposal's defined interim and outcome measures.

**Cost Effectiveness** – Proposals must demonstrate 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 entered

**Summary**

With electronic means of communication and the ease of travel across time zones, the world continues to become a smaller and smaller place. For example, this is the second time in about 5 weeks that I have circumnavigated the globe consulting on, presenting, and holding workshops related to the autism spectrum. There is much autism around and given that similarities rather than differences characterize the autism community, there is every reason for greater collaboration as we work towards our goal of empowering those with autism to a future of fulfillment, productivity, and well being.

*Stephen M. Shore, EdD is Executive Director of Autism Spectrum Disorder Consulting. He also serves on the Board of Directors for the Autism Society of America and serves on the Board of Directors for the Asperger's Association of New England.*

To learn more, please visit his website at [www.autismasperger.net](http://www.autismasperger.net).

programs, website ([www.ahaNY.org](http://www.ahaNY.org)), electronic mailing list and newsletter, we make every effort to provide objective, up-to-date, reliable, evidence based information, and urge you to thoughtfully evaluate any proposed treatment.

The Autism Advisory Committee is hoping to expand such training to other emergency responders such as fire departments and EMS in Westchester County.

into the Autism Speaks Family Services Resource Guide [www.autismspeaks.org/community/family\\_services/](http://www.autismspeaks.org/community/family_services/) to provide families with access to an ever-expanding universe of resources. In an effort to promote further replication and expansion of effective services, later this year Autism Speaks will begin to share the outcomes of the programs the organization funded via Family Services Community Grants at the end of 2007.

A request for applications for the next round of Family Services Community Grants will be announced in late July with an anticipated deadline of late September.

**Treatment Grants from page 11**

Dr. Geraldine Dawson, Chief Science Officer for Autism Speaks. "These grants will support high-quality research that approaches treatment in a variety of ways, but shares the common goal of enhancing the lives of individuals with ASD. As with any new treatment, it is imperative that these approaches be rigorously tested to ensure confidence in their safety and effectiveness."

Lay abstracts describing the thirteen newly funded grants can be found on Autism Speaks' website – [www.autismspeaks.org](http://www.autismspeaks.org).

In 2007, Autism Speaks awarded more than \$30 million in science grants to fund research into the causes, prevention and treatments for autism. The organization will be announcing research grants in the basic/clinical categories in the coming weeks.

**About Autism**

Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships, and is often accompanied by extreme behavioral challenges. Autism spectrum disorders are diagnosed in one in 150 children in the United States,

**Governor's Bill from page 6**

through creation of a voluntary registry of children and adults with ASDs; and (5) development of professional training programs to assist practitioners in diagnosing and treating people with ASD's. In conjunction with the disapproval of S.5760/A.11275, the Governor directed the Commissioner of OMRDD to report on the progress of the Autism Platform within 18 months.

**Collaboration from page 29****Consistency of Strategies Employed**

Speech and occupational therapists use the techniques of their disciplines in conjunction with more behavioral educational strategies such as visual schedules, token economy systems, and the use of behavior intervention plans. The use of such strategies across all interventionists helps with maintaining instructional control where necessary and provides consistency in rules and expectations across staff members and instructional contexts within the school environment. Such consistency is critical to achieving maximal success within speech and OT sessions.

Speech and language therapists work with other members of the team to develop oral motor protocols that focus on desensitization and on the development of deep diaphragmatic breathing. The input from occupational therapists is helpful in this regard, as understanding how the sensory systems are responding to input assists SLPs in creating appropriate plans. Behaviors targeted might include engaging in inappropriate oral play or exhibiting feeding difficulties due to taste, texture, or temperature aversions. Oral-sensory-motor protocols are written collaboratively and carried out by all disciplines throughout the school day.

ABA therapists and occupational therapists are trained by SLPs to use dif-

ferent augmentative communication devices within the context of their therapy sessions and they use communicative strategies to elicit active, self-initiated and meaningful responses from the children. The implementation of the students' various modes of communication, such as sign language, PECS, augmentative devices, and visual supports are trained and supported across all disciplines and all settings. Speech and language related goals can be targeted during movement activities especially during the use of suspended equipment which is highly motivating for the students. Speech and language therapists can themselves conduct parts of their sessions in a sensory-rich environment such as the gym.

