

The Assessment Process and Appropriate Interventions

Clinical Evaluation of Autism Spectrum Disorders

By Celine Saulnier, PhD,
Ami Klin, PhD, of the
Yale Child Study Center and
Linda Quirnbach, PhD, of the
Center for Autism and
Related Disorders at UCLA

Individuals with autism spectrum disorders (ASD) experience a range of vulnerabilities that span across areas of development, as well as vary throughout life. Thus, in order to accurately assess areas of need, a comprehensive, multidisciplinary evaluation is merited – often-times, at multiple developmental stages. This not only involves evaluating various areas of development, including developmental history, level of functioning, the nature and course of development over time, and ability to functionally apply one's repertoire of skills to everyday life across settings and contexts, but more importantly entails effectively integrating and conceptualizing all of the results into one cohesive diagnosis (Klin, Carter, Volkmar, et al., 1997; Klin, Saulnier, Tsatsanis, & Volkmar, 2005). This process requires experienced clinicians who are knowledgeable of ASD, as well as clinicians who are familiar with the intricacies of child development.



Cognitive Assessment

The first and primary component of any evaluation involves obtaining a baseline of cognitive and/or developmental skills. The type of measure used to assess

an individual's cognitive profile depends on the age and level of functioning of the person. For very young children, a developmental assessment is indicated. Examples include the *Mullen Scales of Early Learning* (Mullen, 1995) and the *Bayley*

Scales of Infant and Toddler Development, Third Edition (Bayley, 2005). It is important to emphasize that although standard scores can be obtained on developmental measures, a young child's abilities continue to change throughout early development and for this reason, interpretations or predictions about future levels of functioning based on early developmental profiles should be avoided.

Common measures to assess cognitive ability, or IQ, in older individuals include the Wechsler scales (e.g., the *Wechsler Intelligence Scale for Children, Fourth Edition*; *WISC-IV*, Wechsler, 2003) and the *Differential Ability Scales, Second Edition* (DAS-II; Elliott, 2007). Due to skill variability, as well as differences in attention to tasks, tolerance for task demands, and behavioral regulation, it is important to invest careful thought into the process of selecting appropriate instruments and testing procedures in order to ensure that results are valid. If a child is unable to complete an instrument that is standardized for his/her chronological age, oftentimes it becomes necessary to use instruments that are standardized for developmentally younger individuals.

see *Clinical Evaluation on page 26*

Assessing Young Children with ASD: A Multidisciplinary Approach

By Charles Cartwright, MD, Director
Michelle Gorenstein, PsyD,
Moira Lewis, MS CCC-SLP
Kristin David, OTR/L, and
Erica Pitman, LMSW
YAI Autism Center

According to the U.S. Centers for Disease Control, 1 in 150 children are diagnosed with an autism spectrum disorder (ASD) every year. But how can parents be sure that they have received the proper assessment? And what are the key steps in ensuring that these children receive the necessary level of care?

An assessment should be viewed as an ongoing team effort. At the YAI Autism Center, for example, a team of profession-

als works together to provide a comprehensive assessment of a child's development. We then continue to work with families to make recommendations for educational services, medical care and other critical services for children on the spectrum.

This approach is extremely valuable in creating a comprehensive treatment plan that allows for coordinated interventions and ongoing assessments that accurately gauge a child's progress.

Child Psychiatry

A psychiatric assessment for children with an ASD should be seen within a developmental perspective. The most effective assessments will address cognitive, physical, social, emotional, language, behavioral and neurological issues.

According to a recently published article by H.L. Egger (Egger H.L. *Psychiatric Assessment of Young Children*) there are multiple components of a comprehensive mental-health assessment. Critical elements of any assessments are to provide an interactive play assessment with the child, and a session for parents alone without their child. This allows for more candid conversation, eliminating concern that their child may be affected by what they say. It is also valuable to observe a child at home, in school or at any programs he or she attends. By creating these opportunities, a range of developmental and mental health information can be effectively gathered.

Clinicians should achieve an understanding of how a family's cultural values shape their views of their child, and

impact their motivation to pursue a range of treatments and services. Psychiatrists should also be aware of their own cultural values, and how these values shape their formulations and treatment plans. In addition, careful attention should be paid to potential conflicts between a family's beliefs and perceptions, and the clinician's approach. This allows for the consideration of the whole family system, a critical factor for effective treatment planning.

Psychology

Psychologists play an important role in the multidisciplinary assessment of a child on the autism spectrum. We measure a

see *Multidisciplinary on page 28*

The Autism Spectrum News Editorial Board

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

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

Stephen E. Freeman, Associate Executive Director
YAI National Institute for People with Disabilities

Lynda Geller, PhD, Director, Institute for Cognitive Diversity
Bank Street College of Education

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 Singer, President
Autism Science Foundation

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 Beitchman, DSW, Executive Director
The Bridge

Vice-Chairman

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

Secretary

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

Treasurer

Alan Trager, LCSW, Executive Director & CEO
Westchester Jewish Community Services

Members of The Board

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

Peter C. Campanelli, PsyD, President & CEO
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

Jorge Petit, MD, President
Dr. J. Petit Psychiatry Consulting

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

Alison Singer, President
Autism Science Foundation

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

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: (508) 533-4053 E-mail: dminot@mhnews.org Website: www.mhnews-autism.org

See page 47 for subscription and advertising information. Mental Health News Education, Inc. does not endorse the views, products, or services contained herein. We are not responsible for omissions or errors.

Copyright © 2009 Mental Health News Education, Inc. All rights reserved. Content contained in this publication may be reproduced for one-time personal use. However, any party wishing to reproduce and distribute any content from within this publication for purposes other than personal use must request this intention in writing directly to the publisher. Failure to do so will be in violation of the copyright held by this publication.

Autism Spectrum News - Table of Contents

From the Publisher

- 5 The Importance of a Comprehensive Multidisciplinary Evaluation

Autism Spectrum News Desk

- 6 Scientists to Use Stem Cells in Autism Study
6 Study to Focus on Transitions in Service Use and Coverage
7 Brain Region Responsible for Our Sense of Personal Space
7 Advancing Futures For Adults With Autism Initiative

Our Cover Story: The Assessment Process and Appropriate Interventions

- 1 Clinical Evaluation of Autism Spectrum Disorders
1 Assessing Children with ASD: A Multidisciplinary Approach
9 Parenting an Individual with Autism: A Roadmap
9 YAI/NIPD Helps Adults on the Spectrum Develop Language
11 Autism Research and Treatment at the Seaver Autism Center
12 New Autism Charity Hopes to Carve Out Its Niche
13 Assessing the Functions of Behavior: Communicative Intent
15 Overcoming the Challenges of Assessing Children for Autism
16 An Inside Look At the Grant Assessment Process
18 Supporting Parents in Their Search for the Whole Picture
18 Diagnosing Adults with Asperger's and High Functioning Autism
19 The Importance of a Neuropsychological Evaluation
20 Assessment and Intervention of Mental Health Disorders with ASD
20 50 Years of Personal Experiences Teaching Children with ASD

- 21 Diagnosing Autism Spectrum Disorders
23 Facing the Challenges of Higher Education
24 Diagnostic Features of Autism and Functional Assessment
24 The Three Symptom Domains of Autism Spectrum Disorders
25 Asperger's Students Focus on Social Communicative Competency
27 Assessment for Transition Planning
29 Consent to Medical Care For Minors
31 Robin's Voice - A Resilient Mom's Commentary on Autism
33 The Importance of Community Awareness of ASDs
35 The Intelligent Mind of an Individual with Asperger's Syndrome
39 Roadmap for Parents of a Child Recently Diagnosed With Autism

Autism Spectrum News Upcoming Theme and Deadline Calendar

Winter 2010 Issue:

"Advances in Autism Science"
Deadline: December 15, 2009

Spring 2010 Issue:

"Understanding and Accessing Clinical Treatment Services"
Deadline: March 15, 2010

Summer 2010 Issue:

"Helping Families Cope With Stress"
Deadline: June 15, 2010

Fall 2010 Issue:

"Addressing the Growing Needs of Adults"
Deadline: September 15, 2010

Autism Spectrum News Thanks Our Honored Sponsors

Platinum Sponsor

YAI National Institute for People with Disabilities Network

Gold Sponsor

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

Westchester County Department of Community Mental Health

Silver Sponsor

The McCarton Foundation

Services for the Underserved

We Wish to Thank our Advertisers For Their Participation and Support

AHRC Nassau

Irene Brody, PhD

Asperger Syndrome and High
Functioning Autism Association

Jewish Board of Family
and Children's Services

Association for Science in
Autism Treatment

Life's WORC

Autism Today

Los Niños Services

Children's Annex

Match Konnection

Cody Center

New York Institute
of Technology

Columbia University Press

New York
University Steinhardt

Connecticut Autism
Resource Center

Robert J. Bernstein

Daniel Jordan Fiddle Foundation

Shield Institute

Devereux

Simons Foundation

Discovering Your World

Timothy Memorial School

Donna Klein & Associates

We Animate Character

Doug Stern, Esq.

Westchester Jewish
Community Services

Future Horizons

Westchester Institute for
Human Development

Glenholme School

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

Benefactor: \$25,000

Benefactor Sponsors will receive two full page advertisements and article space in 4 quarterly issues of either Mental Health News or Autism Spectrum News. They will also receive multiple bundles of newspapers as needed for distribution to clients, staff, board members, and satellite programs.

Platinum: \$10,000

Platinum Sponsors will receive one full page advertisement and article space in 4 quarterly issues of either Mental Health News or Autism Spectrum News. They will also receive multiple bundles of newspapers as needed for distribution to clients, staff, board members, and satellite programs.

Gold: \$5,000

Gold Sponsors will receive one half page advertisement and article space in 4 quarterly issues of either Mental Health News or Autism Spectrum News. They will also receive several bundles of newspapers for distribution to clients, staff, board members and satellite programs.

Silver: \$2,500

Silver Sponsors will receive one quarter page advertisement in 4 quarterly issues of either Mental Health News or Autism Spectrum News. They will also receive one bundle (50 copies) of newspapers for distribution to clients, staff, board members, and satellite programs.

Bronze: \$1,000

Advisor: \$500

Friend: \$250

All Sponsors will receive recognition listing on our honor roll page in either Mental Health News or Autism Spectrum News

To Discuss our Sponsorship Opportunities Please Contact:

Ira H. Minot, LMSW, Executive Director
Mental Health News Education, Inc.
16 Cascade Drive, Effort, Pennsylvania 18330
E-mail: iramnot@mhnews.org Phone: (570) 629-5960

From The Publisher

The Importance of a Comprehensive Multidisciplinary Evaluation

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

In this issue of *Autism Spectrum News*, you will find articles by many highly-regarded individuals and organizations that address the many issues involved in the assessment process, and what clinical and therapeutic interventions are appropriate for families to consider. It is vital for parents to understand the assessment process as they begin the process of obtaining a diagnosis for their child. *Autism Spectrum News* is deeply grateful to those who participated in this issue and for their help in giving us an opportunity to present a high level of science-based information on the assessment process and where families may find appropriate resources in the community.

Our lead cover story stresses the need for a child to receive a comprehensive, multidisciplinary evaluation at multiple developmental stages. This involves "evaluating various areas of development, including developmental history, level of functioning, the nature and course of development over time, and ability to functionally apply one's repertoire of skills to everyday life across settings and contexts, but more importantly entails effectively integrating and conceptualizing all of the results into one cohesive diagnosis." The authors from the Yale Child Study Center and Center for Autism and Related Disorders at UCLA also stress the importance of open communication between the multiple professionals performing the evaluation. "With multiple professionals from a wide range of disciplines becoming involved in the diagnostic process, it is imperative that there be open communication and consultation between professionals not only to ensure consistent representation of each individual assessed, but also to implement the most appropriate intervention based on that individual's profile of needs."

Our second cover story also underscores the importance of a multidisciplinary approach that will allow for the creation of "a comprehensive treatment plan that allows for coordinated interventions and ongoing assessments that accurately



Ira H. Minot, LMSW

gauge a child's progress." The authors from YAI emphasize that, "While it is clear that obtaining a proper assessment and the necessary services for children with ASDs may not always be easy, it is important for families to remember that they are not alone. Rather, they are a vital part of a team that includes dedicated professionals committed to helping a child reach his or her fullest potential."

On page 13, The McCarton Foundation highlights the importance of understanding communicative intent when assessing functions of behavior. "Even in learners with a well-established capacity to communicate, there are often very significant deficits in spontaneous communications, in complex communication, and in reciprocal communication. The deficits in communication have wide ranging effects on their ability to socially interact and on their behavioral regulation."

The Fay J. Lindner Center for Autism and Developmental Disabilities, on page 18, answers many of the common questions parents and caretakers have during the assessment process. "Early in the process, families are faced with many difficult issues about which they need to make decisions including acknowledging the need for an assessment, and where to

take their child for an evaluation. Other questions rapidly follow, and can easily paralyze even the most organized and determined of parents. What services does my child need at school, at home, and in the community? Where can I learn about what services and resources are available? When will I have time for all of this? How can I trust another professional after the negative experiences we've had?"

Magyar and Pandolfi on page 20 express the under-identification of mental health disorders in individuals with autism spectrum disorders and why this co-occurring disorder is often overlooked by practitioners. "Despite the statistics that many youth with an autism spectrum disorder (ASD) evidence mental health disorders (MHD), they may be especially at risk for under-identification for a co-occurring disorder. These disorders might not be readily identified by community practitioners. Further, some evidence suggests that those children with an identified co-occurring MHD might not receive the psychosocial and/or psychiatric interventions necessary to treat and/or manage these disorders. Failure to identify and treat co-occurring MHD may moderate a child's response to ASD specific treatment and result in poorer outcomes, greater family burden, and lower quality of life."

Assessment is not only important for children who need early intervention services. On page 27, Ernst VanBergeijk describes the need for young adults to receive an assessment before they graduate from high school. "Prior to leaving high school a young person should have a thorough assessment. Under the Individuals with Disabilities Education Act (IDEA) this can be accomplished through a triennial evaluation or a parent simply needs to put the request in writing to the local educational agency."

The assessment process is a daunting one for parents and their children. The process of diagnosing a person with an autism spectrum disorder is an involved and lengthy endeavor that can be confusing and stressful. Thankfully, as evident in this issue of *Autism Spectrum News*, there are many organizations whose mission is to provide a roadmap for parents to find the assessment and appropriate inter-

ventions their child needs. *Autism Spectrum News* is proud to continue its mission of disseminating safe and evidence-based information to the autism community.

In addition to the articles focused on the assessment process and appropriate interventions, there are many other wonderful articles by parents and experts in the field of autism that we hope will inform and inspire you. Let me conclude by telling you about our exciting roundup of themes in the quarterly calendar of *Autism Spectrum News*. In our upcoming winter issue, our theme will be "Advances in Autism Science." Our deadline for articles and advertising for this important issue is December 15th.

Our calendar continues with our spring issue which will focus on "Understanding and Accessing Clinical Treatment Services." Next summer we will take an in-depth look at "Helping Families Cope With Stress" and next summer our theme will be "Addressing the Growing Needs of Adults."

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community. As a non-profit organization, we ship thousands of free copies of each issue of *Autism Spectrum News* to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website: www.mhnews-autism.org. On our website you can subscribe to receive your own personal hard-copy 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 and staff.

We look forward to hearing from you. Please e-mail us at dminot@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 Fall Season.

***Advertise in Autism Spectrum News and Reach Our Extensive Audience Of
Consumers, Families, Treatment Professionals, and Service Providers***

A Smart Marketing Decision in These Lean Economic Times

See Our Low Cost Advertising Rates on Page 47

AUTISM SPECTRUM NEWS DESK

California Hospital Receives \$3 Million NIH Award

Scientists to Use Stem Cells to Study the Impact of Autism on the Living Brain

By The Children's Hospital of Orange County, California

Children's Hospital of Orange County, California (CHOC) announced today that its Research Institute has received a five-year, \$3 million National Institutes of Health (NIH) Research Grant to generate, investigate, and store neural stem cells derived from skin cells (fibroblasts) donated by children with autism. The research program is designed to provide an important new tool for studying the impact of autism on the developing brain – in a completely harmless and non-invasive way – while assembling the first repository of neural cells from living patients as a resource for the entire autism research community. Awarded through the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the grant recognizes CHOC Children's unique stem cell culture, distribution and training capabilities and is the largest federally-funded, basic science research grant the hospital has ever received.

"This is a completely novel approach to studying the neurobiology of autism and the first time we'll be able to do so



Philip H. Schwartz, PhD

with neural cells actually derived from large numbers of children living with the condition," said Philip H. Schwartz, Ph.D., principal investigator on the NIH grant and founding director, National Human Neural Stem Cell Resource

(NHNSCR) at CHOC Children's. "We hope to confirm over the next several years that neural cells generated from these donated fibroblasts can provide a viable experimental model that will yield insights about the origins, diagnosis, and treatment of autism."

For some time, researchers have believed that neural stem cells might provide a critical tool for the study of autism. However, until now, the only way to obtain these cells was to harvest them from the brains of people with autism after their deaths, a project that the NHNSCR has pursued in collaboration with the Autism Tissue Program of Autism Speaks for the past several years. Recent advances in stem cell research have allowed Dr. Schwartz and his colleagues to overcome this difficulty. It is now possible to convert easily-obtained human skin cells (fibroblasts) to induced pluripotent stem cells (iPSCs), which are then capable of differentiating into virtually any tissue cell type, including neural stem cells.

The NIH-funded research at CHOC Children's will apply this new technology to fibroblasts derived from patients whose autism is clinically very well-characterized, as well as those derived

from individuals without the disorder. This efficient, non-invasive method for generating autism neural stem cells from living individuals will allow research that has never been possible before. This includes studies of the detailed properties of the induced autism neuron; studies of sufficient statistical power to allow researchers to compare and contrast the effects of autism on the developing human brain; and studies of the influence of environmental factors on these processes. Importantly, all data generated by these investigations will be made widely available to the scientific community. The cells lines themselves will also be made available through the existing CHOC-funded stem cell repository, the NHNSCR, which Dr. Schwartz created in 2001.

"This project provides a new way for children with autism and their families to participate in the next era of research through a simple donation of skin cells," said Dr. Schwartz.

As work on the grant progresses, Dr. Schwartz's group at CHOC Children's will coordinate patient participation and cell collection with a clinical team headed by Randi J. Hagerman, M.D.,

see Stem Cells on page 36

Youth with Autism Coming of Age

New NIMH Study Will Focus on Transitions in Service Use and Coverage

By The National Institute of Mental Health (NIMH)

The transition from teen to young adult involves many highly anticipated rites of passage. However, for youths with developmental disorders, coming of age may signal the sudden end of coverage for education and training programs, health insurance, and youth-oriented services. For teens with autism spectrum disorders (ASD) and their families, this transition may be especially difficult. To better understand this issue and how best to address it, NIMH has awarded a five-year grant to Paul T. Shattuck, Ph.D., of the George Warren Brown School of Social Work at Washington University in St. Louis.

With this grant, Dr. Shattuck and his colleagues will pursue a study of socio-economically and racially diverse adolescents and adults with ASD. The researchers will assess data gathered on 922 people with ASD who participated in the U.S. Department of Education's (ED) National Longitudinal Transition Study 2. The 10-year ED study included a nationally repre-



sentative study population of nearly 12,000 youth, ages 13-17 at the start of the study in 2000. In particular, the Shattuck study will focus on:

- Outlining changes in service needs, service use, and health insurance

coverage as youths with ASD enter adulthood

- Identifying resources and barriers associated with use of, and continuity in, health care and other services

- Detailing young adult outcomes (such as employment, housing, independent living, health, and community participation) and examining how these may be linked with prior measures of need, service use, resources, and barriers.

The study also meets a research objective in the Interagency Autism Coordinating Committee's (IACC) Strategic Plan for Autism Spectrum Disorder Research "to support at least two studies [by 2011] to assess and characterize service access, health, and functional outcomes" among diverse demographic groups. Comprising representatives of federal agencies and members of the public, the IACC coordinates efforts within the U.S. Department of Health and Human Services concerning ASD.

"This study will help us one day answer one of the most pressing issues in treating ASD," said NIMH Director Thomas R. Insel, M.D. "Bridging the gap in health care, service use, and insurance coverage as these young people leave the school systems and enter adulthood may help prevent lapses in behavioral, social, and occupational skills that they and their families have worked so hard to achieve."

AUTISM SPECTRUM NEWS DESK

Scientists Find Brain Region Responsible for Our Sense of Personal Space

Finding Could Offer Insight into Autism and Other Disorders

By The California Institute of Technology

In a finding that sheds new light on the neural mechanisms involved in social behavior, neuroscientists at the California Institute of Technology (Caltech) have pinpointed the brain structure responsible for our sense of personal space.

The discovery, described in the August 30 issue of the journal *Nature Neuroscience*, could offer insight into autism and other disorders where social distance is an issue.

The structure, the amygdala—a pair of almond-shaped regions located in the medial temporal lobes—was previously known to process strong negative emotions, such as anger and fear, and is considered the seat of emotion in the brain. However, it had never been linked rigorously to real-life human social interaction.

The scientists, led by Ralph Adolphs, Bren Professor of Psychology and Neuroscience and professor of biology and post-doctoral scholar Daniel P. Kennedy, were able to make this link with the help of a unique patient, a 42-year-old woman known as SM, who has extensive damage



Ralph Adolphs, PhD

to the amygdala on both sides of her brain.

“SM is unique, because she is one of only a handful of individuals in the world with such a clear bilateral lesion of the amygdala, which gives us an opportunity

to study the role of the amygdala in humans,” says Kennedy, the lead author of the new report.

SM has difficulty recognizing fear in the faces of others, and in judging the trustworthiness of someone, two consequences of amygdala lesions that Adolphs and colleagues published in prior studies.

During his years of studying her, Adolphs also noticed that the very outgoing SM is almost *too* friendly, to the point of “violating” what others might perceive as their own personal space. “She is extremely friendly, and she wants to approach people more than normal. It’s something that immediately becomes apparent as you interact with her,” says Kennedy.

Previous studies of humans never had revealed an association between the amygdala and personal space. From their knowledge of the literature, however, the researchers knew that monkeys with amygdala lesions preferred to stay in closer proximity to other monkeys and humans than did healthy monkeys.

Intrigued by SM’s unusual social behavior, Adolphs, Kennedy, and their colleagues devised a simple experiment to quantify and compare her sense of personal space with that of healthy volunteers.

The experiment used what is known

as the stop-distance technique. Briefly, the subject (SM or one of 20 other volunteers, representing a cross-section of ages, ethnicities, educations, and genders) stands a predetermined distance from an experimenter, then walks toward the experimenter and stops at the point where they feel most comfortable. The chin-to-chin distance between the subject and the experimenter is determined with a digital laser measurer.

Patient SM, a woman with complete bilateral amygdala lesions (red), preferred to stand close to the experimenter (black). On average, control participants (blue) preferred to stand nearly twice as far away from the same experimenter.

Among the 20 other subjects, the average preferred distance was .64 meters—roughly two feet. SM’s preferred distance was just .34 meters, or about one foot. Unlike other subjects, who reported feelings of discomfort when the experimenter went closer than their preferred distance, there was no point at which SM became uncomfortable; even nose-to-nose, she was at ease. Furthermore, her preferred distance didn’t change based on who the experimenter was and how well she knew them.

see Personal Space on page 30

Autism Advocacy Groups Join Together for the Advancing Futures For Adults With Autism Initiative

By Autism Speaks

Advancing Futures for Adults with Autism (AFAA), an initiative led by a consortium of leading autism advocacy organizations, today announced the launch of a new web site, www.AFAA-us.org, that will provide updates on AFAA’s ongoing efforts to improve housing, employment, recreational and social opportunities for adults with autism across the country. The site will be hosted by Autism Speaks, the nation’s largest autism science and advocacy organization.

“The face of autism is rapidly changing with a generation of children who will be entering adulthood over the next 5-10 years,” said Peter Bell, Autism Speaks executive vice president for programs and services. “As a society, we are ill-prepared to deal with what will be a boom in demand for housing, employment and other critical services needed to appropriately serve adults living with autism. This initiative is an effort to create, with the input of a wide range of stakeholders, a useful and actionable public policy agenda.”

The first of three phases of the AFAA initiative, an Expert Panel/Think Tank, began this past January when a group of nationally-recognized experts in a variety of fields – program operators, university professors, public policy authorities, specialists from both the public and private sectors, and individuals with autism – was convened to identify existing programs, current challenges and possible solutions for adults with autism spectrum disorder (ASD) in the areas of employment, residential options, recreation and community integration. Information about the results of this meeting will be posted on the AFAA website in late May.

Phase two will be a virtual National Town Hall meeting to be held on November 13, 2009. More than 1,000 participants, including caregivers, advocates, elected officials, family members, and adults with autism, are expected to take part and make recommendations for creating a policy agenda to better address the unique needs of adults with autism. The National Town Hall will be hosted by The Autism Program Service Network (“TAP”) in Chicago, with participants joining the national discussion via web-

casts from at least 14 satellite sites.

The AFAA initiative will culminate with an Autism Congress to be held in Washington, D.C. in 2010. The goal of the Autism Congress is to build a consensus statement outlining the existing challenges facing adults with autism and providing cost effective, evidence-based solutions. This statement will serve as a national agenda from which an action plan will be devised. The Autism Congress will also set forth recommendations for new public policy and changes to existing policy; empower national and regional networks to advance public policy and support of life-long living and learning with autism; and generate awareness and support through earned media. The Autism Congress will be comprised of approximately 60 participants, including individuals with autism, autism advocates, policy experts, elected public officials, public policy experts and university professors/researchers.

“It is critical that we all come together to ensure a brighter future for teens and adults with autism,” said Dr. Cyndy Hayes, founder of Global Communities of Support. “We have a tremendous challenge

Americans will come together across at least 15 cities on November 13, 2009 to create a policy agenda for addressing the needs of adults with autism. Over 1,000 people including caregivers, advocates, elected officials, family members, and adults with autism, will join the discussion to make recommendations on this important issue. The event will be orchestrated from a central hub in Chicago where a national discussion via web cast from remote locations, called satellite sites. The unprecedented scale and diversity of the AFAR National Town Meeting will attract attention to the issue and build momentum behind the policy agenda.

ahead of us that must be met with a sense of urgency and a spirit of collaboration.”

“Tackling these issues isn’t just the right thing to do for these individuals, it is also the prudent thing to do for our society,” said Ilene Lainer, executive director of the New York Center for Autism.

see Futures for Adults on page 31



YAI Autism Center

Believing in abilities.



**He has
dreams**

Hope for People with Autism and Their Families

For more than 50 years, the YAI/National Institute for People with Disabilities Network has been providing comprehensive person-centered services to people with autism spectrum disorders and their families. The new state-of-the-art YAI Autism Center combines our long tradition and expertise of serving people with autism with an early detection and treatment center; a school for children on the spectrum; family support and life planning services; and a resource library.

Our tradition of excellence make us uniquely qualified to serve your family.

**yai.org/autism
1-888-YAI-Autism**

**YAI National Institute for
People with Disabilities**
NETWORK
Celebrating Over 50 Years of Hope and Excellence

Parenting an Individual with Autism: A Roadmap

By Peter DellaBella, MD
Director of Clinical Programs
Premier HealthCare

When a child is first diagnosed with an autism spectrum disorder, his or her parents are confronted with an immense set of decisions. What do I do first? Where do I go? What can I worry about later? Sometimes, this can be overwhelming. In my experience, it is best to simplify the process as much as possible. There are indeed priorities and bases to cover first, but there is also planning that you can do to create a sort of "road map" to guide your next steps in preparing for the future.

Get an Evaluation

The first step for parents who believe that their child may have an autism spectrum disorder is to get an evaluation from a reliable source. These days, in many metropolitan settings there are one or more autism centers, complete with a team of health care specialists who diagnose and treat autism spectrum disorders (ASDs) and similar disorders. Autism centers typically offer a range of services, including psychiatric and psychological evaluations, speech and language services, occupational and physical therapies and other medical



Peter DellaBella, MD

services such as neurology, developmental pediatrics and audiology. While not every center may offer all of these, all should have a physician specializing in diagnosing and treating ASDs. Center-based approaches aren't the only option out there, but they offer the possibility for comprehensive evaluation and a treatment plan that no single clinician can do alone.

Obtain Services

After an evaluation is completed and a treatment plan is in place, the next area to pursue is getting appropriate services. These services are critical, as they target core developmental challenges in autism. The younger a child is when he or she begins to receive services, the more his or her developmental trajectory can be positively affected by intensive educational and developmental interventions.

Early intervention, which can begin at birth and last until a child reaches the age of three, includes home and community-based therapies that help a child build motor and language skills and which encourage development. I've seen many children over the years overcome developmental challenges through intensive early interventions and get onto a normal developmental trajectory.

Early intervention is typically followed by center-based preschool to help a child achieve his or her fullest potential. An important bonus of center-based preschool is that the school setting becomes a place not only for children to learn among peers, but for parents to develop skills for working with their children, meet other parents with similar challenges, and begin to develop a social network for the future. The most effective developmental services are those which are reinforced at home. Parents should meet periodically

with the teachers and therapists, find out what strategies and techniques they are using in the classroom, and learn how to use the same lessons and skill building activities at home.

Children on the autism spectrum are also eligible for special education itinerant teaching and related services at their day-care, pre-school or home. In New York State, families may obtain Applied Behavior Analysis (ABA) through early intervention and special education services if a professional evaluation deems this service necessary to the development of their child.

Find a Good Physician

The other key for meeting the challenges of autism is to find a professional who really knows autism and stick with him or her for the long haul. These clinicians are most often primary care medical professionals or specialists such as psychiatrists or neurologists, but they can also be social workers or psychologists. The key questions are: Can they recognize the range of behavioral and educational issues that typically arise in children with ASDs? Do they have a network of providers for referrals (mental health workers, occupational and physical therapists, and speech and language pathologists)? Can

see A Roadmap on page 30

YAI/NIPD Helps Adults on the Spectrum Develop Language

By Carol Stein-Schulman, MEd, BCaBA
YAI National Institute for People with
Disabilities Network

An innovative pilot program using a technique that develops language acquisition in children on the autism spectrum is proving effective with a group of young adults with limited or no verbal/vocal communication.

