

AUTISM SPECTRUM NEWS™

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SUMMER 2009

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 2 NO. 1

Addressing the Needs of Adults on the Spectrum

What They *Can* Do - Not What They Can't

By Michael John Carley
Executive Director
GRASP

Before this decade, adults on the autism spectrum were rarely considered in our collective psyche. Maybe photos of adults weren't effective fundraising devices as were photos of kids. Maybe adults were considered too damaged by life experience and/or inappropriate accommodation for us to look at them without our hearts breaking. And maybe as a greater community it was too much shame for us to confront. Even if when no one is aware, there really can't be blame.

Several factors contributed to our expanded thinking:

- We suddenly knew a lot more. Through dramatically increased knowledge about the spectrum, we gained more confidence in addressing the needs of everyone diagnosed with an ASD (i.e. there was hope!). We felt we were finally armed with the right tools to tackle the subject of improving the lives of adults.



- As the children of pioneering parent's advocacy groups grew up, their needs, as moms and dads, changed. They subsequently demanded the same alterations to greater society for their transitioning children, as they had advocated for when their kids were much younger.

- Peer-run organizations such as GRASP emerged, showing the potential inherent in adults.

Yet the most instrumental factor in our relative success has been our capacity to listen to those adults. Gone was the myth that everyone on the spectrum (even the

majority) was non-verbal. They felt, they spoke, and many listened.

Those that lent an ear heard stories about what had worked in the lives of adults (what had worked when they were children and what works now) and they also heard stories of what had not worked. Whether the subject was educational strategies, behavioral regulation, employment accommodations, or social skills training, the clinical world (and beyond) that listened benefited enormously.

Many also did not listen, and still don't. Despite the strong protests of adults, certain groups and organizations still use words like "cure" despite the medical *and* ethical problems inherent in the word's use. Vaccine theorists continue to paint people on the spectrum as chemical accidents. And it is an ongoing battle trying to convince the world that the behavioral differences of "spectrumites" are not as threatening as they might think.

Like anyone, adults on the spectrum need to know more about what they *can* do, not what they can't. They can read what's written about them, and they can hear what's being said about them. And while there is

see Can Do on page 51

Meeting the Needs of Adults with Autism Spectrum Disorders

By Cecilia McCarton, MD,
Ivy Feldman, PhD, and
Mary Jane Weiss, PhD
The McCarton Foundation

People with autism spectrum disorders face lifelong challenges and require lifelong services. The services needed vary tremendously from person to person and across different ages. The needs of adolescents and adults with autism are great, yet their access to services is often poor. Families must struggle to secure appropriate placements and to cope with issues of independence, vocational planning, and long-term guardianship. In this article, we will focus on some of the most important

aspects of programming that help increase positive outcomes for adolescents and adults with autism spectrum disorders.

In recent years, parents of young children with autism have had access to more services and resources than ever before. While there is variability in services across states, there is clearly a universal entitlement for appropriate services for children with autism. Children with autism are diagnosed at younger ages, and effective services are more easily obtained than in the past. Many more children with autism are educated in inclusive environments. Of course, many parents of children with autism struggle to obtain appropriate services and need to intensely advocate for their children. But most parents of younger children on the spectrum recog-

nize that their children have access to far better services than any previous group of individuals with autism.

The reality changes and this hope fades as children with autism age. Services that were an entitlement in childhood are rare. When services can be secured, they are often not high in quality. The needs, however, of adolescents and adults with autism remain very significant. The characteristics of autism remain, and may be even more challenging. New skills become essential for independent living. Social deficits put individuals with ASD's at serious risk for social and (even) legal difficulties. Community integration is often far more challenging with older students, as tolerance is limited and the range of acceptable behaviors is smaller.

There are a few strategies that are critically important in helping to ensure that individuals with autism get appropriate and effective services as they become adolescents and adults. The provision of these elements can help ease the severity of issues experienced as the individual with autism ages, and can tremendously increase the success of their vocational, social, and community integration.

What are the Essential
Program Components?

Transition Planning: An effective program for adults starts well before the person with autism is an adult. Planning for

see Meeting the Needs on page 31

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Autism Spectrum News Upcoming Theme and Deadline Calendar

Fall 2009 Issue:

"Understanding the Assessment Process: What Parents Should Know"

Deadline: September 15, 2009

Winter 2010 Issue:

"New Frontiers in Autism Science"

Deadline: December 15, 2009

Spring 2010 Issue:

"Understanding and Accessing Clinical Treatment Services"

Deadline: March 15, 2010

Summer 2009 Issue:

"Helping Families Cope With Stress"

Deadline: June 15, 2010

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From The Publisher

From Entitlement to Eligibility - Transitioning to Adulthood

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

For many parents of a child with autism, the period when their child is transitioning into adulthood is a tumultuous one. When they first found out that their child was diagnosed with autism, it was a scramble to find appropriate early intervention services and advocate for their child at school. Now too old for the entitlements provided by their child's school, parents and their adult children are left feeling desperate for answers to their endless stream of questions as to what to do next: Where can I find services geared towards adults with autism? How am I going to pay for these services? Can my child be successful in college? What are my child's options for living alone? What can I do to help my child gain independence but still get the help he needs? What is going to happen to them, who is going to take care of them, how are they going to survive without me? The questions are endless and the answers can be elusive.