**About Autism Speaks**

Autism Speaks is dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention and treatments for autism, and to advocating for the needs of individuals with autism and their families. It was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Senior Advisor at Lee Equity Partners and served as vice chairman, General Electric, and chief executive officer of NBC and NBC Universal for more than twenty years. Autism Speaks merged with the Autism Coalition for Research and Education (ACRE), the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN), bringing together the nation's leading autism advocacy organizations. To learn more about Autism Speaks, please visit [www.autismspeaks.org](http://www.autismspeaks.org).

New York's Early Intervention (EI) program, administered by DOH, seeks to identify and evaluate as early as possible those infants and toddlers with a disability or developmental delay and provide appropriate intervention. The best practice protocols that will be established by DOH in accordance with this bill will help practitioners identify children with ASD's for referral to the EI program.

**Summary**

A collaborative model enables learners to receive services that address all areas of deficit. The strength of each discipline can be maximized, while the consistency of approach ensures that the learner receives interventions that are individually tailored, maximally effective, and fully comprehensive. ABA provides the framework, with a focus on well-defined instructional strategies, data collection, data-based decision making, and consistent implementation across therapists and environments. Future directions include research aimed at applying ABA methods to the experimental analysis of the effectiveness of speech and OT protocols.

**Give a Family  
The Gift of Hope and Education**

**Send Them a Gift Subscription  
To Autism Spectrum News**

**Go to Our Website  
[www.mhnews-autism.org](http://www.mhnews-autism.org)**

**To Order a Subscription or Advertisement**

**Understanding from page 42**

- computerized tomography (CT), positron emission tomography (PET), single photon emission computed tomography (SPECT), and magnetic resonance imaging (MRI), study of the structure and the functioning of the brain can be done. With the aid of modern technology and the new availability of both normal and autism tissue samples to do postmortem studies, researchers will be able to learn much through comparative studies.

Postmortem and MRI studies have shown that many major brain structures are implicated in autism. This includes the cerebellum, cerebral cortex, limbic system, corpus callosum, basal ganglia, and brain stem. Other research is focusing on the role of neurotransmitters such as serotonin, dopamine, and epinephrine.

Research into the causes of autism spectrum disorders is being fueled by other recent developments. Evidence points to genetic factors playing a prominent role in the causes for ASD. Twin and family studies have suggested an underlying genetic vulnerability to ASD. To further research in this field, the Autism Genetic Resource Exchange, a project initiated by the Cure Autism Now Foundation, and aided by an NIMH grant, is recruiting genetic samples from several hundred families. Each family with more than one member diagnosed with ASD is given a 2-hour, in-home screening. With a large number of DNA samples, it is hoped that the most important genes will be found. This will

enable scientists to learn what the culprit genes do and how they can go wrong.

Another exciting development is the Autism Tissue Program ([www.brainbank.org](http://www.brainbank.org)). The Autism Tissue Program is funded by Autism Speaks and the National Institutes of Health. The ATP works in partnership with the Harvard Brain Tissue Resource Center and the Children's Hospital of Orange County. Studies of the postmortem brain with imaging methods will help us learn why some brains are large, how the limbic system develops, and how the brain changes as it ages. Tissue samples can be stained and will show which neurotransmitters are being made in the cells and how they are transported and released to other cells. By focusing on specific brain regions and neurotransmitters, it will become easier to identify susceptibility genes.

Recent neuroimaging studies have shown that a contributing cause for autism may be abnormal brain development beginning in the infant's first months. This "growth dysregulation hypothesis" holds that the anatomical abnormalities seen in autism are caused by genetic defects in brain growth factors. It is possible that sudden, rapid head growth in an infant may be an early warning signal that will lead to early diagnosis and effective biological intervention or possible prevention of autism.

For detailed information on autism spectrum disorders research, see NIMH research fact sheet, *Autism Spectrum Disorders Research* at [www.nimh.nih.gov/publicat/autismresfact.cfm](http://www.nimh.nih.gov/publicat/autismresfact.cfm).

**Columbia Study from page 7**

to either GI disturbances or autism it should precede their onset. Analysis indicated no role for MMR vaccine in either the pathogenesis of autism or GI dysfunction. Only five of 25 subjects (20%) had received MMR vaccine before the onset of GI complaints and had also had onset of GI episodes before the onset of autism.