A decade ago, I began training staff at the New York League for Early Learning (NYL), a member of the YAI/NIPD Network that provides Early Intervention to infants and children with special needs in the Verbal Behavior approach. This particular approach is a part of the overall scientific methodology of Applied Behavior Analysis (ABA) and utilizes B.F. Skinner's analysis of Verbal Behavior. It promotes language development in children through the use of motivation and reinforcers, such as toys, snacks, or other incentives. Since staff at NYL began using this model, it has helped to enhance the communication skills of many students. Now, the same technique is having a similar effect on five adults with developmental disabilities at YAI's Kew Gardens Day Services program.

"We've developed, adapted, and modified procedures and techniques based upon the principles of ABA. The main objective of this program is to help individuals communicate their wants and



Carol Stein-Schulman, MEd, BCaBA

needs, not just with the staff who work directly with them, but with everyone," said Jimmy O'Brien, a Board Certified Assistant Behavior Analyst (BCaBA) and longtime consultant for YAI/NIPD's Education and Training Department.

When Robert joined the program in the fall of 2007, he was unable to effectively communicate his desires and needs, and often became frustrated. As a result, Robert displayed challenging behaviors which limited his ability to go out into the community. The Verbal Behavior ap-

proach, combined with Robert interacting with his peers every day and staff who constantly reinforce his positive behaviors, helped decrease his frustration and reduced many of his inappropriate behaviors.

"Now, when Robert is acting appropriately and asks if he can go to the grocery store or book store, we provide him with those opportunities," said Scott Callahan, lead Community Training Specialist at YAI/NIPD's Kew Gardens Day Services program. "He's feeling more independent because he has more control over his activities. He's more motivated, he smiles and seems happier."

Joel, who also attends YAI's Kew Gardens Day Services program, has made great progress as well thanks to the Verbal Behavior approach. Previously, he would sit and wait for an adult to ask, "What do you want?"

"Now, when he's thirsty, he asks for a drink of water," said Natali Peralta, Community Training Specialist. Joel also recently went home, expressed to his mother that he wasn't feeling well, and asked her for Tylenol - an unprecedented communication breakthrough.

Wesley is another individual to benefit from this innovative new program. Prior to attending, he tended to simply echo what someone asked him. Now, thanks to the hard work of the YAI staff, he recently said "Oreo," appropriately referring to a cookie. Then, while paging through a magazine, he said "Quaker Oats" when he came upon an advertisement for the product.

"I was so proud of him," said Licha Leonce, a Community Training Specialist/Model Mentor. "I'm proud of everyone. All of the individuals have progressed greatly and we're taking steps to see more progress."

"It's incredible to see Wesley and the others begin to advocate for themselves; even if it's asking for an M&M," said Joy Schumacher, Senior Supervisor of Program Resources at YAI/NIPD. Schumacher also recalls planning meetings with the team and talking to parents before the pilot program began. "They wanted their children to initiate communication more and to be able to accurately ask for whatever they wanted, and that's exactly what's happening as a result of this program."

Today, three of the five participants are enjoying volunteering throughout the community.

"The ultimate goal of our program is to integrate our participants into the community and to teach them the skills that enable them to engage in the numerous opportunities Queens has to offer," said Corinne Romanotto, Ph.D., Senior Coordinator of YAI/NIPD's Queens Day Service programs.

"I knew the approach would work because of the ongoing commitment of the entire team and the participants' motivation to learn," said Joe Alfonso, BCaBA, Behaviorist at the program.

see Develop Language on page 28

The Simons Simplex Collection

Questions raised by
AUTISM
 bring us together.

HELP US
 search for
 answers.



Strength in Numbers

Families connected by autism share a common bond. Their courage is inspirational, their questions are clear. What are the causes? Are there treatments? What does the future hold? Scientists hope to answer these questions with help from 2,000 families with one child on the spectrum.

13 Collection Sites Across North America



2,000 Families, One Mission

At 13 research sites across the country, eligible families with the following characteristics are answering our call for help.

- *One child with an autism spectrum disorder (ASD), age four or older*
- *One or more siblings without ASD, age four or older*
- *Both biological parents willing to participate.*

Can you help us reach our goal? Learn more at www.sfari.org

Autism Research and Treatment: An Update From the Seaver Autism Center

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

The mission of the Seaver Autism Center for Research and Treatment is to discover the causes of autism spectrum disorders (ASD) and to develop breakthrough interventions. The Center functions as a collaborative effort that combines psychiatry, psychology, neurology, molecular genetics, and neuroimaging into an integrated series of unique research programs. The Center also includes the Seaver Autism Clinical Program, which provides state-of-the-art assessment and treatment in ASD.

Genetics in the Service of Patient Care

Within the past 12 months there have been major changes in the understanding of the etiology of ASD. The Seaver Autism Center has been a founding site of several large genetic consortia, including the Autism Genome Project (AGP) and the Autism Case Control (ACC) study. These initiatives have identified several new causal genetic loci underlying specific cases of ASD. This has led to a profound shift in our thinking, such that ASD can now be conceived of as having multiple independent causes where in



Joseph D. Buxbaum, PhD

many cases the cause can be largely attributed to a specific etiological event. This perspective, called the "multiple rare variant hypothesis," raises both great challenges and great opportunities. One challenge is that this complexity may necessitate studying and/or treating different forms of ASD differently. The opportunities are that with these rare causal variants, it becomes possible to give a medical diagnosis for some cases of ASD, to have more predictive power

regarding risk of recurrence in siblings, and to think about novel targeted therapeutic approaches.

To take a concrete example from recent work carried out at the Seaver Autism Center, we identified the cause of ASD in a boy as a novel mutation in the *PTEN* gene. Once this mutation was identified, it could be concluded that this was the cause of the ASD, which immediately led to genetic counseling opportunities. The mother of the child was pregnant but, once she was informed by genetic counselors that the mutation in her affected child occurred spontaneously and would not recur, her concern about her unborn child was ameliorated. Furthermore, *PTEN* mutations are associated with tumor syndromes, and as a result of identifying the mutation, a surveillance program could be put into place.

With such causal genetic variants, one can explicitly model them in mouse and other model systems. For example, several groups have mutated the mouse *PTEN* gene and studied neurobiology and behavior of these mice, which should ultimately lead to therapies based on the insights learned from these animal models. The most dramatic example of such an approach is the recent large-scale clinical trial in Fragile X Syndrome (FXS). FXS accounts for approximately 2% of ASD cases. Detailed analysis of mouse and other models of FXS gave rise to a hypothesis

that over-expression of a glutamate receptor in the synapse underlies some of the cognitive deficits in the disorder. As a result of this hypothesis, drugs that targeted this receptor were tried in mice and other model organisms that had mutations that mimic FXS, and these drugs were shown to correct some of the cellular and behavioral deficits observed in the mice. Since January 2008, there is now a large-scale clinical trial in FXS with a drug targeting the metabotropic glutamate receptor.

In another example of progress, one of the most exciting breakthroughs in the last 12 months in regenerative medicine is the ability to take skin cells (fibroblasts) and revert them to stem cells using a procedure now called the Yamanaka protocol. These cells, called induced pluripotent stem cells (iPSCs), can then be differentiated into other cells including neurons (brain cells). This allows us, for the first time, to examine neurons from patients to tease out molecular and cellular deficits. Rather than looking at gene expression or methylation in blood cells that may have no relevance to processes in the brain, we can look at these processes directly in brain cells. This procedure may have important implications for the study of ASD that we are actively pursuing.

see Seaver Center on page 36



seaver autism center for research & treatment @ mount sinai

Committed to research. Dedicated to care

The Seaver Autism Center for Research and Treatment is dedicated to discovering the biological causes of autism and to developing breakthrough treatments.

for more information about our research or clinical program, please contact:

EMAIL theseavercenter@mssm.edu

CALL 212-241-0961

VISIT www.seaverautismcenter.org



MOUNT SINAI
 SCHOOL OF
 MEDICINE

New Autism Charity Hopes to Carve Out Its Niche, Despite Tough Times

By Debra E. Blum
The Chronicle of Philanthropy

Few nonprofit leaders would consider 2009 an ideal time to start up a charity. But Alison Tepper Singer isn't letting the recession deter her. What she believes is an important gap in autism research can't wait for the economy to rebound, she says.

Ms. Singer created the Autism Science Foundation, in Scarsdale, N.Y., in April, after resigning as a top official of one of the country's biggest and best-known autism charities. The departure was prompted by a disagreement over a hot-button topic: whether to support research into a possible link between vaccines and the onset of autism.

Ms. Singer sees inquiry into vaccines as a red herring that diverts money from other research. "That question has been asked and answered, and the answer is, No," she says. "One more dollar in that area is one dollar too many. It's time to move on and support science that will yield new and useful information."

Her former employer, Autism Speaks, in New York, believes vaccine research remains a small but important area to investigate. "If there are unanswered questions of science, we will explore them," says Mark Roithmayr, the group's president.



**Alison Singer, President
Autism Science Foundation**

Fund Raising a Challenge

Ms. Singer's new autism charity joins an alphabet soup of organizations — most of which were formed in the past decade or so — raising money, seeking attention, and tackling the disorder from different angles, based on competing ideas about its cause, treatments, and potential cures. Just

two dozen groups existed in 1999, and now there are more than 100.

Charity observers say the newest group faces the tough task of carving out its niche and getting its very specific, though nuanced, message out to a broad audience in an already crowded field. And they say how the organization fares may provide clues about whether donors have the will or the means during a recession to support so many charities. "All of the challenges a new organization faces are made more severe by this economy," says Bob Harrington, director of the strategic restructuring practice at La Piana Consulting, in Oakland, Calif. "There's a risk in splitting the potential funding community in too many pieces, especially when money is tight, but, like any new organization, it has to make its compelling case for why people should support it over the others."

Ms. Singer says she intends to keep the Autism Science Foundation extremely lean, with no paid employees and an office in the basement of her home.

The seeds of the new group were planted shortly after Ms. Singer resigned from Autism Speaks, frustrated that even its relatively small investment in vaccine studies was a waste of money and that it wasn't doing enough to counter the increasingly vocal people urging parents to skip vaccines out of concern that they cause autism. She says many parents who blame vaccines for autism choose not to

have their children immunized against other diseases, such as mumps and measles, and they often turn to alternative and, some would say, risky treatments to try to cure the disorder.

Autism is a complex brain disorder, ranging from mild to severe, that affects behavior and impairs social and communication skills. No one knows exactly what causes it — though many scientists believe it is largely genetic, with perhaps some environmental components — or how to prevent it, cure it, or fully treat it. The incidence of autism has been rising fast in the past couple of decades, with the latest estimates saying that as many as one child in every 150 has the disorder.

News Spread Quickly

Whether donors will embrace yet another autism charity remains to be seen.

Adrian M. Jones, who serves on the board of the more-established Autism Speaks, worries that the creation of new groups will simply splinter the autism field.

"Is the community better with Coke and Pepsi? I don't think so," says Mr. Jones, a managing director at Goldman Sachs. "There's enormous merit in serving the community as one entity, bringing everyone in together, driving hard in a

see *Autism Charity on page 33*



AUTISM'S FALSE PROPHETS

BAD SCIENCE, RISKY MEDICINE,
AND THE SEARCH FOR A CURE

PAUL A. OFFIT, M.D.

C O L U M B I A

Read an excerpt at www.cup.columbia.edu

"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*

"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*

"The book is a fantastic read. I recommend it to all physicians and their patients and families."

—Brian Alverson, MD, *Archives of Pediatric & Adolescent Medicine*

The author is donating a portion of his royalties to the Autism Science Foundation.



Assessing the Functions of Behavior: The Importance of Understanding Communicative Intent

By Cece McCarton, MD,
Mary Jane Weiss, PhD,
Ivy Feldman, PhD, and
Jackie Hickey, MA, BCBA
The McCarton Foundation

Autism is associated with significant impairments in language/communication, deficits in social interaction and restricted interests/stereotypical behavior (American Psychiatric Association, 1994). Learners with autism have difficulty in all aspects of communication, including receptive understanding, expressive language, and comprehension. Even in learners with a well-established capacity to communicate, there are often very significant deficits in spontaneous communications, in complex communication, and in reciprocal communication. The deficits in communication have wide ranging effects on their ability to socially interact and on their behavioral regulation.

Learners with ASDs exhibit a wide variety of maladaptive behaviors. Some behaviors are stereotypical, repetitive (e.g., rocking, hand flapping), or ritualistic (e.g., lining things up) in nature. Other behaviors include self-injury, aggression, tantrums, and property destruction. These maladaptive behaviors often interfere with effective learning. Decreasing behaviors



Cece McCarton, MD

that are dangerous, that pose interference with learning, and that are stigmatizing is an important goal of behavior analytic intervention. It is important to identify the functions of these behaviors in order to effectively intervene. There are four primary functions of behavior that have been

identified – attention (to gain attention), escape (to escape or delay demands or social interaction or a sensory aspect of the environment), tangible (to gain access to something desired), and automatically reinforcing (for intrinsic biological/sensory reasons).

Some stereotypical behaviors are automatically reinforcing, or inherently (biologically) rewarding to the individual. Often, however, the occurrence of challenging behavior is related to environmental events. Maladaptive behavior is generally maintained by either positive or negative reinforcement. Examples of positively reinforced behavior include engaging in disruptive behavior to access social attention and/or tangible items. Examples of negatively reinforced behavior include engaging in inappropriate behavior to escape from demands.

Functional Assessment

It is extremely important to understand what variables are maintaining a challenging behavior, and behavior analysts seek to identify the functions of behaviors. Determining the function of the behavior ensures that we have a complete understanding of why the learner engages in particular behaviors. Assessment of the function also enables the clinician to design an effective treatment plan. It is im-

portant that the function of the behavior be matched to the intervention chosen. If there is not good correspondence between the function of the behavior and the treatment plan, it is unlikely that the behavior will be successfully treated.

Identifying the function of the behavior has implications for the selection of antecedent strategies, for the development of replacement skills, and for the provision of contingent consequences. Antecedent strategies help to prevent the behaviors from occurring. If a learner is engaging in escape-motivated behaviors, antecedent strategies might include shorter work sessions or the interspersal of difficult tasks with easy ones. Replacement skills for an escape-motivated learner might consist of teaching the learner to request a break. Consequence strategies might include persisting with demands when challenging behaviors occur to prevent the learner from escaping in response to inappropriate behavior.

Functional assessment is crucial for the development of a behavior intervention plan with effective components. In general, the cause, or the function, of maladaptive behavior, is best determined by conducting a functional behavior assessment (FBA). Functional assessments generally involve using interviews,

see Functions of Behavior on page 32

THE CODY CENTER

FOR
CHILDREN,
ADOLESCENTS,
AND ADULTS

WITH AUTISM
AND
DEVELOPMENTAL
DISABILITIES

CLINICAL SERVICES FOR PATIENTS AND FAMILIES

- Diagnostic Evaluations
- Neuropsychological Testing
- Medication Management
- Individual and Family Therapy
- Parent Training
- Transition Consultations
- Specialty Clinics

EDUCATIONAL AND COMMUNITY SERVICES

- School Consultation
- Behavioral Intervention
- Social Skills Training
- Parent/Professional Workshops
- Respite/Recreation Program
- Family Support Services
- Resource Center

INNOVATIVE PROGRAMS

Sexuality Education, Short-term Counseling, and Reproductive Health Screening Program for Adolescents and Adults with Developmental Disabilities.
Graduate Courses on aspects of Autism and Developmental Disability, including BCBA courses, for teachers and other professionals.



THE CODY CENTER
Stony Brook University

5 Medical Drive, Port Jefferson Station • 225 West Montauk Highway, Hampton Bays
(631) 632-3070 or visit www.codycenter.org

Stony Brook University is an affirmative action/equal opportunity educator and employer.



McCarton Foundation

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

We are proud to announce our move to 331 West 25th Street. Our new home, a former Catholic school with over 30,000 square feet, will allow us to expand our current research and training initiatives and expand the McCarton School.

For more information please contact:

Harvey Weissman - (646) 277-5422

hweissman@mccartonfoundation.org

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

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
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.

Overcoming the Challenges of Assessing Young Children for Autism

By Scott Mesh, PhD, CEO
Los Niños Services

Assessing young children for autism can be very challenging. It can be quite difficult to be confident in a diagnosis of autism at the earliest ages due to many factors that I'll highlight below. At the same time it is very important for parents with concerns about their child to have an evaluation as soon as possible. Once an evaluation is complete and the parents receive a diagnosis for their child (when this is warranted), then the appropriate treatment can be provided. As we say in early intervention, "the earlier the better" the intervention to achieve the best outcomes for the child.

The main challenge of the evaluator is to answer the question, "Are you sure he/she has autism?" For the evaluator to answer, "Yes, I have confidence in my diagnosis of autism," the evaluator has to overcome the following challenges. The evaluator must be clear about the diagnostic criteria for autism and how to identify these criteria in the very youngest children, the evaluator must have sufficient knowledge of autistic disorder, the evaluator must have sufficient supervised training and experience, have adequate skill, be able to understand and sort out variability in a child's performance on the day of testing, be able to validate their own observa-



Scott Mesh, PhD

tions with the parent report, and finally be able to bring all of this information together in a diagnosis and coherent report.

Diagnostic Criteria of Autistic Disorder and Presentation in Young Children

A diagnosis of any early childhood developmental disorder is made by determining if a child meets the criteria of that

disorder as specified in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, 2000). The 3 main features of Autistic Disorder are: Impairment in social interaction, impairment in communication, and restricted repetitive and stereotyped patterns of behavior, interests and activities (DSM-IV-TR, p. 75). The challenge in assessing the youngest children for autism is to determine what is considered "normal" and to know if the child's behavior should be considered an impairment in social interaction. Let's consider evaluating an infant of 12 months for possible autistic disorder. First, one must consider what is normal. At 12 months of age a typically developing infant is highly social towards his or her primary caregiver, for example. Typical social interactions include a high level of eye contact, gesturing for adults (such as reaching for them), moving towards the primary caregiver and preverbal sounds. The infants' movements and gestures might be accompanied by a variety of sounds such as crying, screeching, sounds of delight, laughter, or perhaps a word or a word attempt such as "ma." A significant impairment in social interaction in a 12 month old infant could include one or more of the following characteristics. The infant may not make eye contact at all, or it might be limited compared with what is typically expected at the child's age. The infant might be very "quiet" and might even be considered a

"good baby" in that the baby does not fuss much. The infant might not gesture much toward the primary caregiver, or perhaps they might not mind when the caregiver is not present. Keep in mind that these characteristics are only possible indicators of an impairment in social interaction. Determining if any group of characteristics represents a difficulty in development or signs of autism is very subjective and can only be determined when there is a sufficient amount of data. The data come from 3 sources: direct observation of the infant or child, parent report, and results of formal testing. All of the data of the child's behavior must be examined and compared with what is normal and what is considered atypical. Finally, a diagnosis of autistic disorder is made if the behaviors of the child (based on a sufficient amount of data from the 3 sources) align with the criteria for this disorder. There are formal measures for autism (such as the ADOS and the CARS) and they provide information, along with observations and parent report, to help the evaluator determine the appropriate diagnosis.

The Evaluator's Knowledge of Autism

In addition to understanding how Autistic Disorder presents in the youngest children, the evaluator must know about

see *Overcoming* on page 32



Outstanding, caring professionals providing excellence through Early Intervention, ABA (autism services), SEIT-Preschool Special Education Services. Winner of Best Companies to Work For NY. **Join us.**

To learn more go to **losninos.com**



TIMOTHY MEMORIAL SCHOOL

A non-profit K-8th grade special education school

27 Creeping Hemlock Drive
Norwalk, CT 06851
Phone: (203) 354-9546
Timothymemorialschool.org
MrsKren@aol.com

Where all students find success and purpose

NYUSteinhardt

Steinhardt School of Culture, Education, and Human Development



Does your child with an autism spectrum disorder love music?

The Nordoff-Robbins Center has openings in its clinical treatment program. Our creative approach uses music to help children develop their communication and interpersonal skills.



NEW YORK UNIVERSITY

NEW YORK UNIVERSITY IS AN AFFIRMATIVE ACTION/EQUAL OPPORTUNITY INSTITUTION.

For more information, call **212 998 5151** or visit www.steinhardt.nyu.edu/nordoffrobbins

An Inside Look At the Grant Assessment Process

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

Assessing grant proposals is one of the most exciting and challenging aspects of running a not-for-profit organization whose mission includes awarding grants. The challenges of writing great guidelines, operating efficiently and reviewing requests fairly require a focused vision of the goals of the organization. There are some basic questions that apply to the community of grant givers. How can we clearly articulate what we are looking for? How can we make fair decisions while considering significant differences in capacity and approach? How do we handle conflicts of interest, and our own personal biases? These are significant questions, and their answers impact our effectiveness as grant-givers.

So how does the assessment process begin? It begins with concise and clear guidelines of the type or types of proposals your organization is interested in funding. Some organizations choose to list what they fund very specifically in a bullet-point listing with a brief description of what they are looking for. For example, the PSEG Foundation lists the following areas on their website that they are interested in funding:

Education - PSEG's main focus areas are: workforce development for K-12 or higher education; after-school programs with an educational component; math/science/technology/engineering programs; and, limited funding for special youth programs providing education to underserved populations.



Linda Walder Fiddle, Esq.

Environment - PSEG's main focus areas are: global warming and climate change initiatives; renewables; conservation; community greening; and, energy efficiency.

Community and Economic Development - PSEG's main focus is in revitalizing urban communities by supporting the efforts of community development corporations and other nonprofits that are constructing and/or rehabilitating facilities for affordable or market-rate housing, developing new businesses and entrepreneurial opportunities, creating jobs and/or developing workforces via job skills and life skills training for adults, public safety issues efforts to help protect and preserve neighborhoods.

Other organizations, such as the Bill and Melinda Gates Foundation, have a more general statement that is currently stated as "Grand Challenges Explorations," and then they list three major areas of focus and sub-categories within those. Still other organizations choose to indicate in sentence form what they are interested in funding and what they are not interested in funding. For instance, they might say, "we fund early childhood intervention programs but we do not fund the purchasing of equipment or transportation needs." These and many other forms of grant guidelines exist and it can often be quite confusing for prospective grantees.

Most grantors will tell you that they immediately do not consider any proposal that does not fall within their stated area of funding. Thus, even though prospective grantees may find it difficult to understand what a grantor will fund, if they submit a proposal that does not hit the mark that is where the assessment process will end. It falls upon the prospective grantees to get grant guidelines clarified with grantors and the best way to do that is to contact the organization by e-mail. Grant offices usually have one or two in personnel and it is very difficult and time consuming for them if they have to spend time on the phone when they can answer most inquiries via e-mail. Furthermore, most grantors will not look favorably on random and undirected questions or fishing expeditions and might perceive such inquiries negatively. At the end of the day, even if the grant guidelines are not well crafted, if your proposal is not targeted to them it is a pretty good bet that the process will end there.

Once it is determined by a grantor that your letter of inquiry or proposal

(some organizations may require one or both) is within the realm of their funding, the next step is usually a careful reading and analysis of what the prospective grantee has submitted. Sometimes there is a specific grants staff that just reads proposals. Other times, outside experts or advisors are called in and often board and advisory board members get involved in the process. Each organization generally has some framework for assessment in place. Some organizations have rating checklists where proposals are rated as to how successfully they meet the criteria set forth. The reviewing body, in this first phase of assessment, may adopt a strategic approach that furthers the mission of the organization. For instance, if an organization decides to expand its urban reach into suburban or rural communities, reviewers may favor applications that will help fulfill that goal. If a grantor wishes to support new innovations within its stated mission then that may be factor in the assessment of a program. There are innumerable factors that come into play at this point in the grant assessment process and these factors are often quite particular to a given organization.

Despite differences in how organizations review proposals, universally most grantors look at the entity applying in terms of their track record. Some typical areas a grantor may consider involve experience and expertise. Has the prospective grantee ever run such a program before? What is the prospective grantees level of expertise and how will that impact the fulfillment of the proposal? If

see *Grant Assessment* on page 36

DJF[®]
 The
 Daniel
 Jordan
 Fiddle
 Foundation

...developing programs that honor the individuality of adolescents and adults with Autism Spectrum Disorders and awarding grants to support them...

The Daniel Jordan Fiddle Foundation is a 501(c)(3) National Autism Organization. The mission of The Daniel Jordan Fiddle Foundation is to develop and award grants to residential, vocational, educational, recreational and family programs that benefit adolescents and adults with Autism Spectrum Disorders. For more information visit our website at www.djfiddlefoundation.org.

ADDRESS:
 P.O. Box 1149, Ridgewood, NJ 07451-1149
 PHONE:
 877-444-1149

WEBSITE:
www.djfiddlefoundation.org
 E-MAIL:
info@djfiddlefoundation.org



F.I.T. TOGETHER at the YMCA program developed by The Daniel Jordan Fiddle Foundation
 Pictured here: Peer mentor and program participant

ASRC

For information on how to **EXHIBIT** at our event please call us at (203) 265-7717 or visit www.ct-asrc.org

Southern CT State University
 Michael J Adanti Student Ctr
 345 Fitch Street
 New Haven, CT 06515

FREE ADMISSION

The CT Autism Spectrum Resource Center Announces

4th Autism Spectrum Resource Fair, Saturday November 7th from 12pm until 4pm

Come & speak with EXHIBITORS from

Advocacy groups, adult resources & agencies, alternative therapy, camps, community providers, consultants, financial resources, recreation programs, schools, social skills resources, state agencies & MORE! Morning workshops available.



Creating Real Opportunities For Learning

The Shield Institute creates opportunities for New Yorkers with developmental challenges to participate, develop, learn and grow.



The SHIELD Institute

The Shield operates in five locations in The Bronx, Manhattan and Queens. We invite you to learn more about our services by calling us at 718-939-8700 or visit us online at www.shield.org.

The Shield Institute is affiliated with the Jewish Board of Family and Children's Services and is a member of The United Way.

Photo by Matthew Septimus, 2008

At The Shield, we have special expertise supporting children and adults with autism spectrum disorders and their families.

Special education, clinical and transition services

We offer preschool, integrated preschool and school programs and a wide variety of day habilitation, diagnostic, clinical and transition services.

Augmentative Communications Technology Center

The Center offers assistive technology, facilitating communication for individuals with language impairments.

Pure Vision Arts studio and exhibition space

The PVA studio provides artistic opportunities for adults, as well as career support for professional and emerging artists. Located in the heart of Chelsea, PVA is an important resource for artists on the spectrum.

Visit the studio online at www.purevisionarts.org.

www.shield.org

Supporting Parents in Their Search for the Whole Picture

A Multidisciplinary Team Approach to Assessments for Individuals with Autism Spectrum Disorders

By Halley Ceglia, LMSW,
Georgianna Reilly, BSc, and
Shana Nichols, PhD
Fay J. Lindner Center for Autism and
Developmental Disabilities

For many families and caregivers, entry into the world of autism spectrum disorders (ASD) first begins as part of their search for an accurate diagnosis – the answer that can help explain their child's behavior, strengths, and weaknesses. This "assessment process," which for some families can take years and may involve appointments with numerous professionals with differing opinions, is often reported to be both stressful and overwhelming (Brogan & Knussen, 2003; Goin-Kochel et al., 2006; Osborne & Reid, 2008). Early in the process, families are faced with many difficult issues about which they need to make decisions including acknowledging the need for an assessment, and where to take their child for an evaluation. Other questions rapidly follow, and can easily paralyze even the most organized and determined of parents. What services does my child need at school, at home, and in the community? Where can I learn about what services and resources are available? When will I have time for all of this? How can I trust an-



Georgianna Reilly, Shana Nichols, and Halley Ceglia

other professional after the negative experiences we've had?

Different approaches to ASD diagnosis and assessment are practiced in the professional community and they vary in their extensiveness. Many parents have reported receiving a diagnosis in their

primary care practitioner's office after a fifteen minute meeting, whereas other families have participated in global assessments at specialty clinics. The very nature of ASD as a complex syndrome disorder implies deficits in multiple developmental areas, each of which requires

careful attention. In addition, the variability that is observed across individuals with ASD, and the subtleties of symptom presentation, can make the diagnostic process challenging. For these reasons, a *comprehensive evaluation* most often best meets the needs of families in acquiring a better understanding of their child and informing interventions.

A comprehensive evaluation requires a multidisciplinary team of professionals who are trained in conducting diagnostic assessments and in evaluating many areas of functioning. Typically, a *Multidisciplinary Team Assessment* involves a diagnostician (often a psychologist, psychiatrist, or developmental pediatrician), a speech-language pathologist, and a social worker. Other members of multidisciplinary teams may include an occupational therapist, a physical therapist, and a neurologist. The benefit of a multidisciplinary evaluation is that team members work together and bring their specific discipline's expertise to not only develop a comprehensive understanding of the referred individual, but also to provide recommendations for education and treatment across all domains of functioning. Below we review the steps that are a part of participating in a comprehensive diagnostic assessment.

see *Supporting Parents* on page 38

Diagnosing Asperger Syndrome and High Functioning Autism in Adulthood: Current Resources and Challenges

By Laurie Better Perlis, PsyD,
Nicole Elliott, EdM, and
Shana Nichols, PhD
Fay J. Lindner Center for Autism and
Developmental Disabilities

At our clinic in Brookville, NY, we receive phone calls, emails and letters from individuals across the country and around the globe looking for information related to diagnosing Asperger Syndrome (AS) and High Functioning Autism (HFA) in adulthood. We often hear strikingly similar accounts from the individuals themselves or concerned family members who come across an article, television program or website that resonates with their experiences in a profound way. We also hear about the frustration of being told that there are no local resources for that

individual or that diagnostic centers serve only children and adolescents.

There are specific challenges to the diagnosis of ASDs in adults on the "higher functioning" end of the spectrum that lead them and their loved ones to encounter these and other obstacles. Many such adults whom we have met in our clinic have experienced relative success in academic, occupational and social domains and have developed sophisticated strategies to compensate for underlying challenges. As a result, these individuals may be misdiagnosed with other mental health difficulties such as anxiety and depression or may have never received a diagnosis at all. Several of the major challenges to diagnosing ASDs in this underserved group of adults are as follows:

- Limited number of professionals with sufficient expertise and training in the

assessment of ASDs in high functioning adults

- Limited availability of reliable and valid diagnostic tools designed for bright, verbal adults
- High functioning adults with ASDs often present with a profile of impairments that is inconsistent with current DSM-IV diagnostic criteria
- High functioning adults may have been misdiagnosed or may present with co-occurring mental health difficulties that complicate diagnosis
- The History of Assessing ASDs in Adulthood

The assessment of adults with suspected Autism Spectrum Disorders

(ASDs) has been an area of scientific interest since at least the 1960s (Matson, 1989). However, a search of the relevant literature reveals a scarcity of information specific to assessment in adulthood, particularly when compared to the child/adolescent research. The availability of reliable and valid diagnostic tools for assessing ASDs in adulthood is particularly limited. It is not surprising to find such a discrepancy given that early detection and intervention has been shown to improve long-term outcomes in ASDs (Matson & Minshawi, 2006). However, as research demonstrates that youth diagnosed with ASDs continue to display marked functional impairments into adulthood, assessment of ASDs in adulthood has become an important topic of consideration.