I recently attended the Asperger Syndrome and High Functioning Autism Association of New York (AHANY) Spring Conference on "Issues in Independent Living for Adolescents and Adults on the Autism Spectrum." Many important topics for adults with autism were addressed including transition planning, post-secondary education, vocational training, independent living, building adult relationships, etc. Throughout the day, various workshops were given by professionals focusing on all aspects of life as an adult with autism.

One workshop titled "From Entitlement to Eligibility" really stuck with me because of the parents that participated. The workshop was designed to identify the key differences between special education entitlement services and adult services eligibility and an overview of person-centered planning. There was a sense



Ira H. Minot, LMSW

of tension in the room as parents of adults or soon to be adults with autism expressed their frustrations with "the system" in regards to obtaining services after their child graduated from high school. "I've called and called and they keep telling me that we don't qualify for this, but I know we do. How can we get the services we should be eligible for?" "Books for college used to be paid for under this program but I heard that next year they are cutting costs and books won't be paid for. Is this true?" "SSDI, Medicaid, OMRDD...I'm really just confused as to where to start this process of obtaining financial aid to help lessen the burden of paying for services." The presenters answered some questions and offered their business cards to speak later about other questions. The bottom line was that there are supports out there but you just need to know how to navigate the system in order to obtain them. There are professionals who understand the transition process who can help you along the way and are willing to help you. You are not alone.

For parents of adults or soon to be adults with autism, it is clear that proac-

tive planning is essential in securing services for your child before they graduate from high school or turn 21 and lose their entitlements guaranteed by the Individuals with Disabilities Education Act (IDEA). You need to start planning for your child's future now so that you can be better prepared for tomorrow. Conferences, workshops, and support groups offer wonderful opportunities to meet with the experts in the autism community to ask questions. They will often either have the answers you have been looking for or will be able to point in the right direction.

It is widely known that 1 in 150 children have an autism spectrum disorder. A statistic that is often not considered is that, as these children age into adulthood, 1 in 150 adults will have autism. Much of the scientific research on appropriate intervention and services has been directed towards children as it has been proven that appropriate intervention very early on can benefit children on the autism spectrum greatly in all areas of their development. More federal dollars need to be directed to autism research and intervention in general; however as the population of children with autism age into adulthood, there is and will continue to be an ever growing need for an increased understanding of what these adults need and how best to satisfy those needs to enable them to live as independent and fulfilling a life as possible. More scientific research needs to be directed towards the adult autism population so that appropriate evidence-based services and clinical treatments can be designed and implemented.

Because of the evident need for more information on transitioning to adulthood and accessing essential programs and services for adults with autism, we have devoted this issue of *Autism Spectrum News* to "Addressing the Needs of Adults on the Spectrum." You will find articles from lawyers, educators, adults with autism, service providers, and treatment professionals whose organizations provide vital programs and services for adults with autism.

In addition to the articles focused on addressing the needs of adults on the spectrum, 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 fall issue, our theme will be "Understanding the Assessment Process: What Parents Should Know." Our deadline for articles and advertising for this important issue is September 15th.

Our calendar continues with our winter issue which will focus on "New Frontiers in Autism Science." Next spring we will take an in-depth look at "Understanding and Accessing Clinical Treatment Services" and next summer our theme will be "Helping Families Cope With Stress."

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 site you can subscribe to receive your own personal hardcopy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients 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*.

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AUTISM SPECTRUM NEWS DESK

Albert Einstein College Scientists Propose New Theory of Autism *Suggests Symptoms of the Disorder Might Be Reversible*

By the Albert Einstein
College of Medicine

Scientists at Albert Einstein College of Medicine of Yeshiva University have proposed a sweeping new theory of autism that suggests that the brains of people with autism are structurally normal but dysregulated, meaning symptoms of the disorder might be reversible.

The central tenet of the theory, published in the March issue of *Brain Research Reviews*, is that autism is a developmental disorder caused by impaired regulation of a bundle of neurons in the brain stem that processes sensory signals from all areas of the body.

The new theory stems from decades of anecdotal observations that some autistic children seem to improve when they have a fever, only to regress when the fever ebbs. A 2007 study in the journal *Pediatrics* took a more rigorous look at fever and autism, observing autistic children during and after fever episodes and comparing their behavior with autistic children who didn't have fevers. This study documented that autistic children experience behavior changes during fever.

"On a positive note, we are talking about a brain region that is not irrevocably altered. It gives us hope that, with novel therapies, we will eventually be able to help people with autism," says theory co-



Dominick P. Purpura, MD

author Mark F. Mehler, M.D., chairman of neurology and director of the Institute for Brain Disorders and Neural Regeneration at Einstein.

Autism is a complex developmental disability that affects a person's ability to communicate and interact with others. It usually appears during the first three years of life. Autism is called a "spectrum disorder" since it affects individuals differ-



Mark F. Mehler, MD

ently and to varying degrees. It is estimated that one in every 150 American children has some degree of autism.

Einstein researchers contend that scientific evidence directly points to the locus coeruleus—noradrenergic (LC-NA) system as being involved in autism. "The LC-NA system is the only brain system involved both in producing fever and controlling behavior," says co-author

Dominick P. Purpura, M.D., dean emeritus and distinguished professor of neuroscience at Einstein.