"Over 20 epidemiologic studies have reported no temporal relationship between MMR vaccine and autism, however, no published studies from other research groups have addressed whether measles virus RNA is present in bowel of autistic children with GI disturbances. Here we report results of independent, blinded testing in this particular subgroup for the presence of measles virus RNA in bowel tissues," says corresponding author W. Ian Lipkin, John Snow Professor of Epidemiology and director of the Mailman School's Center for Infection and Immunity.

He adds, "The study design process was a critical piece for us, as there is still so much public concern over the safety of the MMR vaccine. For this reason, we involved the autism parent/advocacy community as we designed the study to ensure that all issues were being addressed. We are hopeful that this process of community engagement will build important partnerships among members of the autism community, physicians, public health agencies, and clinical researchers; serve as a paradigm for the conduct of future studies to understand the causes of

this disorder; and facilitate the rapid communication of clinically relevant scientific findings to the broader community."

The Centers for Disease Control and Prevention provided support for this study through the American Academy of Pediatrics.

About the Mailman  
School of Public Health

The only accredited school of public health in New York City, and among the first in the nation, Columbia University's Mailman School of Public Health provides instruction and research opportunities to more than 1000 graduate students in pursuit of masters and doctoral degrees. Its students and more than 300 multi-disciplinary faculty engage in research and service in the city, nation, and around the world, concentrating on biostatistics, environmental health sciences, epidemiology, health policy and management, population and family health, and sociomedical sciences.

*Dr. Ian Lipkin, MD is the John Snow Professor of Epidemiology, Professor of Neurology and Pathology, and the Director of the Center for Infection and Immunity at the Columbia University Mailman School of Public Health. Mady Hornig, MD is the Associate Professor of Epidemiology and the Director of Translational Research at the Center for Infection and Immunity at the Columbia University Mailman School of Public Health.*

**False Prophets from page 9**

A: The desire by some parents to separate, space out, or withhold vaccines is understandable. This choice, however, is not necessarily without consequence.

First, delaying vaccines will only increase the time during which children are susceptible to certain diseases. And some of these diseases are still fairly common. For example, chickenpox, whooping cough (pertussis), influenza, and pneumococcus still cause hospitalizations and death in previously healthy children every year. For example, before the chickenpox vaccine, every year about 70 children died from the disease.

Second, spacing out or separating vaccines will require children to visit the doctor more often for shots. Researchers have found that children experience similar amounts of stress, as measured by secretion of a hormone called cortisol, whether they are getting one or two shots at the same visit. This study suggests that although children are clearly stressed by receiving a shot, two shots aren't more stressful than one. For this reason, more

visits to the doctor created by separating or spacing out vaccines will actually increase the trauma of getting shots.

Finally, the immunological challenge to an infant's immune system is miniscule compared to what children encounter and manage in their environment every day. Within one week of birth, babies are colonized with trillions of bacteria that line the nose, throat, and intestine. Babies mount an immune response to these bacteria to make sure that they don't invade the bloodstream and cause harm. Indeed, the immunological challenge from an ear infection or a cold is far greater than from all vaccines combined.

Q: I'm sure you've read the August CDC report indicating that measles cases in the U.S. are at the highest level in more than a decade, with nearly half of those involving children whose parents rejected vaccination. What do you make of this?

A: Measles is imported into the United States every year, usually from countries in Western Europe or the Middle East.

Imported cases also started this outbreak. The difference this time is that the disease took hold, spreading from one unimmunized child to the next and eventually infecting about 130 people. The fact that the virus spread easily shows that at least in some communities enough children aren't getting immunized so as to cause a critical breakdown in herd immunity. That's new. And should be a warning shot to those wondering when the tipping point will come—when enough parents have chosen not to vaccinate their children that others are at serious risk. I think that this outbreak shows that the tipping point has arrived.

Q: Why did you choose to donate the profits from this book to Children's Hospital?

A: Probably the most frustrating aspect of the vaccine-autism controversy is how it has diverted the media and the public's attention away from exciting research in autism.