A major challenge to the accurate

see *Adulthood* on page 43

"Hope, Healing & Possibilities"

Autism Edmonton Biomedical Conference 2010

Edmonton, Alberta, March 26th - 27th 2010



www.autismbiomedical.com 780.416.4448

*View Our Award-Winning Publication
Devoted to Providing Science-Based
Mental Health Education to the
Community at www.mhnews.org*

The Importance of Neuropsychological Evaluation for Students and Individuals on the Autism Spectrum

Ilene Solomon, PhD
Institute for Cognitive Diversity
Bank Street College of Education

The decision to have a child or adolescent evaluated is frequently a difficult one for parents to make. Parents wonder if their child is just going through a phase or if their child is developing at a slower pace and will catch up eventually. Often time passes and the child or adolescent has not outgrown the behaviors or the academic problems that were worrisome. At such times parents may decide to have their child evaluated. Because there are many different kinds of evaluations and evaluators, it can be difficult for parents to know how to proceed. This article will familiarize parents and individuals with the purpose and benefits of neuropsychological evaluation.

Parents of children with high functioning autism (HFA) and Asperger Syndrome (AS) are often puzzled by the fact that their children appear to be so smart and competent academically, yet struggle in school. Children with high functioning autism may have subtle learning issues in domains such as reading, writing, and math. Many times however, these children have little difficulty in these academic areas yet they are experiencing problems



Ilene Solomon, PhD

in school. It is often the behaviors that support academic success (organization, follow-through, remembering, flexibility, persistence, focus, social skills) which are known as executive functioning skills that are weak or deficient in children (and adults) with high functioning autism. Parents are often frustrated by what they per-

ceive as "laziness" in their child. What looks like "laziness" or lack of caring may actually indicate the presence of subtle brain dysfunctions which are developmental in nature. It is important to identify these brain related problems so that appropriate academic and behavioral interventions can be implemented in a timely manner. When effective interventions are put in place early, it is less likely that problems will snowball into more severe emotional and behavioral difficulties (Silver, CH. et al. 2006).

It is the province of neuropsychology to understand how problems in executive functioning interact with other weaknesses or deficits to impede academic and life success. Executive skill deficits may interfere with a person's success in life beyond the academic years. It becomes difficult to function on a job if one can't organize and prioritize tasks or has little ability to "get going" or follow through on an assignment. In addition to understanding deficits, a neuropsychological evaluation can also delineate a pattern of strengths which can help form the basis of appropriate compensatory skills.

What Is a Neuropsychological Evaluation?

Neuropsychology is the evidence-based study of brain-behavior relationships. A neuropsychological evaluation is

a systematic assessment of these relationships. Neuropsychology is a specialty within the broader field of clinical psychology. It is conducted by a neuropsychologist, a psychologist who has gone on to have extensive specialized training in neuropsychology. School psychologists are not typically trained in neuropsychology nor do they have the time to conduct these extensive evaluations.

For some children and adolescents school based evaluations may be adequate for identifying their learning differences. However, for other students, common academic evaluations and learning strategies are not sufficient to identify the underlying problems or to formulate effective educational plans. Many students have had repeated school-based evaluations or generic psychological/behavioral assessments that never make clear what the underlying problems are (Silver CH., et al., 2006). It becomes difficult to formulate effective strategies without a clear and detailed picture of those problems. School-based evaluations often rely heavily on summary scores. A child's abilities are more than the sum of his or her scores. Scores do not identify a child's abilities. Scores merely tell us how a child performed on a task relative to same-aged peers. Over-reliance on scores, without

see Evaluation on page 44



THE FAY J. LINDNER CENTER FOR AUTISM & DEVELOPMENTAL DISABILITIES

is proud
to announce its new affiliation and expansion with AHRC Nassau.

New location:
 189 Wheatley Road, Brookville, NY 11545

To Schedule an Appointment: (516) 686-4440
 Visit us online at: www.FayJLindnerCenter.org

Range of Services:

- Comprehensive and Specialty Evaluations
- Cognitive and Behavioral Programming
- Social Skills & Communication Training
 - School Consultation
 - Speech Language Services
- Social Work and Counseling Supports
 - Psychopharmacology
 - Sexuality and Growing Up Clinic
 - Girls with ASDs Program
 - Group Socials
- 2-6 year old Early Bird Assessment Clinic
- Participant in National and International Level Research



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 problems with give and take in conversation?
- Shows "odd" behaviors and mannerisms?

Looking for information and support?

AHA Association can help!

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

(888) 918-9198

Asperger Syndrome and High Functioning Autism Association (AHA) Inc.

Website: www.ahaNY.org Email: info@ahaNY.org

AHA Association is a 501(c)(3) Not-for-Profit Corporation

Issues and Considerations in Assessment and Intervention of Mental Health Disorders in Children with Autism Spectrum Disorders

By **Caroline I. Magyar, PhD** and
Vincent Pandolfi, PhD

Studies suggest that a relatively high percentage of children with an autism spectrum disorder (ASD) also display co-occurring mental health disorders (MHD). For example, specific disorders such as depression, anxiety, Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder, and general behavioral disorders such as aggression and self-injury have been reported at rates of 65% - 80% (e.g., DeBruin et al., 2006). A rate of 72% was reported in a recent study of school-aged children aged five to 17 years (Leyfer et al., 2006). It has been reported that MHD often goes undetected in the general pediatric population (Burns, et al., 1995; Leaf et al., 1996) and therefore, many children do not receive needed treatment.

Despite the statistics that many youth with ASD evidence MHD, they may be especially at risk for under-identification for a co-occurring disorder. These disorders might not be readily identified by community practitioners. Further, some evidence suggests that those children with an identified co-occurring MHD might not receive the psychosocial and/or psychiatric interventions necessary to treat and/or manage these disorders (Magyar &



Vincent Pandolfi, PhD and Caroline I. Magyar, PhD

Pandolfi, 2009). Failure to identify and treat co-occurring MHD may moderate a child's response to ASD specific treatment and result in poorer outcomes (Howlin et al., 2004), greater family burden, and lower quality of life (e.g., Lee, Harrington, Louie, & Newschaffer, 2008).

Although much more research is needed, it is likely that several issues raise the risk for the under-identification of MHD in this population. These issues have implications for assessment and treatment practices for youth with ASD and co-occurring MHD.

Issues

One issue related to under-identification may involve child-specific factors. Given the nature of their disability, many children with an ASD are not able to report accurate information pertaining to alterations in thoughts, feelings, behaviors, level of personal distress and functional impairment. All of this information is critical in assessing for MHDs. Even in those with sufficient language, clinicians may have difficulty understanding idiosyncratic expressions children may use to communicate various needs or emotional states. Third party report and direct observations become an important part of assessment; however, neither provides information regarding the child's subjective experiences. Thus, in many instances, a complete accounting of a child's thinking and emotional adjustment may not be possible and the clinical profile may not adequately map onto established diagnostic categories.

A second issue is the relative lack of research-based knowledge of how co-occurring symptoms and disorders may present. Unfortunately, research has yet to determine the extent to which developmental factors such as social-communication, language, and intellectual

see Mental Health on page 40

Personal Experiences in the Teaching of Children with Autism Spectrum Disorders Over a Fifty Year Period

By **Shirley Cohen, PhD**
Hunter College of the
City University of New York

It is exactly 50 years since I became a teacher of children with autism. As I approach retirement I would like to share my personal experiences and perspective on educational intervention for children with autism spectrum disorders, particularly in and around New York, over the course of that period. A few dramatic changes have taken place during that period although most changes have come slowly and in tiny steps.

I have always been drawn to individuals who are different and needy in some ways, and it was no different when I became a teacher. There was no protection for children with disabilities back then as I learned in my first teaching assignment, which took place in Camden, New Jersey. At the outset my principal directed me to keep good anecdotal records because there would be a boy in my class who had been expelled from the first grade after six weeks the previous year, and she wanted to make sure that the same thing would happen to him in the upcoming school year. Today that boy would likely be identified as having an autism spectrum disorder. We got along, that child and I and the other students. He was accepted and he



Shirley Cohen, PhD

learned; but I knew that no good would come to him at that school. The principal had not been able to expel that boy when I was his teacher, but she had refused to promote him, and I knew that her goal was to expel him the following fall when he would have a different teacher.

When I returned to NYC after that year I requested assignment to a class for "emotionally disturbed children;" there

was no separate educational designation of autism then. I chose to teach at a partly residential school and research center where I was assigned to work with five and six year old children with whom I had fallen in love at first sight when I visited their classroom. Most of the children I worked with over the next three years carried a designation of autism based on psychiatric evaluations, but some went by other labels— psychotic, schizophrenic, primary behavior disorder with neurological involvement—and there were no guidelines for teachers working with such children. I searched the literature and took graduate courses but could not find any literature specific to teaching children with autism and could only find a handful of books on "emotionally disturbed" or "neurologically impaired" children that were at all useful; and my coursework was in general only tangentially helpful.

My first year of working with these children was extremely stressful because I desperately wanted to help them but didn't know how to help some of them. Neither did the visiting principal assigned by the Board of Education whose sole contribution was to give me a jar of gum drops cut into quarters to use with a boy who hid under the table, under blankets, under newspapers, and under my skirt whenever he could. It certainly didn't help anyone that I was the only adult in the classroom

or that just as I had started to make some headway with one child an additional child with severe autism was added to the five already there. There were no assistant teachers or paraprofessionals or co-teachers then. That first year I discovered "task analysis" by myself, along with other strategies that I had not learned in my teacher training at either the undergraduate or graduate level. I wrote my first article, "How to Alleviate the First Year Shock of Teaching Emotionally Disturbed Children" (1966) after that first year to share some of the strategies I had worked out for myself.

By 1994 I had been at Hunter College for over 20 years—as the Director of a Special Education Development Center, chairperson of the Department of Special Education, and Associate Dean of Programs in Education, when something happened to bring me back to autism. Mothers began calling me to ask for students to work with their autistic children in their homes. Ivar Lovaas (1987) and Catherine Maurice (1993) had promised these parents hope for a cure or something close to it through applied behavior analysis (ABA). While professionals argued about the validity of what Lovaas claimed, parents viewed Lovaas as a savior, and they wanted what he offered. By contrast,

see Personal Experiences on page 41

Diagnosing Autism Spectrum Disorders

By Elizabeth Roberts, PsyD and Ruth Nass, MD
Child Study Center
NYU Langone Medical Center

Autism spectrum disorders (ASD) are characterized by impairments in the areas of communication, social interaction, and range of routines and interests. The frequency has increased dramatically in the past two decades as the extent of symptoms required for diagnosis has been broadened. The current prevalence of ASDs is now estimated to be as high as 1 in 150. ASDs are currently categorized in the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) as autism, pervasive developmental disorder-NOS (PDD-NOS), and Asperger's Disorder. ASD subtypes differ with respect to age at diagnosis. Even though concerns typically surface in all three groups prior to the age of three, the average age for formal diagnosis of autism is 3 to 4 years, whereas for Asperger's it is 11 years. This is largely due to the lack of obvious early delays in cognition and language in those with Asperger's. Higher order difficulties in language and cognition become apparent later in academic settings in which advanced comprehension is more important.

Although Asperger's was described in 1944, the disorder was largely ignored until 1980. The "spectrum" concept has



Ruth Nass, MD

emerged over the past fifteen years. Clinicians and researchers recognized that there were children who exhibited the same triad of impairments as children with clear autism but varied widely with respect to language, intellectual ability, social competence, and repetitive behaviors. These variations resulted in dramatic differences in symptom expression. For example, the social skills deficits seen in a severely autistic child who is unable to



Elizabeth Roberts, PsyD

initiate the most basic social overture such as brief eye contact is on a continuum with those of a less affected child who has some motivation and capacity to interact but may do so around repetitive interests. Individuals with Asperger's are on the same continuum; they often seek relationships more actively and successfully but find, without help, that understanding relationships and establishing intimacy are lifelong challenges. All three share

impairment in social interaction, but severity and expression differ widely. Simple, repetitive play with a piece of string by a child with autism is on a continuum with extensive knowledge of intricate time-pieces in someone with Asperger's with respect to the symptom cluster of repetitive routines and narrow interests. Language deficits also vary widely. Language may be absent, delayed, or mechanically normal but pragmatically impaired.

Screening for ASDs

There are a number of autism-specific screening tools designed to be used in physician's offices and school settings. Their purpose is to rapidly and cost-effectively identify children who are at risk of having a problem. A few examples are the Checklist for Autism in Toddlers (CHAT), the Autism Behavior Checklist (ABC), the Childhood Autism Rating Scale (CARS), and the Social Communication Questionnaire (SCQ). Screening tools are not used to make a diagnosis. Children meeting threshold criteria on screening tools are then referred for a comprehensive evaluation.

Physician Assessment

Although ASD is often given as a diagnosis, it is in fact a set of behavioral

see Diagnosing on page 42

AUTISM CONFERENCES ACROSS AMERICA!

Keynoted by one or more of these International leaders speaking on social skills, behavior, medical options and more!



Full Length HBO movie on Temple's life to be released soon!

Dr. Temple Grandin
World's Leading Autism Author
(Herself Diagnosed with Autism)



Dr. Jed Baker
Recently Featured on ABC Nightline!



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

Huntsville, AL Oct 5, 2009
Cincinnati, OH Oct 7, 2009
Orlando, FL Oct 9, 2009
McAllen, TX Oct 15 & 16, 2009

Akron, OH Oct 30, 2009 **CEU**
Kansas City, MO Nov 19 & 20, 2009 **Credits**
Sacramento, CA Dec 11, 2009 **Offered!**

Limited Room. Register Early!

FOR MORE INFORMATION: www.FHautism.com 800.489.0727



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.

Facing the Challenges of Higher Education for Students on the Spectrum

By Judith Cohen, PhD, JD,
Adam Wittenstein, MA, MS,
Stephen Shore, EdD,
and Mitch Nagler, MA, LMHC
Adelphi University

The sections that follow discuss the challenges and recommendations for students on the spectrum who are in college. Included in this article are: a narrative about how a student on the spectrum navigated college without services, a description of a support program at Adelphi University, and finally a discussion of the importance of self-advocacy by students on the spectrum to ensure that supports and modifications will maximize their opportunities for succeeding.

The Unsuccessful "Sink or Swim" Model of No Services and Recommendations for Improvement
By Judith Cohen and Adam Wittenstein

A curious sight struck me. Two people were standing outside my college office and one was a heavy-set young man walking in circles. Next to him was a woman who I assumed to be the fellow's mother. They were a prospective student and his mother who had an appointment for possible admission into a teacher-education program that I co-coordinated. I knew that this young man wanted to be a secondary



Stephen Shore, Judith Cohen, Adam Wittenstein, and Mitch Nagler

math teacher and that his school history indicated special education settings from early childhood through adolescence. I thought the behavior of the fellow very unusual, but shortly thereafter we began our interview and thus began my education about high functioning autism. During our interview, "Michael"* told me that he was diagnosed with classic autism in early childhood and I was startled to

learn about an individual with autism who had extraordinary academic talent (For the full story of this young man's life read *Succeeding with Autism: Hear my Voice* by J.Cohen, Jessica Kingsley Press, 2005. *For the book this young man chose to be identified by his middle name, Michael).

I met Michael in the late 1990's and while I was aware that he attended only

self-contained, special education schools all of his life, he did have a very impressive academic record and very high SAT scores. Michael entered college a "pioneer," as prior to this time very few autistic students were academically successful enough to go to college. In fact, Michael was admitted to the Honors College with a full scholarship. Today, due to the increase in students diagnosed on the spectrum at early age, their inclusion in general education programs, the many support programs they receive, their academic success, and high potential many more students on the spectrum are entering college. Consequently, programs are being developed for this new group of students who often, unlike Michael, self identify and are provided with services to promote their academic and social success.

When Michael entered college, he did not self identify, nor did he seek any modifications or services. His desire was to be "a regular college student in a regular school" and avoid what he perceived to be the stigma of being special. He entered college through what might be called the "sink or swim" model, but luckily he was a good swimmer and really liked the water!

Following is a list of some of the academic and psycho-social challenges that Michael faced in college:

see Challenges on page 34

ASAT
Association for Science in Autism Treatment

Real Science, Real Hope

Celebrating 10 Years
Education
Advocacy
Information

www.asatonline.org. An excellent source for parents, professionals and the media.

ASAT proudly announces the return of its quarterly newsletter . . . Summer 2009

Science in Autism Treatment

- ✓ Featured articles by leading advocates for science-based treatment
- ✓ Clinical Corner responses to frequently asked questions about autism treatment
- ✓ Reviews of published research to help consumers and professionals access the science
- ✓ Discussion of accurate and inaccurate portrayals of autism and its treatment by the media
- ✓ Interviews with professionals advancing science-based treatment and confronting pseudoscience
- ✓ Book Reviews
- ✓ Detailed summaries of specific treatments for autism
- ✓ Guidelines to help consumers access effective treatments
- ✓ and even more

Visit our website at www.asatonline.org today.

Sign up to receive the Science in Autism Treatment newsletter at www.asatonline.org/signup.

Understanding the Relationship Between the Diagnostic Features of Autism and the Process of Functional Assessment and Intervention Development

By **Stephanie Contrucci Kuhn, PhD, BCBA-D, Co-Director, ABA Program Westchester Institute for Human Development**

There is a vast amount of information available regarding autism. This information is constantly changing and evolving with the dissemination of new research. This advancement and progression is a very positive and exciting thing for families with a child diagnosed with autism, but it can be very overwhelming. A compounding factor to the already great needs of a child diagnosed with autism is the likelihood of problem behavior. Children with a diagnosis of autism or a related disorder (i.e., pervasive developmental disorder, NOS; asperger's disorder) are more likely to display problem behavior than typically developing peers and peers with other developmental disabilities (Hartley, 2008). The very behaviors that are described within the diagnostic criteria provide insight into why these behaviors develop and maintain over time. The core features of autism are deficits in social interaction, deficits in communication, and restricted repetitive patterns of behavior. In the absence of skills or ability to appropriately interact with others, inappropriate social behaviors such as touch-



Stephanie Contrucci Kuhn, PhD, BCBA-D

ing belongings of others may develop. Similarly, in the absence of the ability to communicate for attention, food, toys, assistance with tasks, or a break from tasks, inappropriate behaviors such as self-injury and aggression may occur as way to communicate. Likewise, restricted repetitive patterns of behavior such as self-

injury (i.e., head hitting, hand mouthing) and/or stereotypy are often present.

Problem behaviors consist of behaviors that limit or interfere with someone's ability to participate in activities in the home, participate in activities in the school, participate in activities in the community and/or, interact with others. These behaviors may consist of stereotypy (e.g., hand flapping, scripting, rocking), self-injury (e.g., hitting self, biting self), aggression (e.g., hitting, kicking, scratching, biting others), disruptive behavior (i.e., property destruction, banging on surfaces), elopement, tantrums, and pica among others. It is known that the majority of problem behaviors occur to access reinforcement in the environment (Iwata et al, 1994), for example to access attention and/or leisure items as well as to avoid or escape from instructions. It is hard to believe that just a short time ago, little regard was given to why problem behavior was occurring (i.e., purpose or function). All of that changed with the publication of an article published by Iwata and colleagues entitled, "Toward a Functional Analysis of Self-injury" (Iwata et al 1982/1994). Of course, this article was preceded by literature that set the path for this study to be conducted. But, this article is considered the seminal publication.

Assessment should guide intervention, and it has been demonstrated that inter-

ventions based on the identified function of the behavior are more effective than arbitrarily derived interventions (Matson et al, 1999). When the goal is to reduce problem behaviors, identifying effective interventions is of primary importance. Within functional assessment there are indirect assessments, descriptive assessments and experimental analyses. Indirect assessments consist of behavior rating scales, where the function of behavior is inferred based on information obtained from interviews with informants. With descriptive assessment, correlations between antecedents and consequences are made based on direct observation of the behavior in the natural environment, and function is subsequently inferred. Experimental analysis (i.e., functional analysis) involves direct manipulation of both antecedents and consequences in order to identify the function of problem behavior. In most situations, a combination of indirect and descriptive assessment is used. Experimental analysis involves a high level of training and resources, and is typically conducted when initial attempts at treating problem behavior are unsuccessful or when the problem behavior is severe.

There are several categories of reinforcement that are commonly included within functional assessment. These

see Functional Assessment on page 42

The Three Symptom Domains of Autism Spectrum Disorders

By **Patricia Towle, PhD, Psychologist and Training Supervisor Westchester Institute for Human Development**

The diagnosis of an autism spectrum disorder is based on criteria set forth in the Diagnostic and Statistical Manual of Mental Disorders (the DSM), a medical manual for classifying psychiatric and neurodevelopmental conditions. Published by the American Psychiatric Association, it covers conditions, disorders, and syndromes occurring in both children and adults. Here it is established that to meet the criteria for one of the "Pervasive Developmental Disorders," which includes Autistic Disorder, Asperger syndrome, and PDD-NOS, the child must have a profile of symptoms that includes clear indicators from three symptom areas or domains. Thus, an autism diagnosis is never made from one single behavior or even a handful; it is made from a profile of behaviors across the three domains.

Understanding these three symptom domains is important for two major reasons. The first is that to understand *why* someone has diagnosed your child with autism (or if you want to determine this for yourself), you will need to understand these "core symptoms."

The second reason is to understand the basis for intervention. The behaviors pin-



Patricia Towle, PhD

pointed to diagnose the condition are the same ones that are targeted for intervention. As importantly, the behaviors used to diagnose can also be understood to represent core areas of functional competence. The goal of intervention is to create

and strengthen foundational social, communication, and cognitive competence, not just teach a list of random behaviors. Understanding the three domains is to understand more about how direct treatment, educational supports, and environmental adaptations can help your child move forward in skills and independence.

The three symptom domains apply to the whole age range, from infancy and preschool, to school age, adolescence, and adulthood. However, the component behaviors take different forms across this large age range. In addition, children "on the spectrum" range very widely in how severe their disability is. So, although the same core symptoms exist, the specific behaviors that represent them can be present or absent to some degree depending on the particular child.

The First Symptom Domain: Social Interaction

From a very early age, really from birth, young children have ways to get the attention of adults, to respond to social input from adults and others, and to keep this interaction going for a while. When they are the youngest, under 8 months, they cry, gurgle, make sounds, make eye contact, wave their arms and legs and wriggle their bodies. As they get older - from 12 months on - every strategy they use gets more specific and differentiated. They have different noises, facial expres-

sions, and gestures to get a specific emotional message across. They pick up social messages from others with increasing sensitivity and respond accordingly. With this greater social communication skill, they can get social interaction going and keep it going for longer periods of time. The function of this set of skills is to create relationships with others that meet caregiving needs as well as social and emotional needs in the form of ongoing relationships that nurture, teach, and change in a feedback system between the partners in the relationship.

Some specific behaviors signal fundamental differences and difficulties in social functioning related to ASD in young children. They include reduced eye contact when the child is involved with others, as well as reduced "monitoring" of adult face and eyes; less variation in emotional expression on the child's face, making it more difficult to read his emotions; a reduced amount of emotion or affective sharing (glancing up when a child is happy or excited to share a joyful expression with their social partner for a moment); inattention to what others are doing and relative inability to imitate; low ability and tendency to take turns in an activity; reduced social initiation in the form giving a look, handing a toy, vocalizing and making eye contact at the same time, and so on, for purpose of getting the

see Symptom Domains on page 45

Chapel Haven's Asperger's Students Focus on Social Communicative Competency to Lead Independent Lives

Staff Writer
Autism Spectrum News

A stumbling block for young adults with Asperger's Syndrome is often their inability to recognize nonverbal cues such as facial expressions and gestures or to navigate the social norms of conversation.

Chapel Haven's Asperger's Syndrome Adult Transition (ASAT) program, now in its fourth year, bridges that gap by focusing on social communicative competency as its overarching theme.

With the help of certified speech and language pathologists and staff trained in the complexities of Asperger's Syndrome, students in this unique, 24-month residential program learn critical skills such as how to interpret facial expressions and gestures, engage in reciprocal conversations and appreciate another person's point of view. The training ranges from practice in how to pick up the phone and make a social plan to using videotaping and role playing for practice job interviews. Students are coached in speech clarity, speed, phrasing, correct use of formal and informal language, figurative language and irony.

Then, with the help of staff, students practice these skills in "natural set-



Chapel Haven's ASAT Program

tings," such as learning how to speak up in a college level class or negotiating with a roommate. Along the way, their confidence grows.

"SCC groups have really helped me a lot," said Ariana Habib, 21, originally from New York and an ASAT graduate who is now part of the supported living program at Chapel Haven. "My eye

contact has improved. I show interest in other people. I am more empathetic toward friends. I have improved in my ability to terminate conversations appropriately and initiate questions in conversations."

Ms. Habib is a freshman and a public health major at Southern Connecticut State University. When she first started taking classes at SCSU, she recalls that "I did not know how to add or drop a course. I took the wrong classes and did not know how to ask for help from the Disability Resource Center. I did not know how to watch for cues, which professor I should pick, and who would be appropriate to my needs." Now, thanks to her training, "I am able to advocate for accommodations. I'm able to talk to my professors and access resources like the campus writing center, the technology lab and career services."

Fran Dolan, parent of John Dolan, who graduated from the program last year and is now living in the New Haven community, said the social training has helped her son in many ways. She recalls that when he first started the program, he would enter conversations in social settings by asking the same question over and over—"do you like pizza?"

"He would have zero timing on that. It would be disconnected from anything

going on and he would interrupt," she recalled. "As he has gained competence through the program at Chapel Haven, he has become confident enough to go up to a group, listen and comment on what is being said and his timing has improved."

The biggest change Ms. Dolan has seen in her son is his ability to initiate.

"Taking responsibility is really difficult for a lot of these kids," she said. "During John's younger years there were so many issues to focus on that when it came to making social plans (which John really wasn't interested in doing to begin with) I would handle all the arrangements. My goal at that time was to get John into social settings with peers so he would have role models. When John entered the ASAT program the skill of making social plans and everything connected with that, timely planning, making phone calls, compromising, budgeting and follow-through had to be taught. We are thrilled with John's progress in this area."

John is enrolled for a second year at Southern Connecticut State University, and even more impressive, has taken the initiative to join in social activities with other students there. "The level of responsibility in a college class versus high

see Competency on page 46

**AUTISM SPECTRUM DISORDERS
and RELATED DISABILITIES**

INTERVENTION, TRAINING, and CONSULTATION SERVICES

WESTCHESTER INSTITUTE FOR HUMAN DEVELOPMENT
University Center for Excellence in Developmental Disabilities

APPLIED BEHAVIOR ANALYSIS
Consultation and Treatment for Challenging Behaviors

School district contracts, Home-based and Client-centered services

914.493.7070 | ABAprogram@wihd.org



TRAINING IN EARLY CHILDHOOD DIAGNOSTIC ASSESSMENT IN ASD

Inservices, Workshops, and Consultation for Early Intervention and Preschool providers, administrators, graduate trainees and parents

914.493.8212 | ptowle@wihd.org

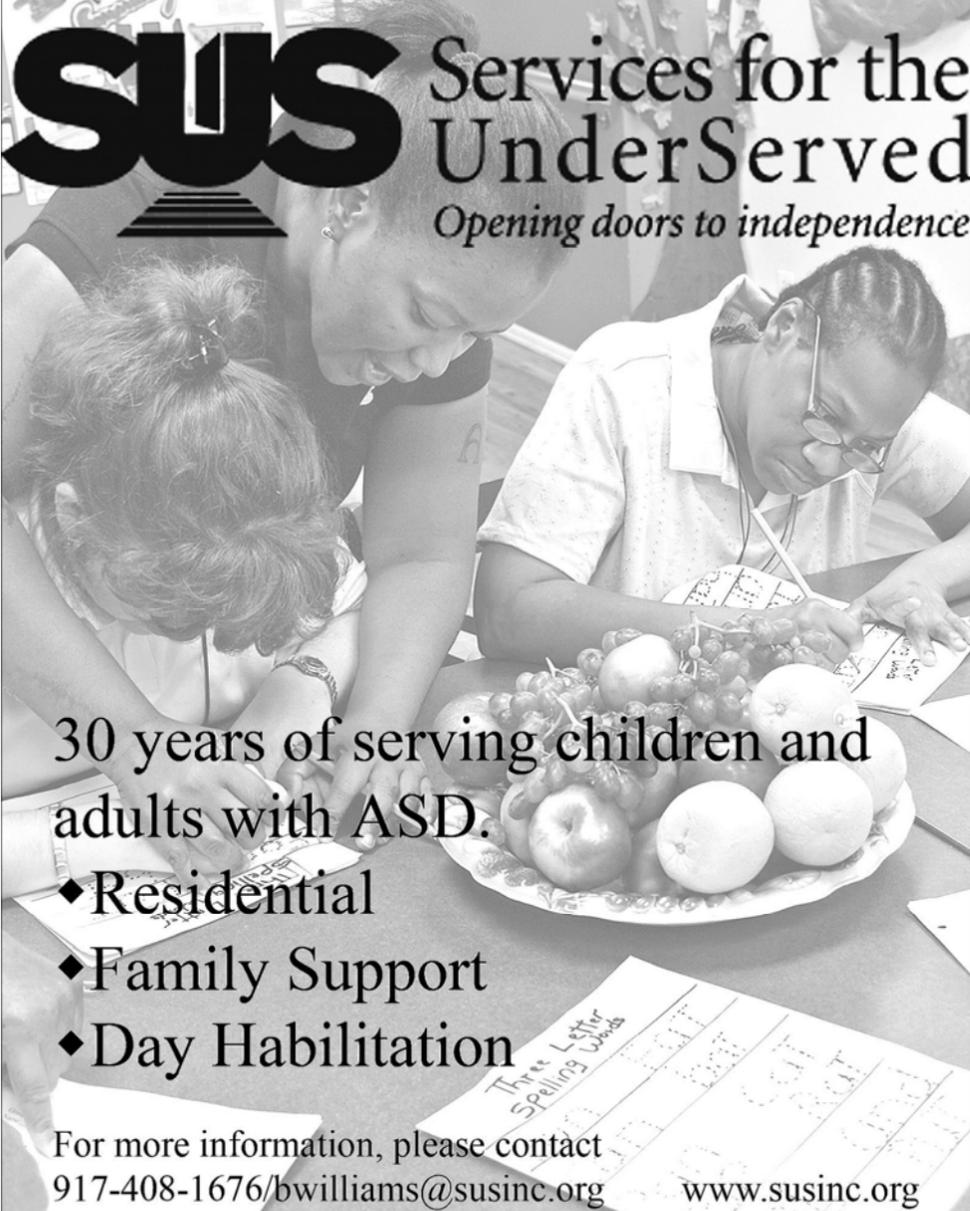
REGIONAL CENTER FOR AUTISM

Training for school districts and agencies in the lower Hudson Valley region focusing on Positive Behavior Strategies and Assistive Technology

914.493.7373 | www.wihd.org/regional_ctr_autism.html



WESTCHESTER INSTITUTE FOR HUMAN DEVELOPMENT
Cedarwood Hall | Valhalla, New York
914.493.8150 | www.wihd.org



SUS Services for the UnderServed
Opening doors to independence

30 years of serving children and adults with ASD.