The locus coeruleus has widespread connections to brain regions that process sensory information. It secretes most of the brain's noradrenaline, a neurotransmitter that plays a key role in arousal mechanisms, such as the "fight or flight" response. It is also involved in a variety of complex behaviors, such as attentional focusing (the ability to concentrate attention on environmental cues relevant to the task in hand, or to switch attention from one task to another). Poor attentional focusing is a defining characteristic of autism.

"What is unique about the locus coeruleus is that it activates almost all higher-order brain centers that are involved in complex cognitive tasks," says Dr. Mehler.

Drs. Purpura and Mehler hypothesize that in autism, the LC-NA system is dysregulated by the interplay of environment, genetic, and epigenetic factors (chemical substances both within as well as outside the genome that regulate the expression of genes). They believe that stress plays a central role in dysregulation of the LC-NA system, especially in the latter stages of prenatal development when the fetal brain is particularly vulnerable.

As evidence, the researchers point to a 2008 study, published in the *Journal of*

see New Theory on page 42

US Senators Introduce the Autism Treatment Acceleration Act *Legislation Addresses Key Issues Facing the Autism Community*

By the Association of University
Centers on Disabilities (AUCD)

On April 2, World Autism Day, Senators Richard Durbin (D-IL), Robert Casey (D-PA), and Robert Menendez (D-NJ) introduced the Autism Treatment Acceleration Act (S. 819). This bill was originally drafted with President Obama when he was in the Senate near the end of the 111th Congress. The new bill introduced yesterday, incorporates some of the provisions of the Expanding the Promise to Individuals with Autism Act introduced by Sen. Clinton in the last Congress, including a revised version of the interdisciplinary training provision. The Association of University Centers on Disabilities (AUCD) worked with the Coalition for Citizens with Disabilities (CCD) and other advocacy groups to provide input before introduction.

The bill establishes multiyear national training initiative supplemental grants to eligible entities, "including University Centers for Excellence in Developmental Disabilities," to develop and expand interdisciplinary training and continuing education on autism spectrum disorders.

The bill creates demonstration projects to increase access to quality health care services and coordination of care as well as to develop and provide an array of services to adults with autism spectrum disorders; establishes a national network to link research and service initiatives at the federal, regional, state and local levels; and, establishes an Interdepartmental Coordinating Committee to coordinate Federal activities relating to research, services, and programs for individuals with autism spectrum disorders.

A requirement that health insurers cover the diagnosis and treatment of autism spectrum disorders, including Applied Behavior Analysis, assistive com-

munication devices and other effective treatments is also added.

The bill was referred to the Senate Health, Education, Labor and Pensions Committee. No similar bill has been introduced in the House.

Overview of the Autism Treatment Acceleration Act

Autism Care Centers Demonstration Project - Creates a demonstration project to develop Autism Care Centers in order to increase access to quality health care services and communication among healthcare providers, educators, and other providers of services; enable beneficiaries to designate a personal primary care coordinator as a source of contact for a family; and provide a full array of medical, behavioral, mental health, educational and family care services to individuals and families in a single location.

Adult Services Demonstration Project - Creates a demonstration project to provide an array of services to adults with autism spectrum disorders including: post secondary education, vocational and self advocacy skills, employment; residential services, supports and housing; nutrition, health and wellness; recreational and social activities; and transportation and personal safety.

Registry - Establishes a voluntary population-based autism spectrum disorders case registry to help understand the root causes, rates, and trends of autism

Public Education and Awareness Campaign - Develops a national multimedia campaign to increase public education and awareness about healthy developmental milestones and autism throughout the lifespan. Campaigns will be targeted at a

see Acceleration Act on page 37

AUTISM SPECTRUM NEWS DESK

Sponsors Support the Vital Mission of Autism Spectrum News *Funding Renewed for Publication's Second Year*



Stephen E. Freeman, CSW

Staff Writer
Autism Spectrum News

Now in its second year of publication, *Autism Spectrum News* was delighted to receive vital funding in the form of sponsorships from premier autism organizations for the 2009/2010 calendar year. These renewed sponsorships include a Platinum Sponsorship from Stephen E.



Diana Jones Ritter

Freeman, CSW, Associate Executive Director of the YAI National Institute for People with Disabilities and a member of the *Autism Spectrum News* Editorial Board, a Gold Sponsorship from Diana Jones Ritter, Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities, a Gold Sponsorship from Joseph D. Buxbaum, PhD, Director of the Seaver and New York Autism Center of Excellence at Mt. Sinai Medical Center and a member of the



Joseph D. Buxbaum, PhD

Autism Spectrum News Editorial Board, and a Silver Sponsorship from Cecelia M. McCarton, MD, Founder and CEO of the McCarton Foundation and a member of the *Autism Spectrum News* Editorial Board.

Peter Beitchman, DSW, Chairman of the Mental Health News Education, Inc. Board of Directors stated, "This renewed sponsorship support from these outstanding leaders of the autism community provides *Autism Spectrum News* with the resources it needs to continue to provide



Cecelia M. McCarton, MD

essential autism education to thousands of families and professionals here in the northeast and around the country. In addition, this support tells us that the autism community is solidly behind our evidence-based mission and that we are providing an essential service which is meeting the needs of the community."