*Dr. Paul A. Offit, MD is the chief of Infectious Diseases and the director of*

*the Vaccine Education Center at the Children's Hospital of Philadelphia as well as the Maurice R. Hilleman Professor of Vaccinology and professor of pediatrics at the University of Pennsylvania School of Medicine. He has received numerous awards, including the J. Edmund Bradley Prize for Excellence in Pediatrics from the University of Maryland School of Medicine, the Young Investigator Award in Vaccine Development from the Infectious Diseases Society of America, and a Research Career Development Award from the National Institutes of Health. An international expert on rotavirus-specific immune responses, Dr. Offit is the co-inventor of the rotavirus vaccine RotaTeq, for which he received the Jonas Salk Award from the Association for Professionals in Infection Control and Epidemiology, the Gold Medal from the Children's Hospital of Philadelphia, and the Stanley A. Plotkin Award in Vaccinology from the Pediatric Infectious Diseases Society. He will donate all royalties from sales of this book to autism research.*

**Self-Injurious from page 37**

difficult to understand and treat. While there is no single medication or behavioral procedure that eliminates SIB, research so far has shown that ABA and newer antipsychotic medications such as Risperdal may alleviate this debilitating condition in some people with autism. Much of the research examining the effects of medications is based on small open trials and anecdotal reports. The limited efficacy reported with each class of medication

strongly indicates the interaction of multiple neurotransmitter systems. This interaction is further complicated by environmental consequences that contribute to SIB. Thus, the origin of a particular individual's SIB and the variables maintaining it may largely depend on that individual's environmental and biological histories. More systematic, empirical data on the basic neurological mechanisms of SIB and analysis of biological and behavioral interactions are needed to fully conquer SIB and its impact on peoples' lives.

**Autism and Culture from page 32**

prevalence in South Korea by the spring of 2009, and though I cannot say what we found, I can say that the prevalence will be higher than Koreans expect.

*Roy Richard Grinker, PhD is Professor of Anthropology and the Human Sciences at the George Washington University and editor-in-chief of The Anthropological Quarterly. The author of Unstrange Minds: Remap-*

*ping the World of Autism (NY: Basic Books, 2007) he is currently completing a prevalence study of autism spectrum disorders in Seoul, South Korea, funded by Autism Speaks. In December, 2008 Library Journal selected Unstrange Minds as one of the "30 Best Books" of 2007, and it received the 2008 Ken Award from the National Alliance on Mental Illness for "Outstanding Literary Contribution to a Better Understanding of Mental Illness."*

**YAI/NIPD from page 6****YAI/NIPD Network Stays on Cutting Edge with Autism Advisory Council**

The YAI/NIPD Network has also assembled an interdisciplinary Autism Advisory Council to provide advice research, training and the provision of services. The Advisory Council comprises:

- Joseph Buxbaum, Ph.D., Director of the Seaver and New York Autism Center of Excellence at Mount Sinai School of Medicine and G. Harold and Leila Y. Mathers Research Professor of Psychiatry, Neuroscience, Genetics and Genomic Sciences
- Vincent Carbone, Ed.D., Director of the Carbone Clinic
- Lynda Geller, Ph.D., Associate Professor of Child and Adolescent Psychiatry and the Clinical Director of the Asperger Institute at the New York University Child Study Center
- Jed Baker, Ph.D., Director of the Social Skills Training Program

**Running from page 8**

part of T4A is the fact that participants are able to direct the majority of the funds they raise to the autism program of their choice.

Our entire family including my wife Kristin and our 13 year-old son Tyler are all training

**Guiding Families from page 13**

Ultimately, the service coordinator's job is to ensure that the child and his or her family are receiving the appropriate evidence-based services, based on a comprehensive evaluation. For all the families who do not have the financial resources to implement the plan themselves, the service coordinator will provide information about how to access city, state and federally mandated services.

"A skilled and compassionate Service Coordinator can be so helpful in supporting a family who is dealing with the complexities of the Early Intervention Program," said Hilda Chusid, Early Intervention Supervisor at LifeStart.

**Learning to Cope**

In addition to helping families implement an early intervention plan, service coordinators offer ongoing emotional support, and reinforce the resourcefulness and resilience of families.

"I think that especially new parents might not recognize certain behaviors as being red flags until 18 months or older," said Carol Stein-Schulman, Assistant Director of the New York League for Early Learning, a member of the YAI/NIPD Network. "But when they go to the park, join play or parent groups, they see that their child doesn't have many of the play skills, social skills and language skills that the other children display. That's when some of these red flags may be more evident."