- ◆ Residential
- ◆ Family Support
- ◆ Day Habilitation

For more information, please contact
917-408-1676/bwilliams@susinc.org www.susinc.org

Clinical Evaluation from page 1

Although standard scores might not be obtainable for the individual in question, the information gathered is quite useful for knowledge of strengths, weaknesses, behavior, and mental age. If a nonverbal measure of intelligence is used (e.g., the *Leiter International Performance Scale, Revised*; Roid & Miller, 1997), caution should be taken in interpreting results solely from one area of ability.

In special cases, additional neuropsychological or achievement testing is merited in order to identify any specific concerns related to attention, concentration, impulsivity, executive functioning, memory, motor planning, sensory-perceptual, or learning vulnerabilities. In such cases, the appropriate comprehensive assessments are indicated, usually upon referral.

Assessment of Adaptive Functioning

Another essential component of the diagnostic evaluation is assessment of functional or “real-life” skills. More often than not, individuals across the spectrum have great difficulty applying their repertoire of skills to naturalistic and daily contexts, regardless of level of ability or impairment. In fact, research has repeatedly shown that adaptive skills in autism fall substantially below cognitive ability, with the most significant deficits observed in social functioning (e.g., Carter, Volkmar, Sparrow, et al., 1998; Klin et al., 2007). One of the most widespread instruments to assess adaptive functioning is the Vineland Adaptive Behavior Scales, currently in its second edition (Sparrow, Cicchetti, & Balla, 2005). The Vineland measures self-sufficiency throughout the lifespan in the areas of adaptive Communication, Socialization, Daily Living, and Motor skills via a semi-structured interview with parents, primary caregivers, or teachers.

Although by definition, individuals with cognitive impairment have deficits in adaptive skills, it is less well known and often overlooked that most individuals with autism *without* cognitive impairment also have deficits in these areas – including in Asperger Syndrome (Saulnier & Klin, 2007). It is lack of independent, functional skills that tends to result in poor outcome in adulthood (Howlin, Goode, Hutton, & Rutter, 2004). Thus, there should be a focus on adaptive skills instruction in all intervention programs, and there is an indication that this instruction should intensify with age.

Communication Assessment

Communication skills in individuals with ASD also vary across age and functioning level. Accordingly, specific types of assessments are used to evaluate communicative abilities at the prelinguistic, early linguistic, and advanced language levels (Paul, 2005). Comprehensive speech and language assessments include measures to evaluate expressive and receptive language, nonverbal communication (e.g., response to and use of gaze, gestures, facial expressions), responsiveness to language, pragmatics (e.g., effective language use in social contexts), and prosody (e.g., rate, volume, tone, inflection of speech). For individuals with fluent speech, particular attention should be given to the assessment of linguistic skills (e.g., phonetics, phonology, morphology, syntax, semantics),



Celine Saulnier, PhD

metalinguistic skills (e.g., comprehension of nonliteral language such as inferences, idioms, multiple meanings, metaphors, irony, and humor), and conversational skills (e.g., topic management, turn-taking, and perspective taking; Klin, Sparrow, Marans, et al., 2000). It is important for evaluations to incorporate both standardized norm-referenced assessments as well as informal observation of the individuals' communicative skills in more natural settings in order to obtain a holistic sampling of the individuals' abilities.

Diagnostic Assessment

The diagnostic work-up of an individual with ASD is twofold in that it involves both a comprehensive developmental history conducted with the individual's parents or primary caregivers *and* direct observation of the individual's behavioral presentation in both structured and unstructured contexts. Both components involve assessing language, communication, and social interaction skills, as well as behavioral presentation, including any restricted, repetitive, sensory or perseverative interests, atypical patterns of behavior, and behavioral dysregulation. Ideally, having the parents participate in or observe the diagnostic assessment allows for additional information on the consistency of their child's history, as well as presentation across settings, and their responsiveness to novel situations and people.

Details on specific symptomatology related to ASD can be collected in various ways. Clinicians can ask parents direct questions based on the diagnostic criteria set forth in the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000), and/or they can utilize various scales, checklists or interviews that probe for similar behaviors. Currently, the most comprehensive, structured measure to obtain diagnostic and historic information relevant to ASD through parent report is the *Autism Diagnostic Interview, Revised* (ADI-R; Rutter, LeCouteur, & Lord, 2003). Though it was developed as a research instrument, the ADI-R is clinically useful in that it offers a comprehensive and structured way of collecting pertinent details related to a child's early developmental history. Questions probe for onset of symptoms, development of language, com-



Ami Klin, PhD

munication, social, and play skills, and patterns of restricted interests, perseverative behaviors, and unusual interests that are characteristic of the disorder.

After gathering a detailed history, the next step of the diagnostic process is to directly observe and probe for symptoms within more naturalistic social contexts. Understanding the variability of an individual's presentation across situations, contexts, and people is critical not only to the diagnostic process, but also to conceptualizing the individual's range of strengths and vulnerabilities so as to determine appropriate intervention strategies.

The *Autism Diagnostic Observation Schedule* (ADOS) is a semi-structured observation measure that was created as a means of standardizing diagnostic evaluation for research purposes, but like the ADI-R, is also quite useful clinically (Lord, Rutter, DiLavore, & Risi, 1999). The ADOS consists of 4 Modules (with a fifth Toddler Module in development) that are based on language level and age, ranging from nonverbal or verbal toddlers to verbal adults, and it involves a series of probes to elicit spontaneous behaviors. In young children, the probes are more play based and involve highly motivating toys/activities that directly elicit social communicative behaviors such as requesting, shared affect, eye contact, gestures, joint attention, and reciprocity. For older, verbal individuals, the probes are more interview based, pressing for insight and awareness into social and emotional experiences.

Regardless of measure or method used to evaluate symptom expression and severity, no single measure can diagnose ASD in isolation. The diagnostic process entails integrating all pieces of information gathered across multiple assessments and making an informed, clinical interpretation. For this reason, it has become the standard in the field that ASD diagnoses are made through expert clinical judgment.

Clinical Diagnosis in Very Young Children

Current nosological systems (e.g., the DSM-IV) and diagnostic measures related to ASD (e.g., ADOS and ADI-R) work well for children over the age of 3, but they tend to be less effective in detecting autism symptomatology or risk factors in very young children (i.e., under the age of 2) or in children below a certain developmental



Linda Quirnbach, PhD

level (e.g., 18 months). Yet, there is a strong focus within the field on early detection, and research has shown that when experienced clinicians do diagnose ASD in young children, the diagnoses tend to be stable over time (Chawarska, Klin, & Volkmar, 2008). Early risk factors or markers of ASD in young children include not only atypical developmental behaviors (e.g., language delay or atypical language development, sensory sensitivities, visual tracking and attention abnormalities), but also include the delay in or absence of normally developing milestones such as eye contact, social smiling, imitation, babbling, responsiveness to name (e.g., Zwaigenbaum et al., 2005). Due to rapid developmental changes early in life, as well as the impact of intensive early intervention, diagnoses in very young children should always be considered provisional and re-evaluated over time. Furthermore, the gold-standard for diagnosing autism in infancy similarly involves the clinical judgment of experienced clinicians who are knowledgeable of both ASD and early child development, and when developmental information is gathered from multiple sources (e.g., Chawarska, Klin, Paul, and Volkmar, 2007).

Summary

In summary, the diagnostic evaluation of individuals with ASD involves a comprehensive multidisciplinary approach to assessing a person's profile of abilities and then effectively integrating the results into one cohesive formulation. Areas to assess include speech, language, communication, social, motor, cognition, adaptive behavior, and psychological/psychiatric functioning, among others. Furthermore, the nature and course of the individual's development over time must be considered, as well as the role of genetic, family, medical, and educational histories and how these might impact an individual's presentation and the person's ability to functionally apply one's repertoire of skills to everyday life across settings and contexts. With multiple professionals from a wide range of disciplines becoming involved in the diagnostic process, it is imperative that there be open communication and consultation between professionals not only to ensure consistent representation of each individual assessed, but also to implement the most appropriate intervention based on that individual's profile of needs.

Assessment for Transition Planning

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



Ernst O. VanBergeijk, PhD, MSW

Prior to leaving high school a young person should have a thorough assessment. Under the Individuals with Disabilities Education Act (IDEA) this can be accomplished through a triennial evaluation or a parent simply needs to put the request in writing to the local educational agency. One major shift in the evaluation will be the use of the Wechsler Adult Intelligence Scale (WAIS) in lieu of the children's version of this I.Q. test. The WAIS is administered to individuals 16 years of age and older. The WAIS score is generally considered very stable and can be used to help an individual qualify for disability services through state offices of developmental disabilities. Full scale I.Q. scores below 70 represent an individual with a developmental disability, i.e., the person possesses a cognitive delay.

However, I.Q. scores alone are insufficient in assessing an individual on the autism spectrum. Many higher functioning individuals on the spectrum possess average to above average I.Q. scores, and yet are unable to live independently. If I.Q. scores alone are used to qualify for disability services, then many of these individuals would not be served despite

needing and deserving assistance. A second critical area that an individual on the autism spectrum should be assessed is his or her adaptive behavior. The Vineland Adaptive Behavior Scales (VABS) assess an individual in 5 domains including: fine and gross motor skills, verbal and written communication, independent living skills, community living skills, and maladaptive behaviors. With an instrument such as the

VABS, a person with average intelligence can demonstrate a developmental disability without having a cognitive impairment. The threshold for eligibility varies from state to state. Therefore, it is important to check with the individual's home state office of developmental disability services for the eligibility guidelines. The parents of children with PDD-NOS and Asperger Syndrome are often dissuaded from completing this crucial assessment. They are often told that their son or daughter is "too bright" for such an evaluation. Intellectual ability is not an indicator of independent living skills. Parents must insist on this type of evaluation. A student with an autism spectrum disorder is neither too bright nor too old for an evaluation of their adaptive behavior. When answering the questions posed by the trained evaluator, it is imperative that parents not answer the question of what the student is ABLE to do. Rather, it is critical to answer what the student ACTUALLY DOES. Many individuals on the autism spectrum are able to bathe and take care of basic self-care skills, but many do not remember to do so. This demonstrates their impairments in executive functioning. In order to qualify for services, the VABS must capture the actual daily functioning of the individual on the autism spectrum.

In addition to assessing the intellectual ability, adaptive functioning, and reading skills of a young adult on the autism spec-

trum, it is important to assess his or her assistive technology needs. This is an often overlooked assessment. Assistive technology can help not only with academic advancement, but daily living skills as well. The assistive technology can take many forms. Most people can readily imagine the use of laptops and tape recorders to help an individual cope in academic environments, but there is a plethora of products available to help with daily living. These can range from low technologically based products like a visual timer to help keep track of time to cell phones with built in cameras that have reader programs. An individual with an ASD can bring these specially outfitted cell phones to a store, plug in an ear piece and scan a list of ingredients on a box in the grocery store. The device will read the ingredients discreetly to the user through the ear piece. This type of device can help an individual live independently and avoid potential allergens. Other applications on cell phones include to-do lists, built in alarm clocks and reminders, and online banking products. A less expensive option for individuals with reading problems include scanning pens that provide the same function as the cell phone based scanner at a fraction of the cost. Laptop and desktop computers not only can be loaded with scanner programs to read to students, but they can also be loaded with

see Transition Planning on page 46

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

NYIT
NEW YORK INSTITUTE
OF TECHNOLOGY

For more information call 631.348.335 or visit www.nyit.edu



**Specializing in Services for
Children with Autism**

- MOMMY & ME MUSIC**
(ages 0-5)
- ART & MUSIC THERAPY**
(ages 5-12)
- SATURDAY RECREATION**
(ages 5-12)
- HOME ABA THERAPY**
(ages 3-12)

For more information
please contact us at
(516)741-9000 ext 470
Visit us at www.lifesworc.org

1501 Franklin Avenue, Garden City, NY 11530

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**

A non-sectarian program offered by Westchester Jewish Community Services
with funding from UJA-Federation
www.wjcs.com



Multidisciplinary from page 1

child's level of cognitive functioning (IQ) and perform assessments for anxiety, depression and other co-morbid conditions. As with many clinicians on the multidisciplinary team, psychologists also administer diagnostic assessments to determine an autism spectrum diagnosis.

An important element in this process is neuropsychological testing, which focuses on the different areas of a child's cognitive functioning. Neuropsychological testing differs from general psychological testing in that it places a greater focus on determining the way the brain functions. Testing often comprises of evaluating an individual's attention, memory, problem-solving skills and language development.

A neuropsychological assessment should be based on an individual's level of cognitive functioning, verbal skills and other relevant information obtained through the referral process. This assessment can help parents of a child with ASD determine appropriate school placement, develop a remediation program and identify the presence of a neurological disorder.

Neuropsychological testing is normally conducted over several sessions, ideally in a quiet environment without distractions. The assessment will help provide a better understanding of a child's functioning, a great asset in determining specific interventions and treatments. If one area of cognitive functioning is found to be a significant weakness, remediation can help improve skills that are deemed lacking.

The psychologist should work closely with the other members of the assessment team to ensure that both the evaluation and recommendations are comprehensive. Each member of the assessment team comes from a different training background and offers a unique perspective. By using a multi-disciplinary assessment team, parents are provided with a deeper understanding of their child's functioning.

Communication

When considering the diagnostic features unique to autism, language and social skills are key areas to assess, especially for young children whose communication skills continue to develop.

Unlike cognitive skills, which can be measured using various standardized instruments, speech and language skills should be measured within both standard tests and subjective measures, such as language samples, observation measures and parent reports.

Supplementing traditional tests with an examination of social communication within a child's natural settings is especially important for children who are higher-functioning, yet demonstrate social vulnerabilities. The pragmatic and social uses of language are often the largest areas of weakness for children with ASD. Unfortunately, they are more difficult areas of language to assess in terms of using standard, objective measures.

A recent paper published by a group

**Charles Cartwright, MD**

of researchers with expertise in language development and ASD recommended that a language assessment for children with ASD should include measures derived from *multiple sources* (Tager-Flusberg et al, 2009). These sources should ideally include natural language samples, parent reporting and direct standardized assessments.

The following are a few ways to enhance language testing by gathering multiple sources of information:

Natural Language Samples - Conversation and narrative (story-telling) samples are often useful for examining spontaneous, real-time language skills. Semi-structured conversations can be collected between a clinician and a child within a short amount of time. The clinician can use specific language paradigms, as well as his or her own discretion, in order to create opportunities to judge areas such as: topic choice and maintenance, turn-taking, echolalia, voice and intonation, intelligibility, and perseveration. This type of sample can be used at the start of an assessment to establish rapport, create a relaxed environment and encourage the child to share his own experiences. Speech analysis software, such as Systematic Analysis of Language Transcripts (Miller & Chapman, 1985), can be used to analyze a child's language skills relating to areas such as: grammatical features, response to comments and questions, and conversational turns. Language sampling over time can also be a useful way to evaluate change or progress in conversational skills.

A short story-telling assessment such as the "Bus Story" (Renfrew, 1969) and picture books such as Mercer Mayer's "frog" series can reveal difficulties at different language levels. Research has shown validity and value in evaluating natural discourse skills in children with language delays and ASD, a linguistic area not typically examined within standard tests.

Parent and Teacher Report - Parents and teachers serve as valuable informants within the assessment process, providing

program.

Last spring, the staff at Kew Gardens, Jimmy and I presented our pilot project at the YAI/NIPD Network's annual International Conference, when we had a very special visitor: Dr. Mark L. Sunberg, an expert in utilizing Skinner's analysis of

information about language skills and social behavior in the home and classroom. Communication and social skills questionnaires, both standard and criterion-based, enable caregivers and teachers to describe areas of social development. These include: initiating and maintaining interactions, responding to peers and adults, understanding social rules, the use and understanding of facial expressions and gestures and the occurrence of teasing or bullying. These instruments provide descriptions and ratings of a child's social behavior outside the testing setting, across varying contexts where real social interactions occur.

Combining the above assessment procedures can capture a complete picture of a child's communication and social functioning, and will lend valuable information for treatment and educational services.

Occupational Therapy

Occupational Therapy (OT) enables children with ASD to develop increased independence in their daily life skills. These activities of daily living include areas of self-care (i.e. ability to brush teeth, dress oneself, or bathe independently), as well as higher level tasks such as coin identification/counting skills, travel training, and social skills training.

A comprehensive OT evaluation for a child with ASD can determine the factors that are affecting his or her ability to function independently. For example, an evaluation may detect sensory processing issues (e.g. visual and auditory impairments) that hinder a child's ability to adapt to his home or school environment. An evaluation can also detect gross motor/fine motor (GM/FM) delays as well as delays in visual motor control, balance and coordination. It can also detect impairments in executive functioning, which includes motor planning, sequencing and step-by-step problem solving.

An occupational therapist looks at all of these areas to determine how they affect a child's ability to function in his or her daily life. Children with impairments in executive functioning, for example, often have difficulty planning and organizing their thoughts into actions. A simple task of making a sandwich may be challenging due to the difficulty of organizing the steps that are needed to complete the task.

According to recent studies, approximately 90 percent of children on the autism spectrum have sensory processing issues. This greatly impedes their ability to function in their daily environment.

For example, a child with impaired auditory processing may become disrupted by the sound of the teacher's voice. Even the sound of the chairs scraping the floor may be overwhelming, resulting in an inability to focus in the classroom.

Once an OT evaluation is completed, the occupational therapist will collaborate with the family and the professional team to develop a treatment plan. All treatment sessions will be client-centered and aim to

Verbal Behavior, who was also presenting at the conference.

"I thoroughly enjoyed the presentation given by the YAI staff regarding teaching verbal behavior to adults with developmental disabilities," Dr. Sunberg said. "They clearly demonstrated that people can learn

improve a child's ability to function optimally and increase their independence in their daily lives.

Social Work

In terms of obtaining evaluations, social workers are often the first point of contact for families. Social workers compile psychosocial evaluations that assess a family's history and observe problems described by a parent or guardian. Social workers also attempt to record the overall developmental history of a child from prenatal care to the present.

This information is often critical in determining the next steps for evaluations. Social workers ideally work in a multidisciplinary context, sharing information with colleagues, who will later meet with family members to determine appropriate services. While other professionals will evaluate a child using assessment tools and standardized evaluations, social workers record the parents' unique perspective. This empowers parents as the experts of their children, and emphasizes their specific viewpoint and the developmental trajectory to date.

The psychosocial interview provides a comprehensive perspective and should reflect the family constellation, current and past interventions, and a catalogue of developmental milestones. Since other evaluations tend to be limited, this is a crucial component of evaluating autism spectrum disorders. These interviews enable us to comprehend a child as a total package from an individualistic perspective.

The social worker also acts as a family's referral source and ongoing contact as they move forward. While the evaluation process can often be a challenging experience for a family as well as the child, social workers provide needed support as the family continues to explore the appropriate steps for their child.

Often, the stress of having a child with special needs such as autism can be significant for a family. Stress can echo into the lives of every member of the family, from the impact on a sibling to distance between the parents. Social workers help to identify and address these emotions early on - before they create lasting divisions within the family system.

Ideally, the evaluation process should be a smooth and supportive experience for a family. The social worker's most important role is to set the tone, to be accessible to the family, and to instill confidence as the process unfolds.

Reinforcing the Team Approach

While it is clear that obtaining a proper assessment and the necessary services for children with ASDs may not always be easy, it is important for families to remember that they are not alone. Rather, they are a vital part of a team that includes dedicated professionals committed to helping a child reach his or her fullest potential.

language at any age, and it is extremely important to not give up on a person's potential to learn how to communicate."

Carol Stein-Schulman, MS Ed., BCaBA, is the Assistant Director of YAI/NIPD's Education and Training Department.

Develop Language from page 9

Because of the success at Kew Gardens, YAI's Education and Training Department is expanding this project to several other day programs and to Project A.S.I.S.T., an in-home rehabilitation

LAW AND THE AUTISM COMMUNITY



The Initial Assessment Process and Consent to Medical Care For Minors

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

What are the rights of parents to make healthcare decisions for their children? The answer to this question may, at first glance, appear to be a simple one. Parents know their children best and children are too young and often lack maturity or the intellectual capacity to make treatment decisions on their own. But with recent FDA warnings on anti-depressants, new confidentiality regulations and a host of other concerns, parents often have more questions than answers relating to what authority they have to consent to or refuse care and treatment for their minor children. The laws in New York which outline the rights and obligations of parents who wish to make medical and mental health related decisions for their children are quite complicated. The following article is intended to provide an outline of the statutes which govern parental decision making with respect to health care. As always, one should consult a professional before taking any action.

Medical Treatment Generally

It is a well established principle in our common-law that a competent adult has a right to decline or accept medical treatment despite the fact that the treatment may be beneficial or even necessary to preserve a patient's life. The patient's right to determine the course of his/her own medical treatment is paramount to what might otherwise be the doctor's obligation to provide needed medical care. Accordingly, a violation of this right may result in civil liability for those who administer medical treatment without consent. In 1972, the New York State Legislature codified this common law principle within the Public Health Law. Public Health Law section 2504 states that, "any person who is eighteen years of age or older, or is the parent of a child or has married, may give effective consent for medical, dental, health and hospital services for himself or herself, and the consent of no other person shall be necessary."

Essentially, most minors, people under the age of 18, are considered legally "incompetent" to make most healthcare decisions and as such, decision making authority vests within the parents. Incompetence, legally, is defined as an individual's inability to consent due a psychological impairment or age. There are circumstances when a minor may make healthcare decisions. Such circumstances include; minors that are married and/or minors who have children themselves. In some states, children, based upon their age, intellect and level of maturity can be declared "mature minors" thereby "competent" to make decisions. This mature minor doctrine in New York law does



Douglas K. Stern, Esq.

not have a very clear (or useful) definition.

The New York State legislature gave a wide berth to parents to make healthcare decisions on behalf of their children but did not intend for Public Health Law Section 2504 to be an absolute right. In other words, a parent cannot make all healthcare decisions regarding their minor children in New York. In 1981, the Court of Appeals held that although a parent has the right to consent to medical treatment on behalf of a child, the parent may not deprive the child of life saving treatment, even when the parents' decision to decline necessary treatment is based on constitutional grounds, such as religious beliefs, as such decision must yield to the state's interest in protecting those who are deemed incompetent. In ratifying certain provisions of the Family Court Act and correlative laws, the state legislature set out guidelines as to when the state, through its family court or Supreme Court, may intervene against the wishes of a parent on behalf of a child so that the child's needs are properly met. This substituted judgment is codified in the Family Court Act, section 233 that states, "that whenever a child within the jurisdiction of the court appears to the court to be in need of medical, surgical, therapeutic, or hospital care or treatment, a suitable order may be made therefore."

This state intervention on behalf of a minor/incompetent is often referred to by the Latin phrase *parens patriae*. It is this *parens patriae* analysis that defines when parental decision-making must yield to the state invoking its substituted judgment. A classic example is the case of a child who may bleed to death because of the parents' refusal to authorize a blood transfusion, courts have held that the state's interest in protecting the minor's health and welfare outweigh the parents legitimate religious beliefs. By contrast, in very limited circumstances, a court has allowed a parent to terminate artificial life

support for a child in a persistent vegetative state. The courts have repeatedly highlighted the importance of parental involvement in making treatment choices. However, it should be noted that parents are not deprived of the right to choose amongst competing serious or life-saving treatments. Accordingly, parents are legally empowered to make treatment determinations, in light of their families' morals, social values and financial ability, to provide reasonable, safe and if necessary life-sustaining treatment for their children.

Apart from general medical decision-making, parents are often faced with situations that require making decisions relating to emergency medical treatment, psychiatric treatment, and disclosure of medical information. The following addresses those areas;

Emergency Medical Treatment - The provision of emergency medical services by a hospital does not require parental consent, or the consent of the child, where obtaining that consent will imperil the child. Stated differently, when a hospital provides emergency medical treatment to a minor, consent to that treatment from his or her parent is unnecessary. Furthermore, if obtaining that parental consent would endanger the minor, such consent is not required.

Psychiatric Treatment - Hospitalization/Voluntary - A child under the age of sixteen may not voluntarily consent to inpatient psychiatric hospitalization. The child must be admitted upon an application by a parent or Guardian. If the child/patient is between the ages of sixteen and eighteen, the director of the facility may accept the minor's voluntary application or that of a parent.

Psychiatric Treatment - Hospitalization/Involuntary - There are no age restrictions on the use of involuntary hospitalizations. The minor will be hospitalized if he/she meets the statutory criteria for involuntary hospitalization defined in the Mental Hygiene Law. More pointedly, a minor will be involuntarily hospitalized if the specific requirements are met regardless of whether or not the parent or guardian consented.

Outpatient Treatment and Inpatient Treatment within a Psychiatric Facility - Child is Consenting - The Mental Hygiene Law states in relevant part that, "[i]n providing outpatient mental health services to a minor, or psychotropic medications to a minor residing in a hospital, the important role of the parents or guardians shall be recognized. As clinically appropriate, steps shall be taken to actively involve the

see *Medical Care* on page 41

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

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

Attorneys at Law

Devoted to the Practice of Law for the Autism Community

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

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

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

220 E. 42nd Street - Suite 505
New York, New York 10017
(212) 279-9200

1111 Marcus Avenue - Suite 107
Lake Success, New York 11042
(516) 829-3838

Personal Space from page 7

“Respecting someone’s space is a critical aspect of human social interaction, and something we do automatically and effortlessly,” Kennedy says. “These findings suggest that the amygdala, because it is necessary for the strong feelings of discomfort that help to repel people from one another, plays a central role in this process. They also help to expand our understanding of the role of the amygdala in real-world social interactions.”

Adolphs and colleagues then used a functional magnetic resonance imaging (fMRI) scanner to examine the activation of the amygdala in a separate group of healthy subjects who were told when an experimenter was either in close proximity or far away from them. When in the fMRI scanner, subjects could not see, feel, or hear the experimenter; nevertheless, their amygdalae lit up when they believed the experimenter to be close by. No activity was detected when subjects thought the experimenter was on the other side of

the room.

“It was just the *idea* of another person being there, or not, that triggered the amygdala,” Kennedy says. The study shows, he says, that “the amygdala is involved in regulating social distance, independent of the specific sensory cues that are typically present when someone is standing close, like sounds, sights, and smells.”

The researchers believe that interpersonal distance is not something we consciously think about, although, unlike SM, we become acutely aware when our space is violated. Kennedy recounts his own experience with having his personal space violated during a wedding: “I felt really uncomfortable, and almost fell over a chair while backing up to get some space.”

Across cultures, accepted interpersonal distances can vary dramatically, with individuals who live in cultures where space is at a premium (say, China or Japan) seemingly tolerant of much closer distances than individuals in, say, the United States. (Meanwhile, our pre-

ferred personal distance can vary depending on our situation, making us far more willing to accept less space in a crowded subway car than we would be at the office).

One explanation for this variation, Kennedy says, is that cultural preferences and experiences affect the brain over time and how it responds in particular situations. “If you’re in a culture where standing close to someone is the norm, you’d learn that was acceptable and your personal space would vary accordingly,” he says. “Even then, if you violate the accepted cultural distance, it will make people uncomfortable, and the amygdala will drive that feeling.”

The findings may have relevance to studies of autism, a complex neurodevelopmental disorder that affects an individual’s ability to interact socially and communicate with others. “We are really interested in looking at personal space in people with autism, especially given findings of amygdala dysfunction in autism. We know that some people with autism

do have problems with personal space and have to be taught what it is and why it’s important,” Kennedy says.

He also adds a word of caution: “It’s clear that amygdala dysfunction cannot account for all the social impairments in autism, but likely contributes to some of them and is definitely something that needs to be studied further.”

Other coauthors of the paper, “Personal Space Regulation by the Human Amygdala,” are postdoctoral scholar Jan Gläscher and J. Michael Tyszka, the associate director of the Caltech Brain Imaging Center and director of Magnetic Resonance Physics. The work was funded by the National Institute of Mental Health, the Simons Foundation, the Della Martin Foundation, and a global Center of Excellence grant from Japan.

This article is reprinted with permission from the California Institute of Technology. View the original press release on their website at http://media.caltech.edu/press_releases/13287.

A Roadmap from page 9

they work with a family over the long term?

Pace Yourself

Trying to identify and meet all the needs of a child with an ASD can be quite overwhelming and very time-consuming. It is important to remember that not everything is an immediate priority. Here are some important things that parents can do at their own pace:

Consider genetic testing - The field of medical genetics is progressing at an extremely rapid pace. In a few years, it may be possible to diagnose the genetic cause of perhaps half of all cases of autism. Knowing a particular genetic syndrome early can allow for more targeted preventive strategies and can help family members understand their risk of passing on symptoms.