These sponsorships will enable *Autism Spectrum News* to broaden its content and

see Sponsors on page 11

Autism Skews Developing Brain with Synchronous Motion and Sound *Lip-Sync Could Explain Staring at People's Mouths*

By The National Institute of Mental Health (NIMH)

Individuals with autism spectrum disorders (ASD) (www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml) tend to stare at people's mouths rather than their eyes. Now, an NIH-funded study in 2-year-olds with the social deficit disorder suggests why they might find mouths so attractive: lip-sync — the exact match of lip motion and speech sound. Such audiovisual synchrony preoccupied toddlers who have autism, while their unaffected peers focused on socially meaningful movements of the human body, such as gestures and facial expressions.

"Typically developing children pay special attention to human movement from very early in life, within days of being born. But in children with autism, even as

old as two years, we saw no evidence of this," explained Ami Klin, Ph.D., of the Yale Child Study Center, who led the research. "Toddlers with autism are missing rich social information imparted by these cues, and this is likely to adversely affect the course of their development."

Klin, Warren Jones, and colleagues at Yale, report the findings of their study, funded in part by the National Institute of Health's National Institute of Mental Health, online March 29, 2009 in the journal *Nature*.

"For the first time, this study has pinpointed what grabs the attention of toddlers with ASDs," said NIMH Director Thomas R. Insel, M.D. "In addition to potential uses in screening for early diagnosis, this line of research holds promise for development of new therapies based on redirecting visual attention in children with these disorders."

A eureka moment in the research came when researchers followed up on a clue

from children's responses to audiovisual synchrony embedded in a nursery rhyme cartoon.

While it was known that people with autism do not spontaneously orient to social signals, it was unclear what early-emerging mechanism may contribute to that. Nor was it clear exactly what they were attending to instead. To find out, Klin, Jones and colleagues tracked the eye movements of two-year-olds with and without the disorder while they looked at cartoon animations on split-screen displays.

The researchers borrowed a technique from the video game industry, called motion capture. They then reduced the movements to only points of light at each joint in the body, like animated constellations. These cartoons played normally — upright and forward — on one half of the screen, but upside-down and in reverse on the other half. The inverted presentation engages different brain circuits and is

known to disrupt perception of biological motion in young children. The normal soundtrack of the actor's voice, recorded when the animations were made, accompanied the presentations.

Eye-tracking data initially showed that 21 toddlers with ASD had no preference for the upright animations, looking back and forth between the two. By contrast, 39 typically-developing toddlers and 16 developmentally delayed but non-autistic toddlers clearly preferred the upright animations.

However, responses to one animation didn't fit the pattern. The toddlers with ASD changed their behavior and shifted their attention to the upright figure as it played a game of pat-a-cake, where the figure claps his hands repeatedly. In this animation (see movie below), unlike the others, the movements of the points of light actually cause the clapping sound.

see Developing Brain on page 42

AUTISM SPECTRUM NEWS DESK

Autism Advocacy Groups Join Together for the “Advancing Futures for Adults” Initiative Autism Speaks to Host AFAA Web Site with Updates and Links to Resources and Information

Staff Writer
Autism Spectrum News

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, spe-

cialists 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 webcasts from at least 14 satellite sites.

see Web Site on page 34

Interactive Autism Network Addresses Significant Unmet Need with Launch of Research Initiative for Adults with Autism

By Paul Law, MD, Director
Interactive Autism Network
Kennedy Krieger Institute

While the number of adults living with autism spectrum disorders (ASDs) grows every day, little is known about them. There hasn’t been a comprehensive, national effort to find out what services adults with ASD are in need of, or to document the ways they contribute to society. In fact, there is no official estimate of how many adults with ASD are living in the U.S. today. Since research into the experiences of adults with autism spectrum disorders is in its infancy, many researchers who want to know more are going to perhaps the richest source of data available: the adults with autism themselves. Through the Interactive Autism Network (IAN) Project – the nation’s largest online autism research project (www.ianproject.org) – adults with ASD and their families can now share information over the web to help researchers answer critical questions.

Launched in April 2007 by the Kennedy Krieger Institute, the IAN Project is an innovative online initiative connecting researchers with individuals and families affected by ASDs. The IAN Project is accelerating the pace of autism research in two important ways:



Paul Law, MD, Director

- Parents of children with ASDs provide valuable information to researchers without having to leave their home or office. As of April 2009, adults with ASDs and their guardians can also enroll and provide much-needed information to researchers.
- Willing individuals and families are notified of local and national studies for which they qualify.

Soon, information gleaned from the IAN Project “Adult with Autism Spectrum Disorder Questionnaire” will be available to researchers investigating the experiences of adults with ASD. The IAN Project has already uncovered new insights and aided research about children with ASD, and by enrolling adults it will use the same proven model to address the many unanswered questions about this underserved population. Including adults with ASD will allow the IAN Project to gain a clearer picture of how adults with ASD are living today, and connect these adults with researchers who are working to understand the disorder at all stages of life.

What Adults Can Participate?