When parents are given the diagnosis of autism, they often look back and replay

- Temple Grandin, Ph.D., Associate Professor of Animal Science at Colorado State University
- Carol Gray, Director of The Gray Center for Social Learning and Understanding
- Larry King, Host of Larry King Live on CNN
- Joseph Levy, M.D., Director of the Division of Pediatric Gastroenterology at the New York University School of Medicine
- Bernice Polinsky, Parent Advocate
- Jennifer J. Raab, J.D., M.P.A., President of Hunter College
- Fred Volkmar, M.D., Director of the Child Study Center at Yale University School of Medicine and Chief of Child Psychiatry at Yale-New Haven Children's Hospital

For information and services for people with autism and their families, please visit [yai.org/autism](http://yai.org/autism) or contact YAI LINK at 1-866-2-YAI-LINK, TDD: 212-290-2787 or [link@yai.org](mailto:link@yai.org).

to compete in marathons to raise funds for such organizations as Autism Speaks. For more information on Train 4 Autism, please visit [www.Train4Autism.org](http://www.Train4Autism.org).

As a father who misses his son more than words can express, continuing to run for autism and our work with Train 4 Au-

**Parenting from page 37**

baby despite knowing the increased probability of having another child on the spectrum; (4) Cutting back on work to devote more time to the care of their children with AS; (5) "Normalization" which the parents described as trying to live life as though one of their children did not have AS; (6) Teaching their child relaxation & coping techniques; (7) Voraciously reading not only self help books on the subject of autism, but medical and research journals as well; (8) Joining houses of worship and reading scripture; (9) Maintaining marital unity in the battles against school districts etc.; (10) Initiating lawsuits when necessary; (11) Joining parent support groups like ASPEN, AHA, etc.; and (12) a coping strategy referred to as "Finding the Gems."

"Finding the Gems" refers to the appreciation of unique abilities that are both surprising and unexpected. One mother in the study developed cancer and underwent chemotherapy. There was a moment when she felt like giving up and was making the decision to stop her treatments. It was her child with AS who said the words to convince her to continue with the treatment. "The problem with you mom, is that you are focusing in on today and not looking at the future we

live with us forever. I'm proud to be Reid's Dad, blessed to have had so many incredible experiences with him and to have met so many special teachers, therapists, and caregivers who continue to give us incredible support. Together, we will make a difference.

Anger, guilt and grief are normal responses for any parent who learns that his or her child has a disability. LifeStart's early intervention service coordinators are there to offer help.

"Expectations are set up for all of us in life that are reinforced by the rest of society, and when those aren't met, there's a sense of loss and mourning. And it's a loss that they keep experiencing over time when they realize that their children may not achieve the goals and successes they were expecting," said Erica Levy, M.S.W., a social worker at the Gramercy School of the New York League for Early Learning. "As professionals, it's so important to engage parents, help them navigate the system and spell out concrete steps for them to take so that they are being proactive in knowing they are doing the best for their child."

Sarah Kern, who has been a service coordinator with LifeStart for two years, works with families who learn at age 18 months and older that their children have an autism spectrum disorder.

One mother Sarah worked with had left her professional career to implement and manage her child's program of services, a full-time position in itself, Sarah said. "She needed to view this as a business project, being very goal-oriented."

However, she learned the realities of child development. There are good days and bad days. A child can be making wonderful progress and then take a step back, instilling the fear of regression. There is evidence that intensive structured behavioral therapy leads to progress. One learns that the rate of progress is not always proportional to hours of therapy or how hard the

child, family and therapists are working.

**Empowering Families**

Service coordinators have many different roles when entering the lives of families affected by autism. "I try to really empower the families, helping them identify their own sense of resilience and resourcefulness" said Maya Goldstein, a LifeStart Early Intervention Service Coordinator for five years. "We're on this journey with them for a number of crucial years in the development of their child. In this time, they find their own voice to advocate for their child."

With so many therapists, doctors, evaluations and paperwork, parents can often become overwhelmed and confused or lose their sense of confidence in their ability to provide the opportunities for growth for their child, explained Maya. It's very important that they feel a sense of confidence in their support of their child during the process of early intervention.

For service coordinators, the experience of being part of a family's journey, and witnessing family members' strengths as well as their struggles, is what makes their professional life so satisfying.