Join a Parent Advocacy Network - I recently typed “autism advocacy” into Google and within 0.19 seconds got nearly 45,000 results which included many resources for parents. I’ve spoken at many parent advocacy network meetings throughout the New York City area and it hasn’t taken long to realize the enormous value of these groups. Isolated parents suddenly meet people who totally understand them. Caregivers receive word-of-mouth referrals for effective, reliable providers, and advice on “how to navigate the system.” There is great power in validation and in numbers, and members of

these networks really end up knowing how to effectively advocate for their children.

Familiarize Yourself with State Funded Programs for People with Disabilities - A good reason to receive intellectual and adaptive functioning testing is to establish eligibility for specially tailored programs designed to help people with developmental disabilities. Family support services for these individuals can include parent training, advocacy, service coordination, financial assistance, crisis intervention and behavior management. These services are often provided at no cost to the family. Many states, including New York, offer the Home and Community Based Services Waiver for individuals with developmental disabilities, which can provide parents with in-home skills training for the child, a variety of respite services, parent education and training, and much more. While Medicaid is a requirement for this waiver, some regions allow certain children under 18 who would typically not qualify, to gain access to Medicaid through the Waiver. As a consequence, these individuals also gain access to clinical services which are often poorly covered by private insurance. The waiver is also the funding mechanism for most day, vocational and residential services.

Plan for the Transition into Adulthood - Perhaps the most major transition time in the lives of people with disabilities is when they age out of school, which in many states is at 21. For those with the social and other pervasive developmental challenges of autism, it makes sense to

start thinking about these post-schooling basics during their teenage years: social/vocational opportunities, legal status, residential options and finances. The Individuals with Disabilities Education Act, in fact, requires schools to assist with transitional planning beginning at age 16. This includes creating linkages with agencies which will provide post-school services.

Quality special educational programming includes school-to-work experiences and embeds skill-building opportunities within the curriculum to foster a successful transition. When this happens, the changeover is far more seamless. From there, a person with a disability is typically eligible for a range of state-funded supports and adult day services to help with job supports, social and vocational skills, and recreational outlets. To find out more, check with your state governmental agency that provides services for individuals with developmental disabilities.

Consider Legal and Financial Planning - Fostering independence is the ultimate aim of all developmentally based programs. Sometimes, a person isn’t capable of making his or her own decisions by the time they reach 18 and are considered a legal adult. In this case, a parent, family member or state-appointed agency can advocate to become an individual’s legal guardian. Parents can learn more by contacting an agency working with people with developmental disabilities, or by attending one of many conference workshops on the topic.

Financial trusts are another important part of the long-term planning process for

a family member with a disability. This issue and companion strategies involving powers of attorney, health care proxies, and estate planning can be investigated through an attorney, a trust company or one of several non-profit advocacy agencies for people with disabilities.

Explore Residential Options - What’s the most common emotion I see in parents who ponder moving their child to a residence in the community? Guilt. But helping a grown child who cannot live on his or her own to successfully transition to a new supported life outside the home is an important developmental step. Though the waitlists can be long, people are typically matched with the level of supports they need, and most residences are learning environments in which trained staff can best help facilitate greater independence and growth.

Remember the Bottom Line

While there may not be a clear endpoint for parents of individuals with ASDs where all is neatly wrapped up, there is certainly hope. Today, there are more Web sites, resources and supports than ever to help parents on their journey. And with each passing year, while the answers won’t be simple, at least the questions are becoming clearer and clearer.

Dr. Peter Della Bella is the Director of Clinical Programs at Premier Health-Care, a member of the YAI Network. Dr. Della Bella would like to thank Judy Omidvaran for her continual inspiration to write and speak on these issues.

children
teens
adults
families
schools
agencies



GOT ASPERGER'S?

Irene Brody PhD
Shokan, NY
(845) 657-5847
ibrodyblue@yahoo.com

therapy
social skills
groups
education
staff training



Discovering Your World, PC

Susan Cortilet-Jones, MS, LMHC
*Life Skills and College Coaching
for Adults on the Autism Spectrum*
New York State Hudson Valley Region
contact: (845) 406-8730

DISCOVERINGYOURWORLD.COM



Robin's Voice

A Resilient Mom's Commentary on Autism

Relationship Development Intervention

By Robin Morris
Freelance Writer

One of the concerns regarding conventional behavioral therapy (ABA) is that it encourages robotic responses to stimuli. Consequently there is a rote type of interaction, not exactly reciprocal conversation.

Relationship Development Intervention (RDI) was developed by Dr. Steven Gutstein. It is a program that uses behavior modification, but stimulates social awareness. He uses dynamic intelligence (www.rdicconnect.com/pages/Dynamic-Education-Program.aspx) to prove his theory. The world is ever changing and in order for children with autism to connect, it needs to be a family affair. Dr. Gutstein describes the 5 essential goals for RDI to be successful:

Experience Sharing - Sharing different perspectives, integrating multiple information channels and determining "good enough" levels of comprehension. Using language and non-verbal communication to express curiosity, invite others to interact, share perceptions and feelings and coordinate your actions with others.

Dynamic Analysis - Determining relative meaning and value of information. Ongoing subjective appraisal of continually changing contextual information, to determine the



Robin H. Morris

best fit. Ongoing evaluation of change. The ability to observe and continually regulate one's behavior in order to participate in spontaneous relationships involving collaboration and exchange of emotions.

Flexible and Creative Problem-Solving (Relational Information Processing) - The ability to obtain meaning based upon the larger context. Solving problems that have no "right-and-wrong" solutions. Developing multiple, equally good strategies for

an imperfect world, including "good enough thinking," improvisation and "work-arounds." The ability to rapidly adapt, change strategies and alter plans based upon changing circumstances.

Episodic Memory and Self-awareness (Foresight and Hindsight) - The ability to reflect on past experiences and anticipate potential future scenarios in a productive manner. Developing an internal mental "space" to consider, reflect, preview, prepare, regulate, evaluate, hypothesize and dream.

Resilience - Coping with a "messy" unpredictable world, where setbacks and errors are unavoidable. Responding to uncertainty in a productive manner.

This clinical list may read as a daunting project. However the basic principle makes sense. RDI is basically about encouraging relatedness. Through declarative language and referencing, it draws children with autism into the typical world, without making sharp demands or commands. It is the subtle relationship information that children need to survive.

We were introduced to the benefits of RDI when our son Paul was 17 years old. The notion that "you can't teach an old dog new tricks" is an understatement. He was resistant to referencing and responding to declarative language.

However, we did learn that the effect of such intervention does have positive outcome. It is very difficult for parents to hold back and wait for children to react to stimuli. (Example: Start in your kitchen. Walk over to your dirty table, and declare "Oh, this table is so sticky!" Optimally, your child will get a sponge, clean the table, while telling you they want to help. Don't expect, you won't be disappointed. When your child does not respond, wait a few beats and make the statement again....and wait again....and again, until you get a response. It is the nature of the relationship development that encourages the connection. Even if you have to gesture to the sponge with your eyes (referencing), it is an accomplishment, because your child will follow your gaze to the sponge and get the idea.

One day Paul and I were in the market. He wanted pineapple juice. He said there wasn't any. I said I saw it on the shelf. He said, no there wasn't (inflexible). I said yes there is. He paused for a moment, then directed..."why don't you just try referencing it?"

I rest my case.

Robin Hausman Morris is a freelance writer and can be reached at RobinHausmanMorris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/x-3565-Hartford-Parenting-Examiner.

What to Do When Your Child Is Diagnosed With Autism: Take a Deep Breath and Take Action

By Robin Morris
Freelance Writer

When your child is diagnosed with autism, the emotional havoc is overwhelming. It is difficult to think in rational sentences and denial is a welcomed fortress. Whether or not your sorrow morphs into rage or possible depression, it is a waste of time. Remember, your heart is

Futures for Adults from page 7

"With the proper support and services, adults with autism can be active and engaged members of their communities. Our collective responsibility is to give them the opportunities to make meaningful contributions."

About Autism

Autism is a complex brain disorder

the conduit for action. Your passion will support every effort. It will be your guide.

The following bullets are simple segues to follow. They are springboards for you to tailor your own path to help your child:

- Buyer beware: anyone selling cure is preaching false promises.
- Be an educated consumer: read data on tried and true interventions.

that inhibits a person's ability to communicate and develop social relationships, and is often accompanied by behavioral challenges. Autism spectrum disorders are diagnosed in one in 150 children in the United States, affecting four times as many boys as girls. The prevalence of autism has increased tenfold in the last decade. The Centers for Disease Control and Prevention have called autism a national public health crisis whose cause and cure remain unknown.

- Contact other parents who have children with autism: share and listen.
- Take a pencil and paper and list your child's deficits: pick your first target and list all issues from severe to mild. Research therapies that are consulted for each area of concern. Historically, speech, occupational, physical, play and behavioral therapies are utilized.

About Advancing Future for Adults with Autism

Advancing Futures for Adults with Autism (AFAA) is a national consortium seeking to create meaningful futures for adults with autism that include homes, jobs, recreation, friends and supportive communities. Our efforts are focused to develop and drive the agenda for life-long living and learning with autism. The consortium is currently

- Know your child's rights: Autism Speaks State by State Resource Guide (www.autismspeaks.org/community/resources/index.php) is a fine tool. Check references!
- Finally, don't let anyone tell you not to panic. It is a natural reaction. Simply let the energy work for you, not against. Keep your eye on the prize. Progress is the operative word.

comprised of members from Autism Speaks, Alpine Learning Group, The Autism Program Service Network, The Daniel Jordan Fiddle Foundation, Easter Seals, Global Communities of Support, Hallmark Community Solutions, New York Center for Autism, Organization for Autism Research, Southwest Autism Research and Resource Center, and University of Miami/Nova Southeastern University Center for Autism & Related Disabilities.

Functions of Behavior from page 13

behavioral observation, and/or, environmental manipulations to determine the function of disruptive behavior.

In general, the more direct the information is about behavior, the more confidently we can make conclusions about the variables influencing it. Behavior analysts have a strong preference for direct observation as a means to gather information for functional assessments. While some assessments include checklists or interviews, it is important that the hypotheses be based on the observation of behavior. At times, these observations might be done by a trained observer who is recording events. At other times, staff members may be asked to complete ABC data sheets, in which they log the events that occur before (A: antecedents) and after (C: consequences) the behavior (B) of interest.

In many situations, behavior analysts also systematically manipulate variables to assess the impact of such manipulations. These systematic Functional Analyses require specialized training, but can yield extremely useful information that may be much more specific than what is learned through other functional assessment methods.

When functional assessments/analyses are completed, the variables that maintain the behavior have been identified. In other words, functional assessments lead to the identification of variables that are responsible for the continuance of the behavior. Functional assessment helps in understanding WHY the behavior occurs. It may be that the behavior is occurring to escape task demands or to access teacher attention or to get desired items. The behavior persists because it has worked in achieving those outcomes.

When the function of disruptive behavior has been identified, the learner can be taught to access the reinforcer maintaining disruptive behavior (e.g., attention, escape) using an adaptive form of communication. It is important that the individual communicate that desire in a more functional, appropriate, and pro-social manner. One goal of functional assessment is to identify the function so that an alternative, replacement skill can be determined. Selecting the modality of the replacement response is essential to effective functional communication training (FCT). In order for the replacement skill to become

integrated into the learner's repertoire, the response must be possible for the learner to engage in, efficient, and reinforced by others in the environment.

Functional Communication Training

Functional communication training (FCT) has been shown to be an effective treatment method for many topographies of problem behavior (Fisher, Piazza, Cataldo, Harrell, Jefferson & Conner 1993; Hagopian, Hagopian, Fisher, Sullivan, Acquisto & LeBlanc, 1998). FCT involves identifying the function of challenging behavior then providing the individual with an adaptive functionally-equivalent response to access that reinforcement. A functionally equivalent response allows access to the same type of reinforcement for the learner, but through a different response. A learner who has escaped demands through disruptive behavior can be taught to instead escape a demand by using a break card. A functionally equivalent response can serve to replace a challenging behavior by providing the learner with a different way to meet his/her needs. The nature of the communication response may be a vocal response, a card touch/exchange, sign language and/or a response made on an augmentative communication device.

Carr and Durand (1985) conducted functional analyses on the challenging behaviors of four learners. The results of the analyses indicated that the individual learners engaged in disruptive behavior for different reasons. Two learners engaged in disruptive behavior to escape from demands, one was accessing social attention, and one participant's behavior was maintained by multiple functions.

After conducting the functional analyses, the authors taught different communication responses to the learners. In each case, they taught responses that matched that individual's function of behavior. In addition, in each case, they taught irrelevant responses (i.e., responses that were not linked to the function of the individual's challenging behavior.) For instance, teaching a learner to request a break if the behavior is escape-maintained would be considered a relevant response (matched to function). Teaching a learner with escape-maintained behavior to request attention would be considered teaching an

irrelevant response. When participants were taught the relevant response matched to the function of behavior, disruptive behavior decreased and communication increased. Perhaps more impressively, the authors found that when irrelevant responses were taught, disruptive behavior continued and communication did not increase. This study supported the need to match treatment to function and suggested that challenging behaviors can be replaced with functional communicative responses resulting from FCT.

Efficiency of response is an important consideration (Horner & Day, 1991, Richman, Wacker & Winborn, 2001). Clinicians need to consider the amount of response effort, the consistency of reinforcement, and the immediacy of reinforcement. If an alternative communication response is difficult or results in delayed/less reinforcement than the target behavior, it is not likely that the new response will replace the maladaptive behavior. It is important that the behavior is assessed adequately for its function and that the right response is selected to train as an alternative/replacement skill.

Summary

One of the most important kinds of assessment done with learners on the autism spectrum is functional assessment of the challenging behaviors they exhibit. A thorough assessment of the functions of challenging behaviors ensures that behaviors are understood in terms of the functions they serve, the reasons for their continuance, and the communicative role that they play. Direct observational methods of such assessments are more valid and are preferable to interview or checklist assessments.

Treatments of challenging behaviors must be linked to these identified functions in order to ensure significant and lasting reduction of interfering behaviors. In addition, functional assessments help in identifying an appropriate skill to target as a replacement skill, so that the individual can get the need communicated in a more positive and successful way. Functional communication training leads to better behavioral outcomes, and is a natural extension of the functional assessment process.

Challenging behaviors do not occur randomly or inexplicably. The use of

functional assessment and functional analysis procedures can unravel the mysteries of challenging behaviors. Functional communication training can help the individual to fulfill their needs and communicate their desires in efficient, effective, and positive ways.

Cecelia M. McCarton, MD is the founder and CEO of The McCarton Foundation. Mary Jane Weiss, PhD, BCBA is the Director of Research and Training at the Douglass Developmental Disabilities Center and a Research Associate Professor at Rutgers University. She consults to The McCarton School. Ivy Feldman, PhD is Educational Director and Jackie Hickie, MA, BCBA is Associate Educational Director at the McCarton Foundation

References

- American Psychiatric Association (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington DC.
- Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis*, 18, 111-126.
- Fisher, W., Piazza, C., Cataldo, M., Harrell, R., Jefferson, G., & Conner, R. (1993). Functional communication training with and without extinction and punishment. *Journal of Applied Behavior Analysis*, 26, 23-36.
- Hagopian, L. P., Fisher, W. W., Sullivan, M. T., Acquisto, J., & LeBlanc, L. A. (1998). Effectiveness of functional communication training with and without extinction and punishment: A summary of 21 inpatient cases. *Journal of Applied Behavior Analysis*, 31, 211-235.
- Horner, R. H., & Day, H. M. (1991). The effects of response efficiency on functionally equivalent competing behaviors. *Journal of Applied Behavior Analysis*, 24, 719-732.
- Richman, D. M., Wacker, D. P., & Winborn, L. (2001). Response efficiency during functional communication training: Effects of effort on response allocation. *Journal of Applied Behavior Analysis*, 34, 73-76.

Overcoming from page 15

the disorder overall. This includes understanding the latest theories about causes of autism, prevalence, sex differences, course of autism over the lifespan, treatments available, and possible outcomes as well as the programs available to assist parents. Having this knowledge makes it easier to speak with parents and to answer the typical questions that arise when parents are faced with this diagnosis.

The Evaluators Supervised Training and Experience

Over the last 15-20 years the Early Intervention Program has expanded rapidly throughout the United States and other developing countries. This has resulted in a large increase in services and evaluations provided to the youngest children. Despite the increase in services pro-

vided under this program the number of evaluators receiving training in this area has not kept pace with the demand. Evaluators, such as psychologists or special education teachers, for example, are required to maintain a license or certification in their area. However, beyond their license or certification, there are no specific requirements that the evaluator have formal supervision or training in the assessment of young children. As the field matures there will likely be further specific requirements in order to ensure that the evaluator is fully competent in this area. The more supervised training the evaluator has, and the more experience the evaluator has, the more likely it is that the evaluator will be able to provide evaluations with an accurate and valid diagnosis so that early help will be received by children who need this help.

The Child's Variability in Performance

(Test/Retest Reliability)

The behavior of young children changes rapidly from moment to moment and day to day. That is one of the delights and challenges in assessing them. One minute they might be laughing and in an instant they might be crying. Factors affecting a child's performance include the time of day of testing, the place of testing, the person(s) accompanying the child in the evaluator setting, the child's reaction to the evaluator, and whether the child is hungry, thirsty, and well rested. The experienced and effective evaluator will assess each of these variables and carefully consider them when working with the child. In addition to considering these variables, the evaluator will try to optimize the child's performance. A short list of techniques to optimize the child's performance include ensuring that the child is well fed, that testing occurs ideally

when the child is well rested, is in a comfortable environment (such as home, or if in an office, then one that is child friendly and appealing), and that the evaluator typically allows the child time to warm up by speaking with the parent first, then playing briefly with the child, and finally testing the child with appealing toys and/or testing materials. Evaluators receiving formal training in the evaluation process through graduate courses or further training should be well versed in the issue of test/retest reliability and carefully consider the variability in a given child's performance when making a diagnosis.

Validating the Observations of the Child with the Parent Interview

Despite the best efforts of the evaluator it may not be possible to obtain an ideal or

Overcoming on page 42

Reaching Parents Before They Are Parents

The Importance of Community Awareness of Autism Spectrum Disorders

By John D. Varlaro, CPT, MBA

Most often, involvement in the Autism community emanates from a personal relationship: a diagnosed child, a friend who is raising a child with autism. These relationships serve as the catalyst to improve the lives of others in similar circumstances. Yet, to affect significant change for those diagnosed with an ASD, we, the engaged community, must reach beyond this bubble to recruit community members without such personal connections who are nevertheless motivated to create change.

Reaching Parents Before They Are Parents is a phrase that focuses on total community awareness and the axiom, "It takes a community to raise a child." The essence of this phrase is that parents of diagnosed children are not the only stakeholders – all of us in the community have a stake. Those who are not parents today could find themselves seeking help from our organizations as parents tomorrow. And even if that were not the case, the rise in ASD diagnoses is significant enough to concern everyone.

This stated, many organizations believe they are reaching their surrounding communities and creating community-wide awareness; yet the messages often fall short.



John D. Varlaro, CPT, MBA

Organizations take action through parent-focused initiatives. These initiatives are crucial, as the organizations exist to help alleviate the stresses these parents face. Unfortunately, these initiatives also contribute to "tunnel vision," where the

organization as a whole begins to focus on reaching *only* parents.

"Positioning" is a foundational idea in strategic marketing, as it speaks to how the target audience perceives a product, service, or even a company. Applied in this instance, parent-focused initiatives *position* the ASD concern as a *parent-only* concern. By marketing only to parents, we communicate, that *only parents* should care.

It is obvious how detrimental this line of communication can be at the community-level. Instead of communicating in a manner that includes the community, it tends to be exclusionary.

However, what is not so obvious is how detrimental this position can be within an organization. "Positioning" can affect internal employees and advocates, as much as it can affect an external audience. Individuals working within an organization internalize this position and focus their attention exclusively on parents. The impact the organization can have within its community is then greatly reduced.

Greater effects can be achieved if we expand the bubble, to where *everyone* is a stakeholder, and we focus our energies towards community-wide awareness.

For example, proper interventions after early detection are proven to lead to improved outcomes for the child, as well

as the family. Yet, parent-focused initiatives, by design, wait until someone is a parent. Would it not be better to begin to communicate the importance of this information *before* the individual becomes a parent through community-wide awareness initiatives?

Community-focused initiatives lead to informed communities that can better serve the individuals in need. Parents rely on friends and family for their own personal support network. Information dissemination strengthens these support networks, reducing the reliance on parental-awareness.

Further still, community members not originally seen as contributors now become involved, ushering in a wealth of experience and vigor that might otherwise have gone untapped.

As members of the engaged community, we must be willing to expand our view of stakeholders, and then communicate accordingly. It is already happening on the international and national levels. Although the Autism Society of America has been celebrating April as Autism Awareness Month since the 1970s, the United Nations voiced international concern by designated April 2 as World Autism Awareness Day on December 18th, 2007. At the national level, Autism Speaks

see Awareness on page 39

Autism Charity from page 12

coordinated way toward what we all want: getting our kids educated, getting them health care and home care, and, eventually, an understanding of autism, its causes, and how to treat it."

The Autism Science Foundation, however, is betting that potential donors will appreciate its role as an alternative.

News of Ms. Singer's resignation from Autism Speaks spread quickly throughout the busy Web sites, blogs, and online discussion lists for people interested in autism.

So many people contacted her, Ms. Singer says, thanking her for taking a stand and entreating her to start a new charity that she felt inspired to do so.

Ms. Singer worked with Karen London, another longtime autism-research advocate who had experience starting a charity. Fifteen years ago, Ms. London started the National Alliance for Autism Research, which merged with Autism Speaks in 2006.

So far, the Autism Science Foundation has relied heavily on word-of-mouth, e-mail messages, and social-networking sites, like Facebook, to introduce itself to potential supporters. When it announced its formation in the spring, it also kicked off what it calls its First 100 Days campaign, a mostly friends-asking-friends effort.

Ms. Singer says the group already has hundreds of donors and volunteers but that it's still too early to make public its finances or share plans for future fundraising efforts. She says donors appreciate that the organization has pledged that

every dollar raised will go directly to grants, which the organization expects to start making by the end of the year.

Louise Bach Capps, from Mechanicsville, Va., whose 5-year-old son has autism, started a Facebook group for parents of autistic children interested in the new organization that has attracted more than 430 members. She says she got involved as soon as she heard about the Autism Science Foundation.

"I'm happy to be involved now with like-minded people interested in really hearing the science," Ms. Capps says.

Ms. Singer is not naïve, about what it will take to turn the group into something bigger.

As a former producer in the broadcasting industry, she knows the importance of communications, she says, and as a key part of the Autism Speaks team that helped to turn the puzzle piece into a recognizable symbol of autism, she understands marketing and developing a recognizable brand name. She says that for now the group needs to lean on its message against vaccine research, but she hopes to be able to move past that over time and attract anyone interested in supporting autism research.

Alison Singer is President of the Autism Science Foundation. Visit www.AutismScienceFoundation.org to learn more about the Autism Science Foundation. Ms. Singer can be reached at asinger@autismsciencefoundation.org.

This article was originally published in the Chronicle of Philanthropy in August 2009 and is reprinted with permission.

DIAGNOSTIC EVALUATIONS FOR CHILDREN AND ADULTS WITH SUSPECTED AUTISM SPECTRUM DISORDERS

- o Psychologists with extensive expertise in ASDs
- o Use of state-of-the-art diagnostic instruments
- o Comprehensive assessment which includes complete history, direct observation and cognitive testing
- o Recommendations for educational programming, support services and other resources.



The Center for Diagnostic and Consultation Services at The Children's Annex

(845) 336-2616 ext. 123 Dr. Jane Nofer - Clinical Director
Office: 70 Kukuk Lane, Kingston, NY 12401
Mailing Address: PO Box 657, Lake Katrine, NY 12449
www.childrensannex.org

Challenges from page 23

- A demanding academic program far more intense than any prior school experience
- Gaps in his content knowledge and some significant deficits in learning skills (especially writing)
- Classes with highly competitive students who were unaccustomed to a “quirky” peer
- Pressure to maintain high grades to keep a scholarship
- Classroom climate very different from the special education model where individual needs were addressed and curriculum was fashioned to accommodate interests and strengths
- Lack of social skills or familiarity with how to behave in a “regular” school environment
- Lack of familiarity with how to relate to college faculty and many issues that need clarification
- Literal and rigid thinking, lack of “common sense” insights, and struggling with how best to communicate
- Myriad social and interpersonal issues including egocentricity and feeling left out and “different”

Of course, there were strengths that promoted this young man’s success, and one should never underestimate the intellectual capacity and potential of students on the spectrum:

- Strong content knowledge in both mathematics and computer science
- Intellectual curiosity
- Ability to focus and sustain attention for long periods of time
- Dedication and strong work ethic
- High motivation to succeed
- Sincerity and a friendly demeanor
- Independent learner and thinker
- Willingness to ask for help

Michael graduated from the Honors College with a double major, succeeded in earning academic awards, and obtained licensure as a secondary mathematics teacher. His professors noted him for his subject skills, but most importantly for his work ethic and sincerity. He made many friends that continue after college, but there were many obstacles that could have been avoided. Given this student’s lack of college preparation here are suggestions that would be wise to consider:

Do an Academic Self-assessment - Determine strengths and challenges in each subject; assess learning skills and styles and what’s needed for success; determine sufficiency of content background; get specific academic support and seek modifications where needed.

Identify Needed Resources - Be sure to have both psychological and medical support identified; be aware of how the family can help; and seek out appropriate mentors.

Social Adjustment - If the school has a peer mentoring program join it; find individuals with similar interests and talents; get socialization experience with other students in general education programs prior to college; be aware of the practical daily living issues of college life and address these prior to college.

The college years were a true laboratory for learning, and Michael benefited from the enriched academic program in the Honors College, fully participated in many aspects of college life, learned to live independently away from his family, and gained significant acceptance and recognition in many ways. While being a truly special individual with unique talents, challenges and abilities, Michael did succeed in his desire to be a “regular” college student in a regular school. When Michael graduated, he said that he had changed so dramatically in the four years of undergraduate school, that he wished he could start college all over again at a time in his life when he would have been better prepared to experience college both socially and academically. And today, this college is ready to help Michael and students like him.

A Model for a Successful College Experience:
The Bridges to Adelphi Project
By Mitchell Nagler MA, LMHC

Students embarking on college life often feel lost and anxious. For students with Asperger Syndrome (AS), the transition from high school to the college experience can often be overwhelming, confusing and isolating. For the most part, students with AS have received substantial support in their K-12 education. However, many higher education institutions have not yet caught up to the needs of this unique population.

Understanding this issue, Adelphi University, through the Office of Disability Support Services, and with a grant from the Jewish Child Care Association, began the *Bridges to Adelphi Project* in 2006. *Bridges* offers counseling, coaching and support services to Adelphi students who struggle with AS and other non-verbal learning disorders. The focus of services provided is on academic, social and vocational issues.

In this program, all students meet at least once a week with a coach/counselor. Depending on their particular needs, most students receive academic support focusing on executive functioning and time management skills. Review of syllabi and scheduling time for schoolwork and studies is commonly provided for most students. However, when necessary, meetings with professors, help with registration, and referrals to the Learning Center for tutoring are among additional services that have been provided.

Because important parts of the college experience are campus life and activities, two socialization programs have been developed. Each *Bridges* student is offered the opportunity to meet with a trained and supervised Peer Mentor for an hour or two per week. Mentors, who are volunteer Adelphi students, provide mod-

els for appropriate social behaviors and the opportunity for *Bridges* students to safely practice socialization skills. As well, there are monthly group meetings and activities where members can meet and get to know each other. Group activities have included trips to museums, bowling, the movies, meals out, and yoga and relaxation training.

Because one of the stated goals of *Bridges* is to not simply graduate students and send them off without some vocational training, another important part of the program is provided through cooperation with the Adelphi Career Development Center. This program has provided students with opportunities to get jobs on campus, develop good work habits, and learn to build their resumes.

As the *Bridges to Adelphi Project* continues to grow, student needs will inspire the growth of services provided. As of the completion of the Spring 2009 semester, 17 of the 21 *Bridges* students have succeeded at Adelphi. In fact, we had our first graduate of the program this past spring. This fall we are expecting 30 students to be enrolled in the program. As awareness of the *Bridges Project* has grown, there have been increased inquiries and applications to the university.

Based on the success of *Bridges*, Adelphi is opening an out-patient community clinic offering group and individual counseling to individuals with AS (ages 15 to 22 years) beginning this fall. This program, which is a cooperative initiative of Adelphi’s Derner Institute for Advanced Psychological Studies, and the Masters Program in School Psychology, is a comprehensive support and guidance program for individuals and their families within the community who have high functioning autism or Asperger’s Syndrome. There is every reason to believe that, given the support services now offered at the University, there will be continued student success and interest from new applicants.

Recognizing Challenges,
Self-Advocacy, and Disclosure
By Stephen Shore, EdD

With buzzing in his ears and a splitting headache, the first day of class for “George” was awful. On the second day, George felt like there was a strobe light in the room and he felt as poorly after this class as well.

Similar to many people on the autism spectrum, George perceives fluorescent lights as most individuals perceive a strobe light. Likewise, with a majority of persons with autism, George has not quite drawn the connection to how this type of lighting interferes with his functioning. Even if George made the connection, how is he going to inform the instructor or another person of his visual difficulties with fluorescent light and then explain why this is a problem?

As with perceiving nonverbal cues and pragmatics, successfully determining one’s challenges, advocating for one’s needs and making a proper disclosure is often very difficult for people on the autism spectrum. The good news is that, similar to decoding body language and meaning “between” the lines, effective self-advocacy strategies can be taught.

The Three-Step Process of
Effective Self-Advocacy

Scanning the environment for chal-

lenging situations is the first step. Answering the questions of what is causing the difficulty is key. These challenges can be scanned in three categories. *Sensory scanning* involves how the person perceives the environment. For example, a successful sensory scan for George would reveal that he is having difficulty with the lighting in his classroom. *Cognitive scanning* centers on how we think. An example could be that George has difficulty with multi-tasking to the point where he is unable to simultaneously listen to a lecture and take notes. The *socio-emotional category* involves perceiving and decoding social cues and how we feel. An example here might be that George has difficulty knowing when his classmates tell a joke and feels left out as a result.