People 18 and older living in the United States who have ever been professionally diagnosed with an ASD can contribute to IAN Project research. If they are independent adults, they can consent to participate in research for themselves and will receive an “independent adult” version of the online IAN Project survey. (Parents of independent adults cannot do the survey for their adult child, but they can inform their child of the project. If their child consents to participate, they may also assist – should this be necessary – with registration or navigating the questionnaire to the same extent they might assist with any other Internet based activ-

ity.) If an adult is under guardianship or otherwise has a legally authorized representative (LAR), then the LAR must consent for the adult and will receive a LAR version of the survey. When LARs answer the survey, they are encouraged to involve the adult with ASD in completing the survey to the greatest extent possible.

What Issues will the IAN Project Address?

The IAN Project will provide much-needed insight into issues affecting adults with ASD, ultimately enabling caregivers, the community, legislators, advocates, and researchers to better serve them. Topics which will be addressed include:

Overall: What are greatest struggles of adults with ASD, and are their needs being met? What are the unique strengths and gifts of adults affected by ASDs?

Public Policy: What changes in public policy or public understanding could make a big difference in the lives of adults on the spectrum?

Home/Workplace: What support is being provided in the home and workplace? Are adults with ASD receiving employment supports such as job coaching or enclave employment? What supports work best

see Research Initiative on page 54

Improving a System for All Ages - NYS OMRDD's Autism Platform

By Kate Marlay, Director
and Dixie Yonkers,
Senior Administrative Analyst
Policy Analysis Bureau
NYS OMRDD

In an effort to quickly bring treatment to the very youngest children with autism spectrum disorders (ASD), policy makers and stakeholders are pushing for early screening, identification and intervention. We know that the earlier treatment begins, the greater the chance of improving a child's outcomes. But, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) also understands that children with ASD grow up to be adults with ASD, and even with early intervention, many people require ongoing supports and services to lead fulfilling lives. With this in mind, OMRDD constructed its Autism Platform — a comprehensive initiative for meeting the needs of those with ASD — to include system improvements that will help the agency better meet the needs of adults on the spectrum.

Improving Practices in Behavior Management

OMRDD recognizes that challenging behaviors often accompany ASD. It is critical that staff within the OMRDD system are able to support people experienc-



Dixie Yonkers

ing challenging behaviors in ways that respect their dignity, appreciate how their ASD may affect their behavior, and keep everyone's safety a top concern.

Since 2006, OMRDD has participated in the Interagency Committee on Restraint and Crisis Intervention under the leadership of the Council on Children and Families. In 2007, the Committee called for human service agencies and providers that use restraints to examine their policies, regulations and training and develop a

plan for bringing these elements in line with coordinated standards and guidelines. In response, OMRDD is creating new regulations that will promote positive approaches to managing behavior and reducing the use of restraint.

"For the first time, the new regulations will provide an official framework for clinicians within our state and voluntary service providers to use in approaching behavior management," said OMRDD Assistant Commissioner of Behavioral and Clinical Solutions, Dr. Jill Pettinger.

The regulations (which will be Section 633.16 of 14 NYCRR Part 633) will govern the preparation and implementation of individualized behavior support and management plans. They will prescribe how and when behavior support and management plans are created, how supervisors review, approve and oversee the plans, how plans are evaluated and revised, and how staff must support individuals with the most positive behavior management approaches possible, saving more restrictive actions for situations of necessity. The regulations will also specify the very limited manner in which restrictive or intrusive measures may be used in those situations and the training required prior to doing so.

At the same time, OMRDD is revising its training curriculum known as Strategies for Crisis Intervention and Prevention – Revised (SCIP-R). The new training curriculum will ensure that staff is pre-

pared to promote the most positive behavior support and management techniques and adhere to the new regulations.

"Together, these dual initiatives will ensure that OMRDD staff and supervisors are held to the highest standards of practice. They demonstrate our commitment to upholding the dignity and safety of everyone we serve," said Pettinger.

New Intensive Behavioral Intervention Services

With the approval of the federal Centers for Medicare and Medicaid Services (CMS), OMRDD will offer Intensive Behavioral Services through its Home and Community Based Services waiver program beginning in 2010. Intensive Behavioral Services will address the behavioral support needs of individuals who require this service in order to continue to live with their family, independently, or in a family-care setting.

These services will be short-term, outcome-oriented services that will facilitate longer term behavioral support and management strategies intended to ensure the health and safety of individuals and to minimize the frequency and intensity of challenging behavioral episodes. The Intensive Behavioral Services provider will complete a functional behavioral assessment of the individual and establish an