"What's so amazing about families I've worked with is seeing so much love and devotion," Sarah Kern said. "To see how much families sacrifice for their children, and how hard they work to see that their children are as successful as possible, is wonderful."

Charles Cartwright, M.D., is Director of the YAI/National Institute for People with Disabilities Network's Autism Center.

## Subscribe to Autism Spectrum News

**Yes!** I want to receive each Quarterly issue by Mail

- Student (\$20/year) School/Program \_\_\_\_\_
- Individual/Family (\$40/year)
- Professionals (\$50/year)
- Group - 50 Copies Each Issue (\$300/year)

*Give a Gift of Hope  
Order a Gift Subscription for Someone in Need*

Name & Title: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

**Include your Check Payable to:  
Mental Health News Education, Inc.**  
(or pay by credit card at [www.mhnews-autism.org](http://www.mhnews-autism.org))

*cut out this coupon and mail it with your check to:*

**Mental Health News Education, Inc.  
16 Cascade Drive, Effort, PA 18330**

**Phone: (570) 629-5960 E-mail: [iramnot@mhnews.org](mailto:iramnot@mhnews.org)**

## Advertise in Autism Spectrum News

- \* 25% Savings - Book 3 Get 1 Free!**
- Business Card - 4 issues (\$320)
  - Eighth Page (1 issue \$300 - 4 issues\* \$900)
  - Quarter Page (1 issue \$500 - 4 issues\* \$1,500)
  - Half Page (1 issue \$750 - 4 issues\* \$2,250)
  - Full Page (1 issue \$1,000 - 4 issues\* \$3,000)
  - Inside Covers & Back Page (please call)
  - Special Multi-page Supplements (please call)
  - Honorary Sponsorship (please call)

Name & Title: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

**Include your Check Payable to:  
Mental Health News Education, Inc.**  
(or pay by credit card at [www.mhnews-autism.org](http://www.mhnews-autism.org))

*cut out this coupon and mail it with your check to:*

**Mental Health News Education, Inc.  
16 Cascade Drive, Effort, PA 18330**

**Phone: (570) 629-5960 E-mail: [iramnot@mhnews.org](mailto:iramnot@mhnews.org)**

*Promote Your Vital Programs and Services for the Autism Community  
And Reach Our Over 160,000 Readers  
Place Your Advertisement for the Year In Advance and Save 25%*

## Deadline Calendar & Ad Size Specifications

### Deadline

**December 15, 2008**  
**March 15, 2009**  
**June 15, 2009**  
**September 15, 2008**

### Release Date

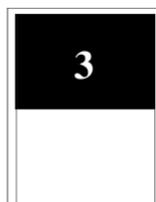
**March 2009 (spring issue)**  
**June 2009 (summer issue)**  
**September 2009 (fall issue)**  
**December 2008 (winter issue)**



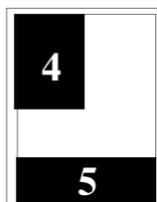
Full Page  
\$1,000



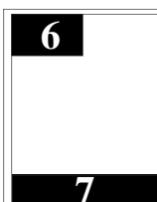
Half Vertical  
\$750



Half Horizontal  
\$750



Quarter V & H  
\$500



Eighth V & H  
\$300

### Ad Sizes - In Inches

	<u>Width</u>	<u>Height</u>
<b>Full Page (1)</b>	<b>10.4</b>	<b>12.8</b>
<b>Half Vertical (2)</b>	<b>5.1</b>	<b>12.8</b>
<b>Half Horizontal (3)</b>	<b>10.4</b>	<b>6.4</b>
<b>Quarter Vertical (4)</b>	<b>5.1</b>	<b>6.4</b>
<b>Quarter Horizontal (5)</b>	<b>10.4</b>	<b>3.1</b>
<b>Eighth Vertical (6)</b>	<b>5.1</b>	<b>3.1</b>
<b>Eighth Horizontal (7)</b>	<b>10.4</b>	<b>1.5</b>



“  
I walk because I want  
the best for my child.  
”

AUTISM SPEAKS™  
**WALK NOW  
FOR AUTISM**

**Join us in 2009 at a Walk near you!**

To register and for more details, please visit us online at  
[www.walknowforautism.org](http://www.walknowforautism.org)



**AUTISM SPEAKS™**  
It's time to listen.

[www.AutismSpeaks.org](http://www.AutismSpeaks.org)