Step two is the *advocacy* effort where George explains his needs in a way that promotes greater understanding in a way the professor (or disabilities office) can provide support. Perhaps George could request a different type of lighting, move to a seat close to the window, or see about disconnecting the light that is above his head. In addition to knowing what accommodations work for an individual, a critical part of successful advocacy is understanding what accommodations are appropriate to ask for. For example, if George has aural sensitivities, it is likely *not* appropriate to ask the manager of a movie theater to lower the volume.

Disclosure or providing an explanation for the requested modification or greater understanding is the next step. Disclosure can be full or partial. A partial disclosure might be where George indicated that fluorescent lights give him a headache because he has sensitive eyes. In other words, George mentioned only the specific aspect of having autism that relates to the situation. Most of the time, a partial disclosure is appropriate, as doing an impromptu mini “workshop” on autism that would come with a full disclosure would be excessive. However, a full disclosure with the student disabilities office at a university is appropriate, because that is required in order to qualify for accommodations.

Summary and Conclusion

The three-step process of scanning the environment, advocating, and disclosure outlined above becomes necessary when the effects of having autism significantly impact a situation or relationship and there is a need for greater mutual understanding and productivity. For example, when in a classroom illuminated with incandescent lamps or natural lighting from window, there is no reason for George to mention his visual sensitivities or that he is on the autism spectrum.

Preparing for successful self-advocacy requires studying and analyzing the situation like a scientist. However, the three-step process of scanning, advocating, and disclosure is often very much an art form as it requires clear communication with another person and decoding if they understand what you have to say.

This three-step approach is very helpful to me in my advocacy efforts and I hope others on the autism spectrum can benefit

see *Challenges on page 36*

The Intelligent Mind of an Individual with Asperger's Syndrome

By Robert Jay Bernstein
Educational Specialist

This is not an article to help individuals with Asperger's Syndrome. This is an article for the rest of us. In fact, there are many individuals with Asperger's who would rather just be left alone and not be helped or "cured." It's time for us to realize that there is something special about this population that could truly benefit society.

We are always impressed when presented with a person with a disability who can do extraordinary things. Take Geordi La Forge of Star Trek who was blind from birth and adapted a sensory device that absorbs and processes information that is well beyond the capabilities of his colleagues. He can clearly "see" things that no one can see. Or take the TV character, Monk, who, because of his obsessive-compulsive nature, sees the slightest difference in a crime scene which proves valuable. It's also no secret that individuals with mental retardation can be exceptional workers because of their care, dili-



Robert Jay Bernstein

gence and pride in doing a good job.

Films like "Adam" introduce individuals with Asperger's Syndrome as just that – an individual – someone we can relate to. That's a good first step. There is no question that these individuals with As-

perger's need to find their own niche so that they can excel in their field, make a living, and live happy and productive lives. However, we can go further; in addition to helping individuals with Asperger's Syndrome find job placement where they can excel and succeed, we need to come to the realization that society can benefit from these very special minds just the way they are.

Because of their clearness of expression and intelligence, this population can help provide insight into those who have been described as "weird" or "odd" and sometimes dangerous. Although one element of Asperger's Syndrome involves difficulty in social situations, these individuals often have tremendous insight into themselves, others, and society.

For example, one client explained why he often acted like a chicken in the park – someone we would all normally be afraid of and would pull our youngsters away from. He explained how he had difficulty initiating conversations with others, and that acting like a chicken was like throwing out a fishing line to see if he would get a response. If someone would say, for example, "Pretty good imitation of a chicken,"

he would then be able to have a conversation with the person. He was not dangerous; he was desperate for social contract.

More importantly, this young adult with Asperger's gave me insight into those who may indeed be dangerous. For example, he spoke extensively about Cho Seung-Hui opening fire in Virginia Tech, answering the question of how to understand the mind of such a person. This individual, on tape, described what Cho Seung-Hui was thinking and how the shooting of 33 people could have been prevented. He talked about how the Seung-Hui needed a friend and how we can accomplish this with planned perseverance. He was so convincing that we wanted to take the tape to "60 Minutes," but his parents rejected the idea at the time.

The point here is that society needs to appreciate the difference between the mind of one with Asperger's Syndrome and that of the neurotypical population. We should focus on the tremendous power and dimensions of their remarkable minds, rather than stigmatizing their social deficits. Let's not feel sorry for these individuals; let's ask them for their insights – they sure have a lot to offer.

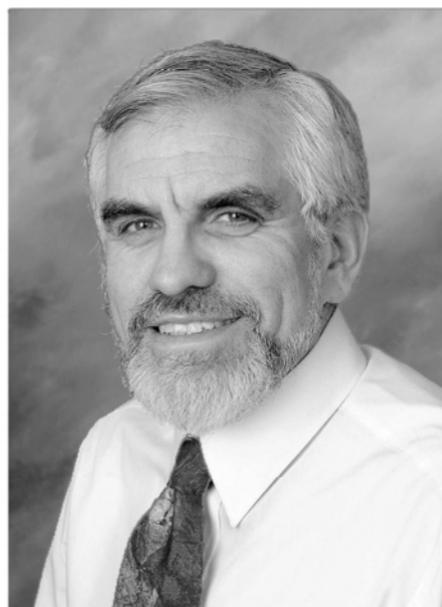
*Provide Autism Spectrum News to Your Clients and Staff
See Page 47 for our Group Subscription Form*

AUTISM: Result-Oriented Therapy



**Give Your Child
the Gift of Success**

*I can help
your child
break
through
Autistic
Tendencies*



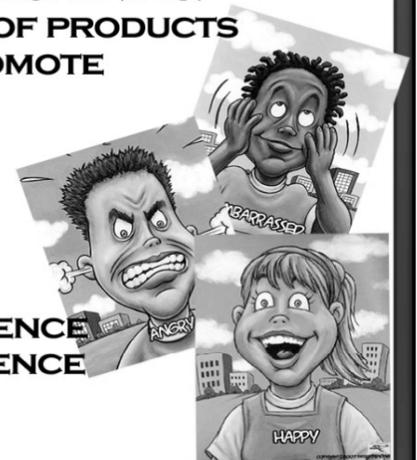
Robert J. Bernstein
Educational Specialist
914.478.4868

email: rjb@autismspeech.com • www.autismspeech.com

WeAnimateCharacter.com

USE OUR PUZZLES TO HELP SOLVE THE PUZZLE. INTRODUCING EMOTIONAL IDS. EMOTIONAL IDS IS A SERIES OF PRODUCTS (FOR K-12) DESIGNED TO PROMOTE GROWTH IN THE AREAS OF:

- COMMUNICATION
- CONCENTRATION
- COOPERATIVE SKILLS
- EMOTIONAL INTELLIGENCE
- INTRAPERSONAL INTELLIGENCE
- INTERPERSONAL INTELLIGENCE
- SPATIAL INTELLIGENCE



EMOTIONAL IDS ARE AVAILABLE IN FIVE PUZZLE PIECE SIZES. NUMBER OF PUZZLE PIECE, DEPENDENT UPON USER'S ABILITIES. MAKE THE CONNECTION; COME VISIT US AT WEANIMATECHARACTER.COM. CLICK THE FEATURED PRODUCT BUTTON AND FIND OUT MORE.



Stem Cells from page 6

Medical Director of the U.C. Davis M.I.N.D. Institute.

The autism spectrum disorders comprise a set of developmental brain disorders affecting social interaction and communication that remain poorly understood yet today represent the fastest growing developmental disability diagnosis in the United States. In addition to its research collaboration with Autism Speaks, CHOC Children's has emerged as a regional leader in the diagnosis and treatment of autism spectrum disorders. In April, 2009, The Family Autism Network was created as a collaboration between two neurodevelopmental programs at CHOC Children's and UC Ir-

vine and the Grandparent Autism Network to provide a one-stop resource for Orange County families impacted by autism.

About the NHNSCR at CHOC Children's

The National Human Neural Stem Cell Resource (NHNSCR) was established to support national research in the field of neural stem cells by providing a reliable source for these cells to investigators nationwide. In addition to acting as a stem cell repository, the NHNSCR also hosts a periodic course on the culture of human pluripotent stem cells and adult stem cells that has trained more than 75 scientists from around the world in these techniques.

The NHNSCR plans to train autism researchers in the use of the new cell lines created under the NIH grant. More information is available at www.nhnsr.org. Inquiries about cell donation should be sent to research@CHOC.org.

CHOC Children's is exclusively committed to the health and well being of children through clinical expertise, advocacy, outreach and research that brings advanced treatment to our patients. CHOC's regional healthcare network includes two state-of-the-art hospitals in Orange and Mission Viejo, several community clinics, a residency program that trains tomorrow's pediatricians, and four centers of excellence - The CHOC Children's Heart, Cancer, Neuroscience, and

Orthopedic Institutes.

CHOC earned the Silver Level CAPE Award from the California Council of Excellence – the only children's hospital in California to ever earn this distinction, and was awarded Magnet designation – the highest honor bestowed to hospitals for nursing excellence. Recognized for extraordinary commitment to high-quality critical care standards, CHOC is the first children's hospital in the nation to earn the Beacon Award for Critical Care Excellence from the American Association of Critical-Care Nurses.

For more information about CHOC Children's, visit <http://www.choc.org/>.

This press release was reprinted with permission from the Children's Hospital of Orange County.

Seaver Center from page 11

Opportunities at the Seaver Autism Center

In recognition of these advances and an ever-changing field, we have introduced state-of-the-art genetic testing to clinical practice and research at the Seaver Autism Center. As part of this, we have partnered with the Department of Genetics and Genomic Sciences and the Institute of Personalized Medicine at Mount Sinai School of Medicine to translate the research findings from the Seaver Autism Center and from other laboratories around the world into genetic tests to supplement behavioral

assessments in ASD. The Seaver Autism Center has always positioned itself to be a leader in defining the standard of care in ASD. It is our vision that using state-of-the-art molecular genetic, neurobiological, and clinical resources, we are now posed to make significant breakthroughs in identifying genetic subtypes of ASD and developing targeted treatments.

In addition to genetic and neuroimaging studies, we are currently conducting important studies examining novel therapeutics, including social skills group therapy, oxytocin, and LUMINENZ-AT™. Our Clinical Program continues to offer *Assessment &*

Evaluation Services, including diagnostic testing, neuropsychological testing, academic testing, and psychiatric evaluations. Evaluation can include genetic analyses. In addition, we offer comprehensive *Treatment Services*, including medication management, social skills groups, parent training sessions, cognitive behavior therapy, and a sibling support program. And 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. Finally, the Seaver Autism Center hosts an annual conference to

address current scientific trends and discoveries that will be held this year in April, 2010.

For more information about Mount Sinai's Seaver Autism Center, please call 212-241-9061, Email: theseavercenter@mssm.edu, or visit: www.seaverautismcenter.org.

Dr. Joseph D. Buxbaum, PhD, is Director at the Seaver Autism Center for Research and Treatment and the G. Harold and Leila Y. Mathers Professor at the Departments of Psychiatry, Neuroscience, and Genetics and Genomic Sciences at Mount Sinai School of Medicine in New York.

Challenges from page 34

from this protocol as well. While secondary students are likely to be reluctant to self-advocate, this skill is very helpful to the more mature college student and should be learned, practiced and applied. Self-

advocacy can be learned and it will be useful in many situations and will maximize one's likelihood for meeting with success.

Judith Cohen, PhD, JD, is a full professor in School of Education at Adelphi University. Adam Wittenstein,

MA, MS, is a secondary school math teacher and an adjunct professor in computer science at Adelphi University. Stephen Shore, EdD, is an assistant professor in the School of Education at Adelphi University. Mitch Nagler, MA, LMHC, is the Director of

the Bridges to Adelphi Project, sponsored by the Jewish Child Care Association, Adjunct Professor at Derner Institute of Advanced Psychological Studies at Adelphi University, and has a private practice in Manhattan and Long Island.

Grant Assessment from page 16

this is going to be new endeavor for the grantee, how successful have they been in implementing past research endeavors or programs is a good way to gauge success. Many grantors will want to know how effective a prospective grantee has been in managing their budget for past programs. Again, there are numerous questions and approaches that are reviewed by grantors.

One of the key elements in assessing grant proposals is budget. The budget of the grantor and the budget for the program presented by the grantee are major considerations. Most organizations that award grants have a Board of Trustees that determines the amount to be allocated in a given year. There are also state and federal statutes that can come into play based upon the size and type of organization the grantor is. Of course a grantor's strategic plan should incorporate the allocation of grant award funding. In terms of the budget of a submitted program, most grantors will look at comparables from their past experience with similar programs. Other times, experts are consulted to assess a proposed program's budget. Some organizations may consider the number of individuals being served or the

impact of the research, for instance, in budget assessment process. Again, there are many variables that impact a budgetary assessment of a grant proposal but regardless, this will be an important area of review for a grantor.

Once the pool of applicants has been narrowed down after a process of careful assessment that includes many of the items previously addressed, there is usually a second round of assessment for the remaining contenders. Often a group or committee does this and there is ample discussion and further review involved. During this part of the process there may be some unanswered questions that may come up about a promising proposal which may require a phone call or visit with the prospective grantee. Other experts may be called in to answer questions at this point in the process as well. This in depth part of the assessment process may take weeks or months depending on the due diligence standards of the grantor. This is also the time when any conflicts of interest are usually addressed and each grantor organization should have a stated policy on this matter.

If a prospective grant applicant has made it through this round of the process then things are looking promising but it is not necessarily a done deal. For instance,

a grantor may decide that it can only offer partial funding and request that the grantee find other sources of funding before a grant award can be made thereby assuring that the research or program will actually happen. Still other contingencies and changes may need to be addressed before the grant is approved. At this point too, a grantor will generally look at the array of proposals as a whole to make sure that the group of grantees for a given cycle reflects their grant giving intentions. As always, particular considerations come into play for each grantor organization.

Finally, the grant assessment process is over when the grantor determines that all of the variables have been thoroughly and completely considered in accordance with their procedures. The successful grant applicants are then notified and the busy work of coordinating and implementing the proposal begins. For many organizations the assessment process ends here, but not for all. Some grantor organizations have a post grant award process whereby grantees are required to submit interim reports and budget updates. There may be other requirements of grantees as well and these should be clearly spelled out to them by the grantor.

The grant giving process is a long, complicated and often challenging one

that requires a great deal of time, focus and tenacity on the part of the grantor. It is my belief that the grantor has a fiduciary responsibility to its donors and supporters as well as the community at large to fulfill this obligation with the greatest integrity and effort possible. Equally, grantees have the obligation to achieve the goals of their proposal and to do so with the highest standards, as presented in their proposal. When these objectives are attained and ongoing assessment assures them then the advancements we seek can be realized.

About the Author

Linda Walder Fiddle, Esq. is the founder and executive director of The Daniel Jordan Fiddle Foundation, a national 501 (c)(3) autism organization with the mission to develop and support through grant-giving, residential, vocational, recreational, educational and family programs that honor the individuality and enhance the lives of adolescents and adults with ASD. The Daniel Jordan Fiddle Foundation has been awarding grants to programs for adults with ASD since 2002 and is the only national autism organization with this specific mission. For more information visit: www.djfiddlefoundation.org.

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

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

For further information contact the facilitators:

**Bonnie Kaplan - Parenttalk@gmail.com
Judith Omidvaran - Judyomid@aol.com**

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

Focused on:

- Employment & Vocational Issues
- College Coaching & Supports
- Socialization
- Self-Advocacy
- Dating & Relationships

On the second Sunday of every month there will be an outing.

For further information contact the facilitators:

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

Meeting Dates:

2009 - 10/4, 10/25, 11/22, 12/20
2010 - 1/24, 2/21, 3/14, 4/25, 5/23, 6/13

New Location:

**Westchester Arc
The Gleeson-Israel Gateway Center
265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532**

Match Konnection

New Possibilities for High Functioning People in Their 20's and 30's with Learning Disabilities, Autism, and Aspergers.

Make Friends, Experience New Things, and Have Fun!
Group Meetings are Sundays at the JCC in Manhattan.

Call Myrna: (917) 653-4751

**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 GL2
White Plains, N.Y. 10603
(914) 686-3116 x 104



The Glenholme School
A Devereux Center



An exceptional boarding school for students with special needs; The Glenholme School offers an individually prescribed learning environment with a steadfast academic curriculum. Using our effective individualized services, we apply a positive behavior support model focused on development of social skills and lifelong strategies for success.

The school's milieu therapy addresses varying levels of academic, social and special needs development in students, both boys and girls, ages 10-18 and postgraduates. We prepare our graduates for continued education in traditional day schools, boarding schools, colleges and universities.

SPECIALIZING IN:

Asperger's/ADHD, emotional, behavioral and learning disabilities

- | | |
|----------------------------|------------------------|
| Self-discipline Strategies | Career Exploration |
| Motivational Management | Multimedia Curriculum |
| Positive Behavior Supports | Social Coaching |
| Character Development | Relationship Mentoring |

**Open Enrollment for
Glenholme Middle School and High School,
Summer Camp Program,
and Glen Ridge Postgraduate**

Contact Admissions for more information
or to schedule a tour.

81 Sabbaday Lane
Washington, Connecticut
admissions@theglenholmeschool.org
Phone: 860.868.7377 Fax: 860.868.7413
www.theglenholmeschool.org

Supporting Parents from page 18

Step 1: Become knowledgeable about the services in your area in order to find a clinic that follows a Multidisciplinary Team Assessment model

If you live in an urban area, your physician may be aware of specialty clinics that serve individuals with ASD and their families. It may also be beneficial to attend a meeting of a local support group, or to participate in a workshop. This provides families the opportunity to network with other parents who have already been through the diagnostic process and who truly understand the complex challenges of parenting a child with ASD. Conducting an online search of reliable websites can also be helpful (for example, *Autism Society of America*). You can often find local discussion boards or clinic websites which describe the range of services provided. For those in the New York area, the *Aspergers Syndrome and High Functioning Autism Association (AHANY: www.ahany.org)* provides free monthly support groups and a daily hotline for parents and caregivers looking for support and information.

Step 2: Contact a clinic and participate in their pre-assessment process

Once you have some referrals for clinics, the next step is to contact the center to inquire about their assessment services and the evaluation process. Ideally, a clinic will have an intake coordinator or social worker who can provide caregivers with clear and comprehensive answers to their questions, and guidance if families are unsure what services they are looking for. An essential question for families to ask concerns the level of experience the clinical staff has in working with individuals who are similar to their child. For example, does the center primarily serve preschool-aged children? Does the clinical team work with young adults with Asperger's? How much experience has the clinical team had in diagnosing girls with ASD? It is very important to find a program that encourages questions and being able to openly share concerns, worries, and hopes. Characteristics of an ideal comprehensive assessment center include:

- An intake coordinator or social worker to support families when they are deciding what services to pursue and throughout the duration of the assessment
- A multidisciplinary team approach
- An assessment process that is clearly described and outlined, including a parent feedback session at the end of the evaluation
- A caregiver interview including a thorough developmental history
- A comprehensive review of school records and prior evaluations
- Use of gold standard diagnostic assessment measures
- Developmental, cognitive, achievement, speech-language, behavioral, play, emotional, and adaptive func-

tioning assessments as needed

- Opportunity for observation of the individual in their home, educational, or other setting if desired
- A multidisciplinary team/family feedback session to discuss the findings and implications of the assessment and recommendations for next steps
- The assessment team incorporates the latest research findings into their clinical practice
- A detailed written report summarizing the assessment findings and outlining recommendations (e.g., educational, social, behavioral, resources) is provided to the family
- Referrals to other pediatric specialists are provided as appropriate (e.g., psychiatry, ear nose and throat, neurology, gastroenterology, sleep clinic, nutritionist, gynecology)
- A post-evaluation appointment with the social worker is available following receipt of the report for families to discuss the assessment findings and recommendations
- Most importantly, a clinical team that is warm, caring, understanding, energetic, and dedicated to assisting the families they work with.

An initial phone intake may be required prior to moving forward with a first appointment. It will be suggested at this time that you gather and submit all reports and assessments completed in the past (e.g., psychological, speech-language, psychosocial, medical, psychiatric), including the individual's most recent Individualized Educational Plan (IEP). Families have reported that it can be extremely helpful to keep a binder to organize these documents and all other paperwork and correspondence pertaining to their child or the individual being referred. The clinic will also likely send out forms and questionnaires to be completed prior to the first appointment.

Step 3: The multidisciplinary assessment

At times, families are not immediately ready to start a full assessment without having had the opportunity to meet with and discuss their concerns with someone from the clinical team. The first stage of a multidisciplinary assessment can often be a consultation with the team social worker, during which parents are provided with more information about available services, and information is gathered pertaining to the child's developmental, medical, diagnostic and educational history. If a family decides that they would like to continue the assessment process, the social worker shares the information gathered during this meeting with the multidisciplinary clinical team. Members of the team must review prior information received and work closely together in order to collaborate on assessment goals and to develop an individualized comprehensive assessment plan. A carefully designed assessment is necessary in order to achieve optimal functional impact of the

evaluation.

The number of appointments required as part of a multidisciplinary assessment can vary. Some centers offer clinics during which most testing is conducted on a single day. Other centers offer appointments over the course of a number of weeks. Ideally, a clinical team will develop an assessment schedule that fits best with the objectives of the evaluation. Waitlists for such assessments can also vary greatly across centers, and typically range from one week to a number of months.

Whether the assessment takes place during a single appointment or over the course of a number of days, families should expect to be kept informed about what will be happening during each session, and what role they can/should play (e.g., sitting in the room, completing questionnaires, participating in an interview). Parents should feel comfortable asking any questions they have during the assessment process, and need to be provided a specific contact person whom they can call throughout the evaluation; this team member is typically the social worker.

The final stage of a multidisciplinary assessment is the parent/client feedback session. The parent(s)/caregiver(s) or clients themselves (if an adult) meet with some or all members of the clinical team to discuss findings, diagnosis, and recommendations. Even though issues related to ASD are often complex, the clinical team should present the findings from the evaluation in a way that is as clear and easy to understand as possible. The team should also encourage a family or client to ask any questions they may have about the information they are receiving. It is never sufficient for clinicians to present findings without also presenting a comprehensive set of recommendations, next steps, and resources. Unfortunately, many families have reported that they "got very little" out of their evaluation and were sent on their way with a diagnosis only and no next steps that they could pursue regarding intervention (Osborne & Reed, 2008).

It is often not easy for parents to process a lot of information during a feedback meeting that can be both emotional and overwhelming. As such, the importance of a comprehensive written report cannot be underestimated. The report from a multidisciplinary team evaluation should provide information about the assessments conducted, the findings from each assessment, a summary and diagnoses, and recommendations for school, home, and the community. Families or individuals should always feel that they have been given concrete suggestions for what they should do next, and what steps are most important to take (e.g., calling the school district to request a CSE meeting).

Step 4: After the assessment

Some time after the feedback session, typically from a week to two months, the written report is mailed out. What happens next? Again, families have reported that following their assessment they often feel left on their own to figure out how to proceed. During an evaluation, a family establishes an important relationship with the clinical team, and it can be highly beneficial for families to be able to reconnect after they have had some time to think about the assessment findings and read the written report. At our clinic, families have the opportunity to schedule a "follow-up

consult" with the team social worker. Next steps are highly individualized and different for each client seen at our clinic for an evaluation. The social worker assists families in navigating resources based on their child's age, diagnosis, recommendations from the clinical team, and current education and community services. If a clinic provides a continuum of services, families may be eligible to participate in interventions that are ongoing. Some of the following suggestions are discussed with families at our program:

Review of the Multidisciplinary Assessment Report: It is suggested to families that they send a copy of their child's report to the school and request a CSE meeting to discuss the recommendations that are outlined. For older clients, we recommend sharing the report with job coaches, post-secondary school counselors, therapists or other service providers as appropriate.

Center-Based Individual Services: Families can discuss the services offered at our Center that are a good fit for their child, such as social skills or cognitive-behavioral therapy groups, individual counseling, psychiatry services, speech language therapy, and recreation activities.

Center-Based Parent Support: Parents can join one of the information and networking groups facilitated by the Center's social worker, participate in individual parent training or family psychotherapy, or attend one of the Center's educational workshops.

Community-Based Services: Recommendations are provided for wide range of community activities and services (e.g., recreation, camps, dentists, social groups).

Other Services and Programs: Eligible families have the opportunity to learn about state and federally funded programs including Medicaid and Medicare, Social Security Entitlement, and Vocational and Educational Services for Individuals with Disabilities (VESID). Families can also learn about community organizations such as GRASP, the Global and Regional Asperger Syndrome Partnership, and community services related to life planning (e.g., supplemental needs trusts, guardianship).

When a child or an adult is thought to possibly have an autism spectrum disorder, obtaining an accurate diagnosis can be a daunting process. It can be time consuming, costly, emotionally draining, and confusing. However, the process can be made easier and result in a wealth of information and guidance when qualified professionals conduct a comprehensive diagnostic evaluation and assessment of functioning in all domains. This article aimed to provide parents and caretakers with information about pursuing such a multidisciplinary team assessment. The Fay J. Lindner Center for Autism and Developmental Disabilities at Advantage Care Diagnostic and Treatment Center, affiliate of AHRC Nassau and NS-LIJ Health System, provides assessment services following a multidisciplinary model. Families, individuals, and professionals are welcome to contact the Center at any time to discuss services. Georgianna

see Supporting Parents on page 44

A Roadmap for Parents Whose Child Has Recently Been Diagnosed With Autism

By Lauren Agoratus, MA
Parent
Family Voices NJ

Parents may not know that testing for autism, or any disability on the autism spectrum, is a process. According to the American Academy of Pediatrics (AAP), first there is developmental surveillance which means watching the child over time. As soon as there is cause for concern, developmental screening is done, and the sooner the better. This means that a short “standardized” tool is used to check if a full evaluation is needed. If so, then a developmental evaluation will be done to find out the child’s specific condition.

Autism is a “Pervasive Developmental Disorder.” This means it affects many areas (pervasive) of what the child can do, and that the child will be behind typical peers in one or more areas of development. Pervasive Developmental Disorders include: autism, Asperger Syndrome, PDD-NOS (pervasive developmental disorder-not otherwise specified), Rett’s Disorder, and Childhood Disintegrative Disorder. PDDs are called “spectrum” disorders because even within the same diagnosis like autism, there’s a wide range of abilities, strengths and needs.

My Child Has Just Been Diagnosed with Autism, Now What?

The most helpful thing to do is find out as much as you can about autism. Once you know what you’re dealing with, you won’t feel so helpless. Parents can get a free copy of the Exceptional Parent magazine resource guide by calling (800) E-PARENT which lists all the national and state autism groups. They also have online matching of families. Support from other parents is also helpful. Parent-to-Parent matches trained volunteer families for free



Lauren Agoratus, MA

to other parents of children with the same condition. To find Parent-to-Parent in your state, go to www.p2pusa.org and click on the map. Another good matching organization is Friends Health Connection at (800) 48-FRIEND. Parents can also find a national listing of support groups at www.selfhelpgroups.org.

Getting Education Services

If your child is diagnosed prior to his third birthday, “early intervention” services are available to help support your child and family. To find the early intervention program in your state, go to www.nectac.org/contact/ptccoord.asp. (Note: You may request an early intervention evaluation if you have concerns about your child’s development even if your child has not been diagnosed with autism.)

If your child is age 3 or older, your local school district will provide “special education and related services” under an Individualized Education Plan (IEP). Please

note that many states and school districts have eliminated the medical evaluation for special education but even without a diagnosis parents can send a letter to your district requesting “evaluation for eligibility for special education” to get services for your child. Also, parents are part of the IEP Team that writes the IEP and makes decisions, including placement decisions. Parents need to know that your child has the right to attend the same school they would attend if they didn’t have autism, and another placement should happen only if services didn’t – or all agree they can’t – work in the home school. If you don’t agree with your school team, contact free help at the Parent Training and Information Center in your state by clicking on the map at www.taalliance.org.

Getting Therapies

Pediatricians and family doctors may refer families to specialists. Specialists in autism are usually developmental pediatricians and pediatric neurologists. It is important that parents check that any specialists are pediatric specialists, who have experience with children.

As a parent, you may not know where or how to get therapies for your child. It’s important to get needed services through early intervention or the school district. These include speech, occupational, and physical therapies. For children with autism, other services on an IEP could include sensory integration (if the child is sensitive to noise, touch, etc.) or social skills on how to relate to others. For the school bus, services on an IEP can include a bus aide and door-to-door transportation. Many times schools may suggest that some services are done throughout the day or done in groups. You and the rest of the IEP team can decide if your child gets these services one-to-one, how long the session is, and how many times a week. Parents can

collaborate with schools by asking and discussing, and most importantly keeping the focus on your child by saying this is what your child needs.

Parents also need to know that, while healthcare insurance coverage is changing, there can be a limit on policies for benefits children receive over their lifetime. Finally, if you have problems with healthcare issues, you can contact Family Voices and the Family to Family Health Information Center in your state by clicking on “State FV” at www.familyvoices.org.

How Do I Know What Will Help My Child?

Parents may hear about many therapies or even cures. It’s important to look at what has been researched and what works, not just one family’s story or book. “Educating Children with Autism” at www.nap.edu is national research and which therapies so far have been proven to help. Many states have used this document to develop their guidelines on autism for both early intervention and special education. The Maternal/Child Health Bureau has an autism “knowledge path” with resources at www.mchlibrary.info/KnowledgePaths/kp_autism.html. The AAP also has autism resources for parents and professionals at www.aap.org/healthtopics/autism.cfm.

As parents, you need to know that often your instincts are right. If you are concerned about your child’s development, it’s best to speak up as soon as possible. Research shows that children who get therapy earlier have better results. If needed, rather than waiting, get a second opinion. Remember, you are also an expert on your child!

In addition to her work with Family Voices, NJ, Lauren Agoratus, MA, is a volunteer for the NJ Caregiver Community Action Network-National Family Caregivers.

Awareness from page 33

has launched a series of campaigns targeting the general population’s awareness of ASDs.

We may not be able to connect through shared experiences or struggles; however, we can connect in our shared desire to improve the lives of children. This desire is one that can be shared amongst parents of children who have been diagnosed and those who have not, as well as concerned community members. People can empathize and connect with a mission regard-

less of their status – if the case is positioned properly.

I, for one, speak from experience. I am not a parent; yet I work with an organization whose focus is parental support. Often asked, “How do you connect?” my response is, “whether I am a parent or not, this is a great cause.”

I encourage everyone reading this article to take the initiative to expand the bubble. If you are a board member or a manager within an organization, take the time to assess how your organization is communicating to the community. Ensure

that your message is one that is both effective for your mission, as well as inclusive of the broader community; not just the main constituents.