see OMRDD on page 45

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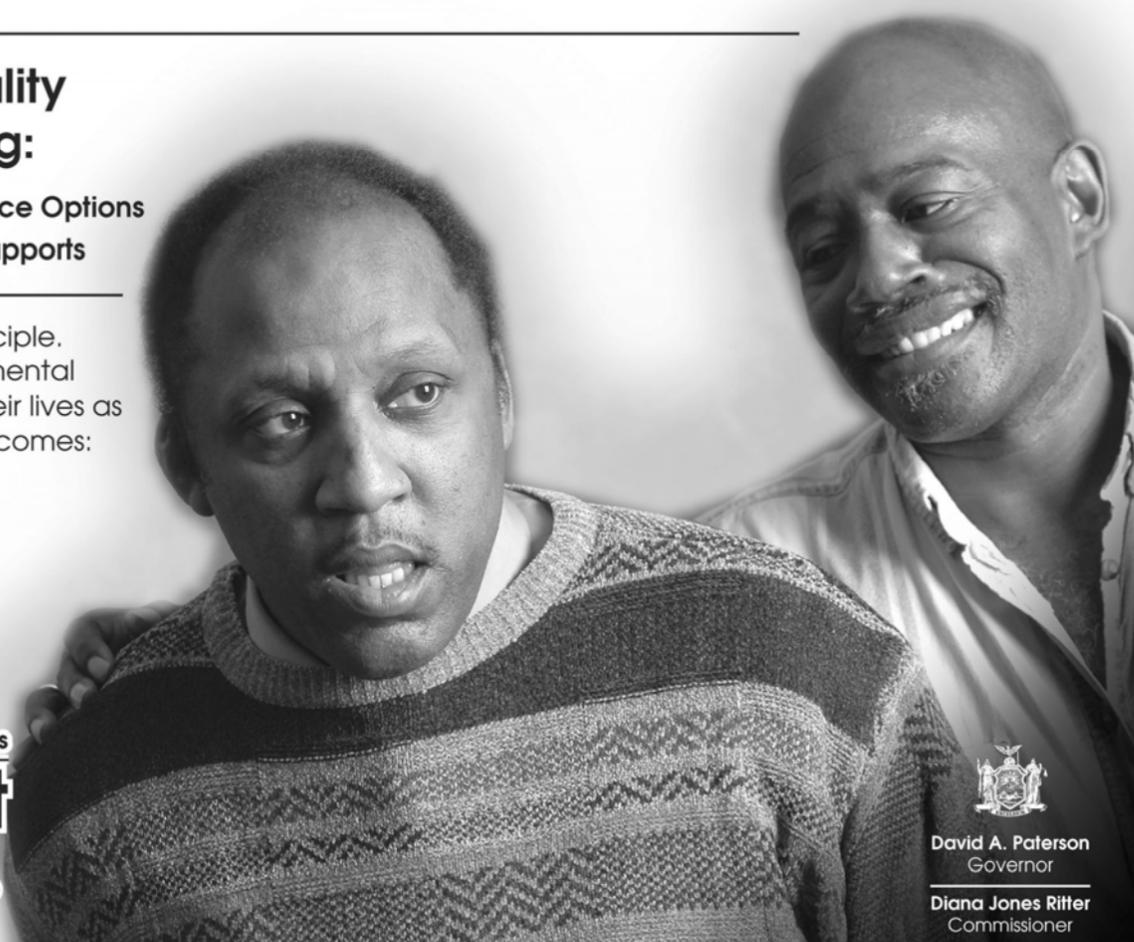
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Navigating the Transitional Years - With a Little Help

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

Each year, Andrea Melvin welcomes young adults with autism spectrum disorders to Manhattan Employment Services at YAI/National Institute for People with Disabilities, where she is supervisor. Having aged out of the school system, these young adults are often highly motivated to work and have excellent employability skills. "Many of the challenges that we help people on the spectrum to overcome are related to social skills, rather than work skills," Andrea said. "A person may be highly qualified for a professional job, but if he can't maintain eye contact, he may never make it past the interview phase."

Andrea and her staff coach young adults with ASD and other disabilities on how to accept constructive feedback, work in teams and develop relationships with co-workers. "At YAI, we really strive for people to be integrated into their environments. People on the spectrum can have a hard time developing relationships and coworkers may have a hard time understanding their behaviors, which leaves them feeling isolated. We help them to pursue their dream careers at the same time as we help them tolerate a work environment."

Finding and adapting to a job is just one of the many new aspects of adult life that confronts people with autism after they graduate from high school.

Good Planning is the Key to Transition

"When young adults with autism and other disabilities reach the age of 21, they are no longer entitled to the same services that they were in high school, which often leads them feeling anxious and unprepared," said Tom Ott, a YAI social worker who helps people with disabilities and their families access services. "It's important to work with people with ASDs and their families to devise a transition plan that will help them become as independent as possible upon graduation. Through a variety of YAI programs, including clinical services, information and referral, in-home habilitation, travel training and social groups, we help people with autism build the skills and confidence they need to function and succeed in the adult world. In addition, it's essential to begin planning for residential support services as early as possible, while they are still in school."

The transitional period is stressful for people with autism as they learn to find



Charles Cartwright, MD

their way as adults and develop their place in the community. But it's often just as discouraging for their families.

"There is a lack of coordinated knowledge about programs and services geared for adults and a lack of collaboration regarding services," said Linda Walder Fiddle, Founder and Executive Director of The Daniel Jordan Fiddle Foundation. "It's confusing and often overwhelming for families, and rightfully so—there are no more teachers or school staff to ask for advice. There's not the same support system in the adult world."

The Daniel Jordan Fiddle Foundation is a national organization focusing on the providing suitable and sustainable opportunities for young adults and adults with autism to participate in all aspects of community life.

"Because we develop and work with programs throughout the United States for adults on the spectrum, I know that families are in need of good information about the types of programs that are available in their community and how to access them, especially during transition," Linda said.