It takes a community to raise a child; by reaching parents before they are parents, the community is engaged to significantly help bring about the changes for which we so desperately fight.

About the Author

The Humanistic Strategist, John is a management consultant who focuses

on how organizations engage their stakeholders, thereby improving sustainability. Among his many volunteer activities, he occupies the Marketing and Communications seat on the Board of Directors for the Rhode Island Parent Information Network (RIPIN); a nonprofit dedicated to creating an environment that empowers special needs individuals and their families regarding health and education. You may read more information about him and his consulting at www.thehumanisticstrategist.com.



Autism Spectrum News

Your Trusted Source of Evidence-Based News and Resources That Are of Vital Interest to the Autism Community

From the Publishers of Mental Health News

Visit our Website to Read All of Our Current and Back Issues

www.mhnews-autism.org

Mental Health from page 20

disability moderate the presentation of MHDs that have been identified in the general population. In fact, there is even a lack of agreement in the research community as to whether some disorders are truly co-occurring, or part of the ASD. For example, some argue that ADHD should not be diagnosed as a co-occurring disorder because problems with attention, hyperactivity, and impulsivity are pervasive in this population. There is also no consensus as to whether or how diagnostic criteria should be modified for this group of children. However, the best clinical and research evidence to date suggests that children with ASD often present with emotional and behavioral syndromes in need of specific intervention. We also know that much more research is needed to inform clinical practice.

Another issue affecting assessment and treatment is the lack of assessment measures for MHD validated specifically for youth with ASD. More research on existing measures may facilitate better understanding of MHD in this population, and conceptual advances can inform the development of new measures. Clinically, results based on measures that have not been studied in youth with ASD are of unknown validity. Use of such measures can result in misdiagnosis and inaccurate conclusions regarding the specific nature of a child's problem.

Similarly, while there is some emerging evidence that cognitive-behavioral treatments (e.g., Wood et al, 2009) and certain medications may be beneficial for some individuals with ASD and co-occurring MHD, there is not yet a strong evidence-base to establish a standard of care to inform clinical practice. The effectiveness of some psychosocial interventions developed for use with the general population (e.g., exposure and response prevention for some anxiety disorders) may greatly depend on the therapist's skill at tailoring the therapy to align with the developmental characteristics and learning style of those with ASD.

Collectively, these issues present formidable challenges to community health-care providers. Relatively few will have the clinical experience and knowledge of the research literature that will be needed to make the best clinical decisions for these children. In our experience, even the most seasoned professionals are challenged at times to make valid diagnostic and treatment decisions. Most clinical, primary care, and school providers may not recognize the symptoms of MHD and/or may attribute emotional and behavioral symptoms to the child's ASD (referred to as diagnostic overshadowing). Moreover, once one leaves the major metropolitan areas, there are shortages of psychological and psychiatric professionals; and, of those professionals residing in rural areas, lack of professional development opportunities may preclude development of specialized knowledge of assessment and treatment in ASD. When MHD is recognized, developing an appropriate treatment protocol and identifying qualified providers is challenging.

Considerations

Better identification and treatment is possible through at least two broad but related efforts. First, information regarding best practices in assessment and inter-

vention, and information about how MHD's may present in children with ASD should be made available to community healthcare providers, school personnel, and parents. Second, community capacity-building initiatives are necessary to create the infrastructure needed to improve access to quality care.

Community Education: Increasing Awareness & Knowledge

Continuous assessment of children with ASD is extremely important. The emerging literature suggests that children with ASD are at higher risk for a co-occurring MHD, so they should be closely monitored over time. Identifying changes in baseline functioning with respect to severity of autism symptoms, aggression, self-injury, sleep, and appetite may be helpful in determining the presence of or heightened risk for, a co-occurring MHD. Risk factors that have been associated with co-occurring MHD in the general population should be assessed, which can include child-specific developmental factors, quality of the parent-child relationship, caregiver stress, family history of MHD, acute stress, and chronic adversity (e.g., low SES, poverty). The mental health of children with ASD is just as likely to be affected by these factors. Multiple assessment methods are necessary to gather the evidence required to separate ASD- and MHD-related symptoms. The reports of those who know the child well are critical to understand behavioral idiosyncrasies. Furthermore, prospective assessment is important for the differential diagnosis of mood disorders (e.g., unipolar vs. bipolar disorders).

Clinicians should be aware of the psychometric properties of assessment instruments used with this population. In our research, we have found the parent report Child Behavior Checklist 1.5-5 (Pandolfi, Magyar, & Dill, 2009) assesses the same emotional and behavioral syndromes in children with ASD as for the general population. We are completing a study on the CBCL 6-18 Parent Report Form, and preliminary results are supportive of this measure. The content of any measure should be inspected to be sure that it assesses for the specific types of behavioral and emotional concerns presented by each individual child. We recommend the use of semi-structured clinical interviews such as the K-SADS (Kaufman et al., 1996), which has also been modified for use with those with ASD (see Leyfer et al., 2006).

Until an evidence-base is established for various treatments, principles of effective practice should be considered in the treatment of specific MHD. For example, the principles of Cognitive Behavior Therapy (CBT) can be used for those with anxiety and depressive disorders. However, the therapy needs to be tailored to the developmental level and learning style of the individual. The use of shorter sessions, direct instruction of skills, visual supports, rule cards, and social stories™ are often effective in helping youth with ASD acquire new skills. A focus on pivotal skills such as coping statements and problem-solving skills appear very much needed. Specific behavior support plans may be needed to maintain motivation and set the occasion for the application of new skills in different settings. Parent training and involvement in therapy is an important part of the process.

Parent education should assist parents in recognizing changes in their child's behavior that may signify that he/she is developing symptoms of a MHD. For example, parents should be educated on how to determine if changes in behavior represent changes in baseline functioning or normal variability in child behavior. Parents should be provided with information on the importance of changes in their child's sleeping or eating habits and their child's report of somatic symptoms such as stomachaches and headaches. If a child has a history of anxiety, increases in worries or fears may indicate changes in the severity of his/her anxiety. Additionally, displays of aggression or self-injury or changes in the frequency, duration and/or intensity of these behaviors may also indicate changes in the child's mental health status. Finally, parents should be provided with information on the importance of noting changes in some of their child's autism symptoms, particularly worsening or decreases in social behavior (such as increased social withdrawal, increases in risk taking behaviors that have social consequences) and changes in preferred activities (such as decrease/increase in time spent on circumscribed interests or stereotyped behaviors). These behavioral changes, alone or in combination, may suggest that the child is experiencing some alteration in emotional and behavioral health status that warrants formalized screening by a professional.

Building Community Resources: Improving Access to Care

Our communities can benefit from broader dissemination of information on the assessment and treatment of autism and related disorders. This community education effort can be spearheaded by a number of organizations and entities. For example, informational products and community education events can be offered through state autism regional centers and/or national organizations that provide community education. Community-based research can assist in identifying gaps in diagnostic and treatment resources and professional expertise, and local, state and federal funding can be sought to engage in capacity-building activities to fill those gap areas. Professional organizations involved in the routine treatment of individuals with ASD, such as pediatricians, family care practitioners, and school psychologists, could benefit from continuing education on best clinical practices in the assessment and treatment of ASD and co-occurring or related disorders, and the establishment of guidelines for screening this at-risk group. These efforts will require a collaborative approach across systems of care in order for them to be effective in creating a seamless system of support for individuals with ASD.

About the Authors

Caroline I. Magyar, PhD is an Associate Professor of Pediatrics in the Strong Center for Developmental Disabilities, Division of Neurodevelopmental and Behavioral Pediatrics, University of Rochester School of Medicine & Dentistry, and Director of the Rochester Regional Center for Autism Spectrum Disorders. Vincent Pandolfi, PhD is an Assistant Professor in the School Psychology Department at the Rochester Institute for Technology. Dr.'s

Magyar and Pandolfi have published on assessment practices in autism spectrum and other developmental disorders, and the psychometric evaluation of mental health screening tools in autism populations. They have co-presented on autism spectrum and mental health in their local community, as well as at the national and international levels, and have a long history of working together on clinical and applied research projects in the area of autism spectrum and related disorders. In addition to their academic work, Dr.'s Magyar and Pandolfi maintain a small clinical practice with specialties in diagnostic assessment and cognitive-behavioral treatment in developmental disabilities and co-morbid disorders.

References

- Burns, B.J., Costello, E.J., Angold, A., Tweed, D., Stangl, D., Farmer, E.M.Z., & Erkanli, A. (1995). Data watch: Children's mental health service use across service sectors. *Health Affairs, 14*, 147-159.
- DeBruin, E.I., Ferdinand, R.F., Meester, S., deNijs, P.F.A., & Verheij, F. (2006). High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders, 37*, 877-886.
- Howlin, P., Goode, S., Hutton, J., et al (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 45*, 212-229.
- Kaufman, J., Birmaher, B., Brent, D., Rao, U., & Ryan, N. (1996). Kiddie-Sads-Present and Lifetime Version; Version 1.0 of October 1996. <http://www.wpic.pitt.edu/ksads>
- Leaf, P.J., Allegria, M., Cohen, P., Goodman, S.H., McCue Horwitz, S., Hoven, C.W., et al. (1996). Mental health service use in the community and schools: Results from the four-community MECA study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 889-897.
- Lee, L.C., Harrington, R.A., Louie, B.B., & Newschaffer, C.J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders, 38*, 1147-1160.
- Leyfer, O.T., Folstein, S.E., Bacalman, S., Davis, N.O., Dinh, E., & Morgan, J., et al., (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism and Developmental Disorders, 36*, 849-861.
- Magyar, C.I. & Pandolfi, V. Psychiatric disorders in autism: Examination of needs and community practice. American Psychological Association Annual Conference, Toronto, CAN. August 2009.
- Pandolfi, V., Magyar, C.I., Dill, C.A. (2009). Confirmatory Factor Analysis of the Child Behavior Checklist 1.5-5 in a Sample of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 39*, 986-995.
- Wood, J.J., Drahota, A., Sze, K., Har, K., Chiu, A., & Langer, D.A. (2009). Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: A randomized, controlled trial. *Journal of Child Psychology and Psychiatry, 50*, 224-234.

Personal Experiences from page 20

parents often voiced disdain over what special education offered their children; not much at all, these mothers told me. Something important was going on, and I felt a need to find out more about it. *Targeting Autism* (1998) reflected what I learned about the explosion of applied behavior analysis (ABA). Parents of preschool age children who could afford the cost were instituting 40 hour a week in-home ABA programs. Parents who could not afford to do that were extremely angry and began to lobby the NYC Board of Education and the NYS Education Department for such intervention cost-free.

In the years between my teaching of children with autism and the mid 1990's, much had occurred to change special education, including the Individuals with Disabilities Education Act (IDEA) with its introduction of autism as an educational category in 1990. Once autism was recognized in this way what began to occur was a blurring of the distinction between "therapy," as the behaviorists called their intervention, and special education. That blurring became more notable when states like New York began supporting behavioral intervention for children with autism spectrum disorders, but only when it was delivered by special education teachers or clinicians with the highest degrees in their disciplines. Parents, motivated by the promise of ABA, then began demanding that the NYS Education Department take action to better prepare

special education teachers to work with their children in ways that they wanted. What parents sought was a state teaching certificate in autism focused on ABA. That didn't happen.

In the year 2000 I helped the New York Autism Network survey the state of teacher education for autism across the state. The preparation of special education teachers to work with autistic children was a very sad story, I reported to the NYS Education Department. In 2002 the NYS Education Department moved to do something about that, and 17 colleges, including Hunter College, received grants to prepare teachers to work with children with autism. At last some action has been taken, I thought, although much more was obviously needed.

One of the stipulations of IDEA was that students with disabilities were to be educated in the "least restrictive environment," which was defined as education with non-disabled peers to the extent appropriate; but little inclusion of students on the autism spectrum was occurring in New York City in the 1990's. In 2001 Dorothy Siegel, parent of a young adult with ASD as well as a researcher at NYU, set out to do something about that for part of the population of children with ASD, and she enlisted me as her partner. A few years later the ASD Nest program was born, and it is now in 14 elementary schools. That program serves children with ASD and higher cognitive functioning in inclusion classes starting at the kindergarten level. It includes many strate-

gies and supports that are considered best practice, including special training for new staff, which is conducted at Hunter College each summer (See the article on the ASD Nest program by Koenig, Bleiweiss, Brennan, Cohen, and Siegel in the September/October issue of *Teaching Exceptional Children* for more information).

More small signs of progress: All Deans of colleges in NYS with approved preparation programs for special education teachers were notified that the Commissioner's Regulations required their programs to include preparation in teaching students with autism; and as of September 2, 2009 candidates applying for a certificate in special education through individual transcript review must complete a mandated three hour training workshop on autism. That requirement also applies to administrators and supervisors assigned to special education after September 2, 2009. Three hours is not much (I made a plea for 15), but it is a start.

A noticeable shift has occurred in the nature of intervention programs for children with autism spectrum disorders in the past few years. The exclusiveness and rigidity of different approaches in the 1990's are not as striking or as rigid today. Discrete trial teaching is no longer thought of as the heart of applied behavior analysis; social cognitive strategies are crossing boundaries between approaches; and sensory-motor issues and interventions are beginning to be recognized in spite of a recent and somewhat shallow research base. My outlook has changed somewhat

too. I am more appreciative and respectful of the knowledge base and technical skills incorporated into good behavioral models (while still abhorring the narrowness that was widespread in many behavioral models in the 1990's and earlier).

I'm getting ready to retire, but I wanted to see even more openness. Thus, one of my most recent endeavors was an 18 month, foundation-supported mentoring project for a small group of younger professionals with wonderful skills and potential for leadership in the intervention field. The central goal of that project—The FAR FUND Fellows for the Future—in addition to advancing the skills of the Fellows in some areas, was to open their minds to ideas from different sources and approaches. That goal seems to have been achieved. Fellows steeped in ABA are incorporating strategies from social cognitive and relationship-based approaches which are quite consistent with some of today's more naturalistic ABA models, while Fellows wedded to social cognitive or relationship-based approaches are recognizing the value of some ABA practices. I believe that this openness will lead to better educational intervention for children with ASD.

About the Author

Shirley Cohen is a Professor in the Department of Special Education at Hunter College and Director of the Regional Center for Autism Spectrum Disorders at Hunter.

Medical Care from page 29

parents or guardians, and the consent of such persons shall be required for such treatment in non-emergency situations, except as otherwise provided.

A mental health practitioner may provide outpatient mental health services or perform an initial interview with a minor voluntarily seeking such services without parental or guardian consent if the mental health practitioner determines that:

- (1) the minor is knowingly and voluntarily seeking such services; and
- (2) provision of such services is clinically indicated and necessary to the minor's well-being; and
- (3) (i) a parent or guardian is not reasonably available; or
 - (ii) requiring parental or guardian consent or involvement would have a detrimental effect on the course of outpatient treatment; or
 - (iii) a parent or guardian has refused to give such consent and a physician determines that treatment is necessary and in the best interests of the minor.

*Thus, when the abovementioned three determinations are made, a mental health physician can provide either outpatient services to a minor or psychotropic medications to a minor as an inpatient at a hospital without his or her parent's consent.

A minor sixteen years of age or older who consents may be administered psychotropic medications without the consent of a parent or guardian or the authorization of a court where:

- (1) a parent or guardian is not reasonably available, provided the treating physician determines that
 - (i) the minor has capacity; and
 - (ii) such medications are in the minor's best interests; or
- (2) requiring consent of a parent or guardian would have a detrimental effect on the minor, provided the treating physician and a second physician who specializes in psychiatry and is not an employee of the hospital determine that
 - (i) such detrimental effect would occur;
 - (ii) the minor has capacity; and
 - (iii) such medications are in the minor's best interests; or
- (3) the parent or guardian has refused to give such consent, provided the treating physician and a second physician who specializes in psychiatry and is not an employee of the hospital determine that
 - (i) the minor has capacity; and
 - (ii) such medications are in the minor's best interests. Notice of the decision to administer psychotropic medications pursuant to this subparagraph shall be provided to the parent or guardian.

* Thus, a consenting minor over 16 years of age does not need parental consent or a court's permission in order to receive psychotropic drugs when the abovementioned requirements are met.

Treatment with Psychotropic Medications - Child is Not Consenting - A minor pa-

tient who objects to any invasive medical treatment or procedure may not be treated over their objection except as defined below. It is worthwhile for a parent to review the following relevant portions of the New York Code, Rules and Regulations:

- (1) Emergency treatment. Facilities may give treatment, except electroconvulsive therapy, to any inpatient (including minors), regardless of admission status or objection, where the patient is presently dangerous and the proposed treatment is the most appropriate reasonably available means of reducing that dangerousness. Such treatment may continue only as long as necessary to prevent dangerous behavior.
- (2) Minors.
 - (i) Except as provided in subparagraph (ii) of this paragraph, a patient who is a minor may be provided treatment over his or her objection if the patient's parent, legal guardian or other legally authorized representative has consented to the treatment, and the treatment is not one for which the consent of a minor would be legally sufficient.
 - (ii) If an individual, who is a minor and is a patient in a State-operated psychiatric center, (or a facility licensed by the Office of Mental Health) objects to psychotropic medication to which his or her parent, legal guardian or other legally authorized representative has consented, such medication shall not be administered pending the completion of the

following process, which shall be fully documented:

- (a) Upon the patient's objection to the proposed treatment, an independent review shall be conducted by a physician who specializes in psychiatry and is not an employee of the facility. Such independent reviewer, designated by the clinical director, shall review the patient's clinical record, meet with the patient, and provide a recommendation to the clinical director based on an assessment of:
 - (1) the need for the proposed treatment in light of the patient's current condition, the goals for the treatment, the patient's treatment history, any alternatives to the treatment and the therapeutic implications of treating the patient over his or her objection; and
 - (2) the patient's reasons for objecting to the proposed treatment, his or her ability to understand the factors described in subclause (1) of this clause, and the treatment staff's responses to the patient's objection.
- (b) Following the completion of the independent review, the clinical director shall also conduct a review as described in clause (a) of this subparagraph. Based on the clinical director's review and the independent reviewer's recommendation,

see *Medical Care on page 45*

Diagnosing from page 21

characteristics that are seen in specific medical conditions which can currently be identified or will be identified in the future as medical knowledge advances. At this time tests like EEGs and MRIs do not help make or confirm the diagnosis. Some specific medical conditions can be diagnosed by observation and confirmed by genetic testing or research brain imaging. Boys with fragile X often have prominent ears, large heads and long thin faces. Special chromosome or DNA studies are used to make the diagnosis of this X linked disorder – carried by asymptomatic women who pass the disorder to their sons. ASDs are more frequent in Down's syndrome than in the general population. The particular facial features of a Down's syndrome child are recognizable by many who watch them participate in the Special Olympics. Down's syndrome occurs sporadically often in children with older mothers. Several neurocutaneous disorders (affecting the skin and brain) have a high frequency of autism. Tuberous sclerosis is the most common diagnosable cause of autism. White ash leaf shaped patches on the skin suggest the diagnosis; MRI and gene testing can confirm it. Tuberous sclerosis is an autosomal dominant disorder with variable penetrance meaning that it looks different in different family members. It can also occur as a spontaneous mutation as the embryo is forming. Prenatal diagnosis is possible in many of these disorders if you know to look. Children with ASD generally have normal neurological examinations, although some have low tone and some, perhaps most commonly those with Asperger's, are clumsy. Many have relative large heads (15-35%) especially during the toddler years. Head size is thought to reflect changes in brain connectivity over time.

Overcoming from page 32

optimal performance of the child on the day of testing. While young children are typically seen for one evaluation session, a child can be seen for further visits if indicated. No matter if the child is seen for one session or more the evaluator must compare their observations with the parent report. It is ideal when the parent states that the child's behavior was typical on the day of testing. However, when the parent states that the child did not behave typically, then the examiner must probe for more detail into the differences

Functional Assessment from page 24

categories are access to attention, access to tangibles, escape from tasks, and automatic or sensory reinforcement. Access to attention and tangibles are both examples of positive reinforcement where the behavior occurs to gain access to either attention (e.g., "don't hit me, it hurts!") or tangible items (e.g., preferred toys or edibles). Escape maintained behaviors are a case of negative reinforcement where problem behavior occurs to avoid or escape (i.e., get out of) non-preferred tasks (e.g., academic tasks or self-care tasks).

Autism Specific Assessment Tools and Neuropsychological Testing

Autism, the most severe of the ASDs, is one of the most reliably diagnosed disorders in child neuropsychiatry practice. Careful history-taking and informal observation in the hands of an experienced professional will often yield an accurate diagnosis. The less severe forms of ASDs are less reliably diagnosed in part because agreement concerning diagnostic criteria for PDD-NOS and Asperger's has yet to be established. These less affected children and adolescents require formal, comprehensive assessment to determine whether an ASD or some other learning, language, or psychiatric disorder is at play. The gold standard tools for diagnosing ASD are the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). The ADI-R is a semi-structured, investigator-based interview for caregivers of individuals with ASDs. It is a comprehensive tool that covers the central areas of concern - social interaction, communication, and behavioral repertoire. The companion instrument, the ADOS, is a standardized protocol for the observation of social and communicative behavior and play in children and adults suspected of having an ASD. The ADOS is administered at 4 levels (modules); Modules are selected on the basis of communicative ability, with module 1 used for children with almost no words and module 4 administered to verbally fluent adolescents and adults. While each module differs in format, the information gathered with each module is scored for the presence or absence of behaviors associated with the areas of central interest in ASD. An ADOS for toddlers under the age of 3 has recently been developed. Cut-off scores have been established that have been found to reliably identify children with autism and PDD-NOS, particu-

larly when both instruments are used. Diagnosis using the ADI-R and the ADOS serves families best if these procedures are supplemented, when appropriate, by neuropsychological testing. These test results yield important information concerning general intellectual ability and intellectual strengths, language and language pragmatics, attention, executive functions, visuospatial skills, motor and motor planning, learning and memory, academic skills, and social knowledge such as theory of mind, and face and facial expression processing. Findings generate a set of specific recommendations for educational programming and outside services and flag a child's strengths. Because ASDs are outcomes of atypical brain development interacting with acquired learning through experience, each child's neuropsychological profile can be very different. Children vary widely with respect to language and language pragmatics and may show specific strengths or weaknesses in nonverbal processing. Many children with ASDs exhibit executive function weaknesses primarily affecting math and writing in school. Many children have sensory hypersensitivities or preferences that adversely affect social interaction. A child may have better verbal expressive abilities but more impaired social cognition abilities a profile that makes him or her initially seem more typical. However, a thorough history would reveal impeded relationship development despite superficially adequate day to day interaction. Other diagnostic procedures may be necessary to identify co-morbid disorders such as anxiety, ADHD, and depression. Occupational and physical therapy evaluations are often valuable, as many children with ASD have fine or gross motor delays. It is also important to learn about the child's home situation, the health of siblings, whether there are stressors present, and in general, the degree to which the child's environment is support-

between the parent report and what was observed, and possibly consider another testing session. Keep in mind that the parent or primary caregiver has many more observations of the child than the evaluator. In addition, they may have a strong wish either for their child to receive or to not receive a diagnosis of autistic disorder. It is certainly very understandable that a parent would not wish for their child to receive this diagnosis and this might affect their report of the child. All of this makes it more challenging for the evaluator to make the final diagnosis.

Some behaviors occur regardless of environmental consequences and these behaviors are thought to be automatically maintained, or maintained by sensory reinforcement (i.e., something that is internal to the individual engaging in problem behavior). Problem behavior can be maintained by one of these sources of reinforcement, or in some cases multiple sources of reinforcement. The results of functional assessment guide intervention by informing what to do as well as what not to do. For example, if a functional assessment indicates that a child's aggressive behavior is maintained

by access to attention an appropriate intervention may involve 1) teaching the child an appropriate way to request attention and delivering reinforcement contingent on that appropriate response and 2) no longer providing attention contingent on problem behavior. In this way the functional assessment provides information about what reinforcement should be included within an intervention as well as about discontinuing reinforcement for problem behavior. This is an important piece because it is known that interventions in which problem behavior continues to be reinforced are less likely to be

effective. Classroom observation and interview with teachers and other adults working with a child allow the evaluator to form a complete picture.

effective. Classroom observation and interview with teachers and other adults working with a child allow the evaluator to form a complete picture.

Conclusions

So what is important about how we *understand ASDs*? We know that the symptom clusters that characterize ASD represent a complex, dynamic interplay of dysfunction occurring across multiple brain systems. We understand that these interact in an unfortunate synergism with experience such that, without intervention, weak skills weaken further due to lack of success, leading to lack of opportunity and avoidance, leading to further deterioration of skill. We recognize that early identification and treatment has been found to predict better outcome. We understand that children's behavior also varies across settings and people and that a completed evaluation is a "sample" of behavior. We understand that most individuals with ASD change over time. With the exception of a small group of children who exhibit a period of regression around two years of age in many cases change occurs in a positive direction such that with intervention and for a host of reasons that are not fully understood, children improve over time. We understand the importance of an individualized evaluation that highlights a differentiated treatment program for each child. Finally, we understand that no matter what age a child or adolescent is diagnosed, identifying and encouraging strengths such as expertise in a particular area and promoting self- and social awareness can lead to a satisfying leisure activity, success at work, satisfying relationships or full independence in adulthood.

Elizabeth Roberts, PsyD, is Neuropsychologist and Ruth Nass, MD, is Pediatric Neurologist at the Child Study Center, at NYU Langone Medical Center.

Making the Diagnosis: Putting it All Together

Finally, the effective evaluator must make the final determination of whether or not the child presents with sufficient characteristics to make the diagnosis of Autistic Disorder, Pervasive Developmental Disorder-Unspecified, or perhaps another disorder. There is no substitute for gathering as much data as reasonably can be gathered in a short period of time. Then, the evaluator must simply compare the child's behavior with the available diagnoses and make a determination. The

more experience the evaluator has, the more likely it is for him or her to have confidence in an appropriate diagnosis that will then allow the child to obtain any needed services. Remember that there are now several effective treatments for autism and the sooner the intervention the better.

Scott Mesh, PhD, is CEO at Los Niños Services. Scott can be reached by phone at (212) 787-9700 or by email at scott.mesh@losninos.com. To learn more about Los Niños Services, visit their website at www.losninos.com.

effective. Once an effective intervention is identified, caregivers must be trained to implement the intervention. Effective strategies used to train caregivers to implement interventions include written instructions, modeling, role-play, and direct feedback. Written instructions should be as detailed as possible, including information about consequences for appropriate and inappropriate behaviors, proactive strategies, reactive strategies, data collection procedures, and a plan for evaluation and re

effective. Once an effective intervention is identified, caregivers must be trained to implement the intervention. Effective strategies used to train caregivers to implement interventions include written instructions, modeling, role-play, and direct feedback. Written instructions should be as detailed as possible, including information about consequences for appropriate and inappropriate behaviors, proactive strategies, reactive strategies, data collection procedures, and a plan for evaluation and re

see Functional Assessment on page 45

Adulthood from page 18

assessment of ASDs in adults is the change in the profile of impairments that seems to occur across the lifespan. Multiple studies following children diagnosed with an ASD into adulthood have found that the symptom presentation changed over time. For example, unlike children and adolescents, adults with an ASD may not demonstrate significant impairments in all three domains (communication, social, and repetitive/restricted behaviors) (Akande et al., 2004). Rather, studies have found that while social interaction problems are likely to persist into adulthood, behavioral difficulties tend to be more variable (Billstedt, Gillberg & Gillberg, 2007). In other words, with age, some common childhood traits of autism may have disappeared or reduced in severity (as cited in Matson & Neal, 2009).

Adults at the higher functioning end of the autism spectrum appear to have the most difficulty obtaining an accurate diagnosis. Whereas most of the adult assessment research has focused on more severely impaired individuals, few studies have focused on the development and evaluation of measures designed specifically to assess for Asperger Syndrome (AS) and High Functioning Autism (HFA) in adulthood.

Current Research and Diagnostic Tools

There are both widely-used and recently developed screening and diagnostic tools appropriate for assessing individuals at the more able end of the autism spectrum. The Autism Diagnostic Observation Schedule - Revised (ADOS-R; Lord, Rutter, DiLavore & Risi, 1999), for example, is a standardized, psychometrically sound and widely-used instrument designed to diagnose ASDs in children and adults. While the ADOS Module IV may be used to evaluate high-functioning verbal adults, there is limited research specific to its application in this population. Additionally, in our clinical experience we have found that some elements of the ADOS-R Module IV may not be relevant or appropriate for use with high functioning adults.

The Adult Autism Spectrum Quotient (AQ - Adult) is a self-report, non-diagnostic screening tool developed specifically for adults by Baron-Cohen et al. (2001). The AQ-Adult assesses for characteristics consistent with autism spectrum disorders (ASDs) in adults by asking respondents how much they agree or disagree with certain statements. Studies using the AQ have found that eighty percent of individuals with Asperger Syndrome typically receiving scores of 32 or higher.

While other diagnostic tools have been developed specifically to assess higher-functioning individuals, the research to support wider use of these instruments is still limited. Baron-

Cohen and colleagues (2005) report preliminary evidence of validity for the Adult Asperger Assessment (AAA), a diagnostic system for assessing AS in adults. The AAA is comprised of a questionnaire based on DSM-IV criteria, and administration of the AQ and another screening measure (Ritvo, Ritvo, Guthrie, Yuwiler, Ritvo & Weisbender, 2007). The Asperger Syndrome Diagnostic Interview (Gillberg et al., 2001) is a diagnostic instrument developed specifically for higher-functioning individuals.

It is our hope that as the field of autism research continues to evolve, programs such as ours will continue to grow and benefit from ongoing research specific to the assessment and treatment of ASDs in adulthood.

Facing the Challenges: Our Clinic's Approach to Assessing Adults

At our clinic, we have developed a comprehensive program for the assessment of ASDs in bright, verbal adults. We utilize a multidisciplinary team approach in which professionals from psychology, speech and language pathology and social work provide several unique perspectives to ensure a comprehensive understanding of each individual. Utilizing the most current research instruments and information available, we attempt to overcome the challenges to accurate diagnosis in order to provide an essential service to adults and their families. It is our hope that our clinic's training model, through which graduate students in all three disciplines learn from more experienced clinicians, will contribute to increasing the number of professionals with knowledge and expertise in this area.