Like the YAI/National Institute for People with Disabilities Network and The Daniel Jordan Fiddle Foundation, many disability service organizations provide families with help finding services, creating long-term plans and coping with transition. But for some families, the greatest antidote for isolation and lack of information comes from other families who have already been through the process.

"There is great value in having parents and people with autism who have navigated transition successfully to help support other families," Linda said. "They can offer support, advice and perspective on potential pitfalls."

Families Helping Families

Support networks established by families, which have existed for decades, offer many benefits in the areas of advocacy, navigating the system and coping. Further benefits are found when parents are formally trained as mentors in order to guide other families through the process of transition and other milestones. During an overwhelming time, they can offer support and perspective on finding employment or day programs; long-term residential and life planning; evidence-based health care options; social and sexuality training; and recreational programs.

Peer-Mentoring

The Daniel Jordan Fiddle Foundation has implemented successful peer-mentoring programs for people with ASDs. "There is great value in people on the autism spectrum mentoring one another," said Linda Walder Fiddle. "The programs have enhanced social skills, empathy and self-esteem of the participants in our programs that embrace this model. We all need support in our lives, whether or not we have challenges, and it's wonderful when individuals on the spectrum are empowered to share their own experience to help another person."

Cultural and Linguistic Sensitivity

Helping underserved populations access information and services is one of the most compelling reasons for implementing parent-advisor programs. Numerous recent studies (Liptak et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Ittenbach, Levy, & Pinto-Martin, 2006; Mandell et al., 2009) have shown that people with autism who are members of racial and ethnic minorities are less likely to receive diagnoses, treatment and services than their white, English-speaking counterparts. According to a 2000 study conducted by the United States Public Health Service, people of color are underrepresented within the field of mental health. Additionally, services may not reflect the cultural values, religion and beliefs of families. Because language and culture are intrinsic to who each of us is, providing culturally sensitive information to families in their first languages is essential for effectively accessing and utilizing services.

Empowering Families

Being advised by informed, well-trained peers is also empowering. Studies have shown that peer-to-peer mentoring

may help parents gain confidence, better cope with their circumstances, and develop leadership skills (Searcy & Lee-Lawson, 1995). Parents who have been mentored by other parents are also more likely to efficiently utilize the service-delivery system, seek out programs and resources and advocate for their loved ones (Cohen & Canan, 2006; Searcy & Lee-Lawson, 1995).

Knowledge is Power

Parent advisors can help families discern evidence-based theories and treatments from the glut of unproven programs available today. They can also help families understand their legal rights in the communities and states they live, as well as the benefits they are entitled to by the federal government. Many families with limited knowledge of English are unaware of federal and state benefits and programs for people with disabilities and their families.

A Model for Training

In order to be effective mentors, parent advisors should receive extensive training in the following areas:

- Autism spectrum disorders and autism resources available in the community and state.
- Evidence-based practices with regards to autism assessment and treatment.
- Empowerment and advocacy, in order to help families know their rights, advocate for services and become more self-sufficient.
- Legal and educational rights of adults with special needs.
- Cultural-linguistic competence, in order to advise families in a culturally appropriate way.

Service coordinators, social workers, support networks and parent advisors are all effective avenues for people with autism and their families to find their way in the adult world. More options create more opportunities for people to receive services and become active members of their communities.

"It's really important that we honor the individuality of each person, listen to them and respect the wonderful diversity of those with autism," Linda said. "We should focus on the strengths and talents of each other, and using this positive approach of support, we can overcome barriers and help people realize their potential."

Sponsors from page 7

distribution to more families whose lives are affected by autism spectrum disorders and to those organizations that provide services to them. This vital funding

will allow for *Autism Spectrum News* to continue its mission of providing vital evidence-based information, education, advocacy, and resources to the autism community.

Autism Spectrum News is a nonprofit quarterly publication that provides read-

ers with a trusted source of news, information and resources on scientific research, evidence-based clinical treatment, and family issues that are of vital interest to the autism community. Directed towards a broad audience of families, treatment professionals and service

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College Coaching for Students with Asperger Syndrome

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

Most college disability officers tell us that there has been a recent and significant increase in students on the autism spectrum attending college. This increase stems from a number of factors including the early recognition of these conditions and appropriate intervention during the developmental years, the recognition of these conditions by school and college staff, and the self advocacy movement within this population that motivates potential students on the spectrum to realize that college is a realistic plan for them and to act on that knowledge. Most college students on the spectrum are the product of mainstream education and IDEA-mandated supports for whatever educationally disabling characteristics they manifest. However, colleges, used to serving more neurotypical students, are often at a loss as to how to effectively support such students on campus, and the less specific ADA laws do not delineate specific supports. In fact, ADA really only gives students the right to equal access to higher education and it is up to them to negotiate realistic accommodations.

There have been a number of specialized programs developed that can give intensive support to college students with



Lynda Geller, PhD

Asperger Syndrome. Some support students to pursue traditional academic degrees and others are certificate programs that help train the student in the life skills that may not have been addressed in a mainstream educational program, but are critical for lifetime independence. Some college disability offices have staff that

are educated about Asperger Syndrome and give an excellent effort to supporting such students in multiple ways, while others have no specific interventions designed for this population and simply make available whatever supports are generically available to classified students.