Given that adults on the more-able end of the spectrum may present with different symptom profiles and have likely developed compensatory strategies that tend to mask underlying difficulties, it is essential to obtain multiple forms of information (written, verbal, behavioral, informant, video). It is also essential to evaluate individuals on a number of different dimensions. Several of the major domains that we assess include:

- Social Functioning (e.g., interpersonal difficulties, insight into relationship development)
- Communication (e.g., ability to articulate emotional experience, ability to initiate and maintain reciprocal conversation, limited or atypical nonverbal communication)
- Behavior (e.g., presence of restricted interests, atypical or repetitive behavior)
- Compensatory Strategies (e.g. strategies developed to mask under-

lying sensory issues or impairments in social understanding)

- Mental Health (e.g., anxiety, depression, obsessions and compulsions)
- Psychosocial (e.g., quality of life, occupational success, interpersonal and family functioning)

Our comprehensive assessment process typically includes the following elements:

- Completion of questionnaires/informational packet:
 - Individuals and family members (when available) are asked to complete an informational packet related to developmental, medical, academic, occupational, social and family history
 - Individuals and family members (when available) are asked to complete questionnaires including the AQ-Adult and a measure of executive functioning
- Diagnostic Assessment:
 - Includes elements of the ADOS-R Module IV and the Adult Asperger Assessment (AAA)
 - Includes assessment of co-occurring mental health difficulties
 - Includes an assessment of spontaneous behavior and social interaction
 - May include interview with a relative to further assess developmental history
 - May include viewing of childhood home videos when available

- Supplemental Testing (when appropriate):
 - Semantic-Pragmatic Speech and Language Evaluation
 - Cognitive (IQ) Testing
 - Assessment of Adaptive Functioning
- Discussion of Results
- Comprehensive Written Report

Receiving a Diagnosis: What Happens Now?

For many of the adults we have evaluated, receiving a diagnosis of autism represents a significant and per-

haps life-altering event. For some, it is the final piece to a life-long puzzle that created much confusion, disappointment and heartache. For others, receiving the diagnosis is an official confirmation of something that through research and reflection they had already begun to realize on their own. The adults we have assessed have reported reactions ranging from relief to disbelief, confusion to clarity, and elation to disappointment. For most, however, receiving the diagnosis marks the beginning of a new chapter in their lives. In this chapter begins the process of understanding oneself anew and reflecting on a lifetime of experience with a new perspective. One adult we diagnosed articulated a new feeling of belonging in the world whereas she had spent most of her life feeling like an outsider looking in.

At our clinic, we emphasize that the evaluation process is one that does not end upon receiving a diagnosis. Rather, it is then that the real process of understanding and at times healing can begin. We encourage individuals and family members to seek support from every avenue: relatives, friends, therapists, speech and language pathologists, community groups, advocacy organizations, and local and international workshops and conferences. The Internet also provides an incredibly rich and valuable resource for newly diagnosed adults and their families. There are exceptional websites, list serves and opportunities for online communication that provide an essential outlet to adults attempting to understand their lives and their experiences in a new way and to connect with others.

We also encourage individuals to seek support in disclosure of their diagnosis to others in his or her life. We recommend seeking additional support through a therapist to provide guidance on this complicated issue and also recommend the book *Ask and Tell: Self Advocacy and Disclosure for People on the Autism Spectrum*. Editor, Stephen P. Shore, 2004.

Programming at the Fay J. Lindner Center

For more information regarding the comprehensive adult evaluation program at the Fay J. Lindner Center for Autism and Developmental Disabilities, Advantage Care Diagnostic and Treatment Center, Affiliate of AHRC Nassau and NSLIJ Health System, please contact our intake coordinator, Georgia Reilly, at 516-686-4440.

Laurie Better Perlis, PsyD, is Staff Psychologist, Nicole Elliott, EdM, is Psychology Extern, and Shana Nichols, PhD, is Clinical Director at the Fay J. Lindner Center for Autism and Developmental Disabilities at Advantage Care Diagnostic and Treatment Center, affiliate of AHRC Nassau and NSLIJ Health System.

Evaluation from page 19

knowledge of brain-behavior relationships, often leads to misdiagnosis. General academic or cognitive scores do not indicate whether your child can persist at a task or pay attention, or how your child best processes information (Koziol, LK and Budding, D., *in press*). Many times a school-based evaluation or generic psychological evaluation will not find the underlying problems because they are sampling a limited domain of behaviors. These limited domains are often the domains that children with HFA excel at. For example, a child with AS or HFA will often perform well on IQ tests or academic achievement tests.

A neuropsychological evaluation systematically assesses all the domains that effect school performance with an understanding of how these domains relate to each other. These domains include:

- cognitive ability
- attention
- learning
- memory
- language
- visual-spatial ability
- sensory-motor ability
- executive functioning
- social-emotional processes including social skills

What Is Executive Function?

Executive functioning skills are skills that support many academic and life tasks. They include, but are not limited to planning, getting started (initiation), organization, problem-solving, persistence, flexibility, and self-regulation. Individuals with Asperger Syndrome and high functioning autism often have difficulty with these executive function skills. This keeps them from most successfully using their intellectual abilities. People with these difficulties may not complete assignments, may complete them and not hand them in, may not know what their assignments are, and may not know how to get started or how to break down tasks into their smaller components. Executive function is an area seldom assessed by school-based or generic psychological/behavioral evaluations. These skills are neurodevelopmental in nature. Problems with executive functioning may indicate subtle dysfunctions in brain circuitry. Many parents, students and adults are frustrated by these behaviors and view them as emotional in nature or as a moral failing on the part of the child, adolescent or adult. These attitudes further reinforce low self-esteem and poor effort. It is important to understand that these are brain-based behaviors that are weak or deficient for

particular people. A neuropsychological evaluation should delineate the profile of strengths and weaknesses in executive functioning in order to build on assets and propose appropriate intervention for deficits. Timely intervention is important because executive functioning deficits can and do persist past the school years and can affect independent functioning on a job and in social interactions. Sometimes parents in their frustration and worry act as their children's "executive functioners" in order to get them through the school years and high school graduation. This behavior is understandable in the face of fear of failure and difficulty in getting your child to change. However, such behavior does not assist the child/adolescent/young adult to learn how to compensate and be independent further limiting life choices in several realms: occupational, social, knowing how to make effective life decisions despite being "smart," and knowing how and when to advocate for oneself.

Why Evaluate Language?

Students with Autism Spectrum Disorders (ASDs) who are considered to be high functioning typically appear to be fluid with language. They often have good vocabulary, remember lots of information, and have good oral speaking ability. They will often score well on tests of basic language skills. However, some of these students may have subtle but real difficulties with higher order language and pragmatics. Pragmatic language is the social aspect of language. For example, turn taking behaviors and topic maintenance in conversation are aspects of pragmatic language. Higher order language refers to abilities such as understanding inferences, nuance, and ambiguity. It is important to assess these language abilities as they affect reading comprehension, written expression and social interactions. As students progress in their schooling, the ability to utilize higher order language skills becomes increasingly more important and some children with HFA may start to have academic problems.

How Will a Neuropsychological Evaluation Be of Benefit?

It is well-known that children with ASDs often receive several misdiagnoses before being correctly diagnosed. Most neurodevelopmental problems (reading disorders, learning disorders, attention deficit disorder etc.) have symptom overlap. For example, the inability to sustain one's attention to a boring task is a symptom of many neurodevelopmental problems not just ADHD. Without taking a thorough history and systematically sampling multiple domains, your child might receive a misdiagnosis. A neuropsychologist is trained to know the correct questions to ask and tasks to give to arrive at the best diagnostic formulation.

A neuropsychologist integrates the findings from the domains discussed above to arrive at an understanding of the brain behavior relationships and their

impact on academic, behavioral, and life skills performance. School-based evaluations are often performed by multiple evaluators within their area of specialty (Speech, Education etc.). However, the results are seldom integrated into a greater understanding of how one domain affects another.

With this understanding, a neuropsychological evaluation should yield results that lead to an appropriate and effective educational plan or transition plan for an adolescent or young adult. It should help adults with the transition into the work world, and help them understand their strengths and their limitations in terms of job and career choice. For example, a person might have difficulty with multi-tasking and should not take a job that involves the intense levels of multi-tasking that confronts a pilot. A mere diagnosis is not sufficient. In the case of children and adolescents, an evaluation should give parents suggestions for how to help your child at home. There is no point in having such an extensive evaluation without it resulting in a detailed plan of how to approach your child educationally and behaviorally. The plan should be based on the findings of the evaluation and should be of sufficient detail and clarity for parents, educators, and adults to understand the best methods to teach your individual child or to support independent adult functioning. It should include information about:

- Strengths and weaknesses
- How your child learns
- Recommended educational approaches
- Recommended strategies for abilities that support academic achievement and life skills such as social skills, pragmatic language, and executive function abilities.
- Recommended strategies for home
- Anticipated problems as academic demands change
- Recommended resources and referrals
- Steps for transition planning
- Occupational direction

A diagnosis alone is not sufficient to tell us what the individual needs.

My Adolescent is College-Bound. How Can a Neuropsychological Evaluation be Helpful?

Colleges are held to a different standard for providing services and accommodations than are elementary, middle and high schools. Public schools are mandated to provide services to students who meet criteria under IDEA (Individuals with Disabilities Education Act). Colleges and universities are providing services under ADA (Americans with Disabilities Act). It is not enough

under ADA to have a diagnosis; one must demonstrate functional impairment to meet criteria under ADA. ADA gives students with disabilities the right to equal access to higher education. Specific accommodations are not mandated, and students and their families must then negotiate appropriate accommodations. (Some colleges are better equipped than others to provide necessary accommodations.)

To qualify for accommodations, most colleges and universities require a comprehensive evaluation that samples the domains of a neuropsychological evaluation, as indicated above. Adolescents with ASDs who are college-bound will typically look fine on intelligence and achievement testing alone, and will not demonstrate their actual functional impairments if only these types of tests are given. A complete neuropsychological evaluation should help colleges better understand the student's needs. It should help the student understand his or her own learning profile, strengths and weaknesses and be better prepared for self-advocacy.

References

Koziol, LF, Budding, DE, (2009) Pediatric Neuropsychological Testing: theoretical models of test selection and interpretation. *In press*

Silver, CH, Blackburn, LB, Arffa, S et al. (2006) The importance of neuropsychological assessment for the evaluation of childhood learning disorders NAN policy and planning committee. *Archives of Clinical Neuropsychology*, 21, 741-744

Ilene R. Solomon, Ph.D. has practiced psychology for twenty-five years. Much of her professional career has been devoted to helping children and their parents with a wide range of neurodevelopmental problems including Asperger Syndrome and high functioning autism as well as other learning and social learning problems. She specializes in the neuropsychological evaluation of developmental disorders as well as providing therapeutic assistance to parents, families, and children. She has a particular interest in the interface between evaluation and developing educational programming and consults to schools about Asperger Syndrome. She has worked in school, hospital and private practice settings and has taught on the university level. She has post-doctoral certificates in Neuropsychology and Organizational Development. She is an associate of the Institute for Cognitive Diversity at Bank Street College of Education in Manhattan. Her offices are in Nassau County and Manhattan. She can be reached at irsphd@gmail.com and (516) 747-8583.

This article was originally published in the Fall 2009 issue of On The Spectrum, the newsletter of the Asperger Syndrome and High Functioning Autism Association (AHA) www.ahany.org.

Supporting Parents from page 38

Reilly, intake coordinator, can be reached at (516) 686-4440.

Halley Ceglia, LMSW, is Social Worker, Georgianna Reilly, BSc, is Intake Coordinator, and Shana Nichols,

PhD, is Clinical Director at the Fay J. Lindner Center for Autism and Developmental Disabilities at Advantage Care Diagnostic and Treatment Center, affiliate of AHRC Nassau and NS-LIJ Health System.

References

Brogan, C.A., & Knussen, C. (2003). The disclosure of a diagnosis of an autism spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. *Autism*, 7, 31-46.

Goin-Kochel, R.P., Mackintosh, V.H., & Myers, B.J. (2006). How many doc-

tors does it take to take an autism spectrum diagnosis? *Autism*, 10, 439-451.

Osborne, L.A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12, 309-324.

Symptom Domains from page 24

other person involved; reduced responding to the social bids of others; and a general low social interest, including interest in other children.

The Second Symptom Domain: Communication

Communication also starts from an early age. Below about six months, the infant's communicative output needs to be interpreted by the parent (for example, how different cries sound), and thus the parent bears the majority of the responsibility for understanding the specific message. From that point on, with increasing skills, the child is able to bear more of the responsibility and uses vocalization, eye contact, and gesture to effectively communicate. With ASD, not only is the vocal and verbal output usually delayed, but gesture and social components are specifically affected. As the child develops, children with milder symptoms learn to speak yet retain difficulty in truly effective communication because of gaps in knowing how to use social means to get their message across.

Signs of ASD in young children include a reduced amount of "gaze shifting" from an object to a person and back to indicate that they want the person to give them that object; of following the gaze or the point of others that are meant to give the child information about where to look; and of "repairing" a message that the parent didn't respond to by repeating, getting louder, or adding a gesture. Another distinct area of difference is related to types of communicative messages, or "intentions." By around 18 months, a child can usually send a variety of types of messages, including gaining attention, requesting objects or actions, commenting on objects or actions, protesting, requesting information, or greeting, to name a few. In contrast, the child with ASD does not easily develop all these differentiated messages. Finally, there are specific atypical or "autistic" behaviors such as echolalia, wherein the child repeats what he has heard, but usually not in the context it belongs. When a child repeats a lot of dialogue he or she has heard in videos or on TV, it is referred to as "scripting." Other atypical communication behaviors are unusual sound patterns of the voice, such as using a monotone, or using a high ques-

tioning pitch all the time; pushing and pulling or placing the adult's hand where the child wants it, called "hand leading," and over-generalizing phrases (using the same phrase for multiple purposes).

The Third Symptom Domain: Stereotyped and Repetitive Behavior

This area has come to encompass a large and varied set of behaviors. On the one hand, it involves the stereotype of autistic behavior, that is, unusual movements such as spinning and rocking, walking on toes and hand flapping, as well as unusual sensory behaviors such as starting at lights and fans, smelling things, watching rolling credits on videos, feeling textures, and so on. On the other hand, the repetitive feature is also seen in children who develop obsessions with topics and want only to learn and talk about superheroes, trains, weather, sports statistics, and so on. For very young children, their unusual behavior and interests need to be understood by evaluating their play development. Play and object use progresses in a known, predictable developmental pattern starting from 3-4 months, which is when children can actually reach out, grasp, and start to manipulate objects. They move through phases of exploring toys based on the toy's sensory properties (6-9 months), to using them as they are "intended" (rolling a toy car, putting objects in containers, touching a crayon to a paper, 10+ months), and eventually to using toys in an imitative, pretend manner (putting a spoon to a doll's mouth, 15+ months). Thus, the 24-month-old typically developing child has a fairly complex and developed play repertoire, so it is not difficult to evaluate if a child is developing typically in this way by 18 months.

A brief summary of the range of repetitive and stereotyped behaviors are as follows:

Seeking (or avoiding) physical sensations - Seeking whole body movement: rocking, spinning, swinging, twirling on a tire swing, running around constantly; seeking deep pressure: burrowing into furniture or crawling and rolling around on the floor, seeking hugs and wrestling with caregivers, squeezing into tight places such as between sofa cushions or between furniture and wall.

Seeking sensory sensations - Fascination with and seeking out textures by playing with adults' hair, patting or rubbing clothing, carpet, or textures of toys and objects.

Seeking visual stimulation - Watching patterns of light and dark, watching spinning things such as overhead fans, twirling and tossing toys and objects to watch them spin, spinning wheels on toy vehicles, looking at objects out of side vision, holding objects very close, turning them to watch visual effects, watching credits scroll at the end of a video, fascination with logos on objects, restaurants, cars.

Restricted interest in mechanical workings and part of objects - Opening and closing doors, lock mechanisms, buttons, and lights on household electronics, household electronics in general, cause-effect toys; this interest is to the exclusion of a broader play repertoire.

Seeking to maintain sameness - On a circumscribed level, performing preferred play patterns repeatedly, not varying the activity, not wishing to move off of one activity to another; on a broader level, resisting transitioning from house to car, or to school or a different setting; on the broadest level, having a strong aversion to new settings and caregivers, upset over changes in daily routine or the order in which things are done; upset over change of route when traveling around the community; forming habits focused on color, visual effects, order or sequence of events.

Areas of high interest and ability - Early abilities with recognizing letters, numbers, shapes, colors; high ability with puzzles and visual-spatial activities, especially relative to language and social skills; early reading, musical ability, ability with numbers that is above skills in a most other areas; fascination with characters (Thomas the Tank Engine, Disney characters, superheroes, other TV or video characters); fascination and high level of knowledge about a single area (sports, weather, trains, mammals, amphibians); uncanny knowledge about geography, subway or train routes.

Conclusion

When a child suspected to have ASD

support to handle these situations.

The hardest and arguably most important part of the entire process is implementing the intervention with accuracy and fidelity in the absence of the therapist. This is of critical importance, because an effective intervention provides no benefit if it cannot or is not implemented. Although this is the most important piece, it can also be the most difficult. It requires

undergoes an evaluation, then, the history gathered from the parent, clinical observations, and more formal evaluation measures all will be structured around these three areas. Each child can be a unique presentation of the particular behaviors they display, how severe or mild their symptoms are, what their general intelligence level is, and what other issues may be exerting an influence, such as those around sensory sensitivities, difficulties with eating, sleeping, or attention and behavioral regulation. Regardless of the clinical picture, the child is nonetheless his or her own unique blend of strengths and challenges, with much potential to change and grow.

Some books that are recommended for parents that give good overviews:

- Wendy Stone & Theresa Foy DiGeronimo. *Does My Child Have Autism: A Parents Guide to Early Detection and Intervention in Autism Spectrum Disorders* Jossey-Bass, 2006.
- Tony Charman & Wendy Stone. *Social and Communication Development in Autism Spectrum Disorders: Early Identification, Diagnosis, and Intervention*. Guilford Press, 2006.
- Nancy Wiseman. *Could It Be Autism?* Broadway Books, 2006.

Videos:

- Newly available from Westchester Institute for Human Development: *Autism Spectrum Disorder in Young Children: A Visual Guide, Volume I: An Overview/Learning to Observe Across the Three Symptom Domains*. Patricia Towle, PhD, 2008 - Available from www.childdevelopmentmedia.com
- First Signs, available from www.firstsigns.org
- Video Glossary from Autism Speaks at: www.autismspeaks.org

Patricia Towle, PhD is a psychologist and training supervisor in early intervention and diagnostic assessment at the Westchester Institute for Human Development, University Center for Excellence in Developmental Disabilities in Valhalla, NY.

Functional Assessment from page 42

view of the intervention. Modeling involves demonstrating correct implementation of the procedures with the child for caregivers. Role-play involves demonstrating the procedures with the therapist and the caregiver (i.e., the therapist takes the role of the child while the caregiver implements the procedures). Feedback is

provided throughout modeling and role-play procedures and during in-vivo training with the caregiver and child. It is important to anticipate potential increases in problem behaviors or the emergence of new topographies of problem behavior when caregivers first begin to implement the intervention as well as when new interventions are introduced. Therapists should provide caregivers with information and

Medical Care from page 41

the clinical director shall determine that the treatment:

- (1) be administered over the patient's objection; or
- (2) be administered after the delay of a specified period of time to permit efforts to obtain the patient's agreement; or
- (3) not be administered as not in the patient's best interests.

(c) The clinical director shall provide the patient and his or her parent, legal guardian or other legally authorized representative with a full explanation of the clinical director's determination. If the determination is made to administer non-emergency treatment over the patient's objection, the Mental Hygiene Legal Service shall be notified and the initiation of the treatment shall be delayed at least four calendar days thereafter. If, within the four

-day period, the Mental Hygiene Legal Service files a legal action on behalf of the patient challenging the clinical director's determination as "arbitrary and capricious", the treatment may be initiated three calendar days thereafter, unless otherwise ordered by the court.

Medical Records – Consent for Release - Generally, a parent may consent to the disclosure of protected health information for a child if the

stamina and persistence that can be difficult in an already complicated life. Caregivers must prepare themselves for the fact that there is no "easy fix" in the vast majority of cases and that therapists must make every effort to identify not only an effective intervention, but a doable intervention. To do this, all aspects of the child's life must be examined and the caregivers must be included in this process.

child fits the definition of a minor as stated above. This disclosure may be made regardless of the consent of the minor.

Conclusion

In sum, medical decisions are often difficult to make and a parent is best suited to determine what is in their children's best interest. Hopefully, with some understanding of the laws that govern this area a parent will feel more confident with their decision.

Competency from page 25

school is so different, we were not sure he was going to be able to attend college," Ms. Dolan said. "Not only does he go to Southern and take classes, he joined an Anime club there, all on his own. We were thrilled that he went through the effort to do that, to take the bus on his own and join the club. He's very successful and he loves it."

Developed in conjunction with the Yale Child Study Center in New Haven, Conn., Chapel Haven's ASAT program was guided by an advisory board comprising some of the top Asperger's experts in the country, including Fred R. Volkmar M.D., director of the Child Study Center at Yale University School of Medicine, and Ami Klin, Ph.D. director of the Autism Program also of the Child Study Center at Yale University. Dr. Ruth B. Eren, who chairs the special education department at Southern Connecticut State University, helped write the curriculum and is a key advisor, along with Michelle Garcia Winner, MA, CCC-SLP, who coined the term "social thinking" and developed the social thinking treatment approach for individuals with high-functioning autism, Asperger's and similar challenges.

Dr. Volkmar said the program's focus on teaching skills that can be practiced in real life settings is unique. "There are very few programs that focus on the needs of individuals with social disabilities," said Dr. Volkmar. "It is clear that lack of 'real world' or adaptive skills is a major obstacle for many individuals being able to successfully make it on their own. Chapel Haven has a strong developmental focus with realistic expectations to hone in on these needs."

"Social communicative competency is the core of the disability for students with Asperger's," noted Virginia Hodge, director of Chapel Haven's ASAT program and a certified speech and language pathologist. "A student who can't cook dinner can still get take-out food. But a student who can't interact will see an effect in every part of his or her life."

Zach Delman, 25, is a graduate of

Chapel Haven's ASAT program who now lives on his own with a roommate and participates in Chapel Haven's supported living program. For the past 1.5 years, he has worked as a pollster at Quinnipiac University's famed Quinnipiac Polling Institute. The instruction he gained at Chapel Haven has helped him in many ways, his mother said.

"We just see such a change in him," said Danae Delman, of Alexandria, VA. "Ginny has taught him to listen and even if he is not engaged, give facial expressions indicating that he is listening. Whereas before he would just walk away, he can sit at the table now at Thanksgiving and Christmas, where there are 20 people at a table, and engage in conversation."

Increased confidence and self esteem has helped Zach live an independent life. "He goes to his doctor's appointments by himself. He knows the New Haven transportation system better than some people who have lived there a long time, which again, goes back to self confidence. He can get anywhere he wants to," his mother said.

To measure a student's progress, Chapel Haven uses an assessment tool created in-house that measures dozens of variables in the four domains: social communicative competency, self determination, independent living skills and career and vocational preparation. The assessment tool is highly detailed. In just the SCC component alone, staffers use 50 different criteria to measure student growth, ranging from "states the main idea of presented explanations" to "initiates conversation by using appropriate nonverbal and verbal communication." For each criterion, student progress is tracked in four settings: the social realm, the apartment, out in the community and employment or college.

The assessment tool helps staff at Chapel Haven establish baseline data and then continue to measure progress throughout the 24 month program in regular meetings with staff, student and parents, at 45 days, six months, one year, 18 months and two years.

Along with Social Communicative

Competency, Chapel Haven's ASAT Program also teaches:

Self Determination - an individual's awareness of personal strengths and weaknesses, the ability to set goals and make choices, to be assertive at appropriate times and to interact with others in a socially competent manner. These skills are taught by aiding the student in identifying his/her own emotions, needs, interests, and values as well as developing an understanding of his/her strengths and challenges. Instruction in this area of the curriculum also teaches the student to expect to achieve personal goals, to have feelings of self-respect and confidence, and to develop a belief in his/her ability to be successful. Time is spent on developing one's ability to assertively state one's own wants, needs, and rights as well as determining, pursuing, obtaining and evaluating needed supports. This area of the curriculum teaches coping skills so that the student can complete tasks, and consequently compare his performance on those tasks to an established performance measure. As important as the coping skills are the skills to set personal and achievable goals and the measure to achieve those goals.

Independent Living Skills - those skills that allow individuals to deal with current and future adult day-to-day demands and responsibilities. This portion of the curriculum focuses on:

1. survival skills, including use of the telephone, financial management, grooming, preparing nutritionally appropriate meals and traveling independently;
2. leisure pursuits, including identifying and engaging in at-home and community based leisure activities, both alone and in groups;
3. managing basic home responsibilities, including setting up personal living space, apartment cleaning, security measures, successfully doing laundry and home repairs;
4. maintaining a structured, nurturing

home environment while becoming involved in the community.

Career/Vocational/College Preparation

The emphasis in this part of the curriculum is on identifying the life goals of the participant and then supporting the acquisition of skills necessary to be successful. These skills might be acquired in college, technical school, in the community, or at the worksite.

Chapel Haven's program is centered in a self-contained apartment building, housing each participant in a private bedroom. Weekly house meetings are held to address domestic responsibilities, meal preparation, social engagements, shopping for food, community involvement, personal appointments, work and school schedules and planned free time.

"Students learn everything from how to cook, take the bus and pay their bills, to how to interject into daily conversations so they can make friends," said Betsey Parlato, President of Chapel Haven. "We also focus on breaking students out of their daily habits so they can experience new and exciting things. One student entered the program and spent 22 hours a day on the computer - a safe, non-threatening environment. He no longer feels the need to isolate and is out in the world, pursuing a happy life."

Chapel Haven's curriculum is designed as a two-year program. Students who continue to live in the Greater New Haven Community can still receive assistance from the ASAT Community Support Program for a minimum of one year.

About Chapel Haven

Founded in 1972, Chapel Haven teaches adults with cognitive disabilities and social disabilities to live independent and productive lives. For more information about the Asperger's Syndrome Adult Transition (ASAT) Program or Chapel Haven's other programs (REACH and Chapel Haven West), call the Admissions Office at (203) 397-1714, ext.113 or 148. Read more at www.chapelhaven.org.

Transition Planning from page 27

dictation software to help students compose letters and other forms of correspondence. Some of these simple interventions can help a student on the road to independence.

Local school districts may not be able to assess the vocational skills of a student on the autism spectrum. To assess this vital dimension of a student's ability to live independently, a parent will need to contact a state office of vocational rehabilitative services. These agencies are able not only to assess the vocational skills and aptitudes of a young person, but they are also able to assess a student's readiness to drive an automobile and their ability to use mass transit. Travel skills are critical for a student to secure and maintain employment. Additionally, for the student who will enter the world of work directly, these agencies can arrange job placements, sheltered work experiences, supported work programs, and job coaches. Knowing a student's job readiness can help a parent decide what post secondary

education his or her son or daughter may need, if any.

Now that a parent has all of this data, what does he or she do with the information? The parent, along with his or her son or daughter must decide what the next steps are for him or her. The data should tell the parents what kinds of options they should be pursuing. Those options are: continuing to work on IEP goals at the local high school, attending college and pursuing a degree program, and attending vocational training or enrolling in a transitional program. Once a student graduates from high school he or she is no longer protected by IDEA where education is a right. Rather, the student is now protected by the Americans with Disabilities Act (ADA). Under this law, the emphasis changes from education being a right to education being a privilege. The student must be "otherwise qualified" to pursue a college degree. A student must have not only the intellectual ability to attend college, but they must also have the requisite social and executive functioning skills to

navigate the post secondary environment. A family must decide which option will most likely lead to a life of independence.

For some students this might mean foregoing graduation with their peers and staying at high school to complete their IEP goals. Under IDEA those students who have not graduated or had a committee on special education exit interview are entitled to continuing their education until their 21st birthday at the local educational agency's expense. Other students may pursue a career at a vocational training center where they can pursue not only traditional trades such as carpentry, automotive repair, plumbing, etc., but other career paths such as small animal care, personal trainer, and computer networking certificates are also available. Other students on the spectrum need a combination of vocational, independent living, and social skills training. They are ideal candidates for transitional programs. Transitional programs can address IEP goals dealing with these three areas very effectively because the student must live and

practice the independent and social skills. The goals of transitional programs are to either prepare a young person on the autism spectrum for the world of work and independent living or matriculation in a degree bearing program.

A comprehensive assessment prior to leaving high school will provide parents and young adults on the autism spectrum with a solid inventory of his or her strengths and areas of weakness as well as provide them with a blueprint for designing the scaffolding necessary to live a life of independence.

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

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)

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

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)

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

*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 Date

Winter Issue - December 15, 2009

Spring Issue - March 15, 2010

Summer Issue - June 15, 2010

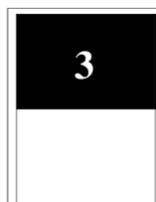
Fall Issue - September 15, 2010



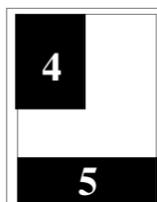
1
Full Page
\$1,000



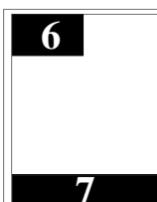
2
Half Vertical
\$750



3
Half Horizontal
\$750



4
Quarter V & H
\$500



6
Eighth V & H
\$300

Ad Sizes - In Inches

	<u>Width</u>	<u>Height</u>
Full Page (1)	10.4	12.8
Half Vertical (2)	5.1	12.8
Half Horizontal (3)	10.4	6.4
Quarter Vertical (4)	5.1	6.4
Quarter Horizontal (5)	10.4	3.1
Eighth Vertical (6)	5.1	3.1
Eighth Horizontal (7)	10.4	1.5

AUTISM SPECTRUM NEWS



Helping families understand and cope with a child on the spectrum can only be achieved by providing them with information that is based upon the best scientific research and medical evidence.

Autism Spectrum News provides news, information, education, advocacy, and resources in the community that adhere to our strict evidence-based standards.

Learn how Autism Spectrum News can help provide your organization or community group with an affordable and trusted source of autism education.

*Call us today at (508) 533-4053
or visit our website at www.mhnews-autism.org.*