As in all service arenas that offer a range of intensity of assistance, from mental health to child advocacy to early intervention, a system is at its most effective when it can match the specific level of need to the appropriate service level. Overly intrusive help stifles independence and inadequately intense assistance lacks effectiveness. This is also true for college support for students on the autism spectrum. Those who try to function without any assistance and find themselves having an unsuccessful experience may have only needed some regular but contained support, yet without that they are not succeeding. They may not have required a self-contained specialized program, but often cannot find other options addressing their level of support need. In addition, we would all like to see these students being able to take advantage of any college experience that is otherwise their choice without having to limit their selections to a small number of colleges with specialized services for students on the spectrum. Thus, we see an ever-increasing demand for more individualized supports for college students who may have excellent academic potential, but need unique

supports to be able to continue their schooling successfully. Oftentimes, college students who were mainstreamed may have not received supports from their school in social, vocational, and life skill areas because of their academic success, but in college find themselves lacking in these areas. For students who needed academic support and received it through their IEPs, the transition to college with its relatively lesser protections through ADA, may be a jolting surprise and lead to academic and life management failures. It is important that all areas of function that may impact college adjustment are considered and appropriate plans to address them are made. Students, their families, and their educational team need to consider the following aspects of the young person's functioning during the planning period before college:

- Academic: what modifications have been in place and how does the student perform in various types of the classroom settings?
- Psychological well-being: what therapies and medications are currently being utilized?
- Physical well-being: how independent is the student in managing exercise, medications, diet, and sleep cycle?

see *College Coaching* on page 36



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Closer to the Dream of a Brighter Future for Adults with Autism Spectrum Disorder

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

In 2002, when The Daniel Jordan Fiddle Foundation developed its first three programs for adolescents and adults with Autism Spectrum Disorder (ASD) and awarded grants to support them, no one in the autism community was talking about adults with autism. That was the point. During my son Danny's lifetime, I had realized that after he aged out of the educational system entitlements mandated by the Individuals with Disabilities Education Act (IDEA), there were no federal or state laws specifically mandating that he would be entitled to the supports and services he would need in adulthood. And, as I researched to learn what, if any programs existed in the United States that could provide residential, vocational, recreational and educational opportunities for him, I came up with merely a handful of options and none that specifically related to ASD. A few years later, friends and family encouraged me to continue to focus on ASD after Danny's untimely death at age 9, and I knew that the not-for-profit organization bearing his name would have to focus on adults, because no one else was.

During the past seven years much has changed for the better in the adult world



Dorothy Leung Blakeslee, Appointee of NJ Senator Richard Codey and Linda Walder Fiddle, Esq., Appointee of NJ Assembly Speaker Joseph J. Roberts, Jr. to the New Jersey Adults with Autism Task Force.

of ASD. I would like to credit the dedicated Board of Trustees and Advisors of our national autism organization for some of those changes. The Daniel Jordan Fiddle Foundation has developed and supported programs in rural, urban and suburban settings throughout the United States

that focus on young adults transitioning from school to adult life and adults as they follow paths to live, work and recreate in communities throughout the country. When I look at the map and see all the ground our small, all-volunteer organization has covered, I feel grateful to have

been inspired by individuals with ASD, their families and those who serve them so that we can create more of what I had wanted for Danny: to have suitable, sustainable and stimulating opportunities to participate in and contribute to community life.

What is also gratifying is to now see that others in the autism community are starting to focus on the question The Daniel Jordan Fiddle Foundation asked in 2002 has been answering ever since, "What is going to happen to my child when he or she becomes an adult?" The topic of adults on the spectrum is now part of the conversation among autism organizations and has resulted in an exciting collaborative initiative called, *Advancing Futures for Adults with Autism*, which will host nationwide town hall meetings on November 13, 2009 to develop a policy agenda to address the needs of adults. The Daniel Jordan Fiddle Foundation is a member of the Steering Committee for this effort, composed of a powerhouse of autism organizations and advocates, and all involved are committed to engaging the voices of concerned Americans on this topic.

The topic of adults and ASD has finally become a part of our national and state agendas as legislators across the country are initiating and enacting bills

see Brighter Future on page 45

Strategies for Effective Advocacy

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

How can one person's voice make a difference? That question is often posed, or at least thought about by most people. You read something in the paper and know for a fact it is misinformation; you hear about an incident that reeks of injustice; you are personally impacted by thoughtless and unsupportive acts: all of these, and other things too can inspire fury—but do they inspire you to take action? In many instances, the answer is no.

We cool down a bit. We weigh the pros and cons of making a fuss, of speaking out, and maybe we discuss the inequity with friends and family and get over it. BUT, there are times when this will just not suffice, which then begs the question—how can one person's voice make a difference? Asking this question is the beginning of advocacy.

Recently I had the opportunity to speak with a group of parents of adult children on the spectrum about advocacy. Most of the attendees, when asked whether they had ever acted as an advocate for themselves or anyone else, said, "no, not really." When asked to think about this a little more and write some potential

"advocacy moments" on paper, many surprised themselves and were able to identify and recount for the others a particular instance when they advocated on behalf of something or someone. Several of these "advocacy moments" had nothing whatsoever to do with autism. I suggested to the group that the method or "tools" they used to advocate in that instance could be applied to advocating on other issues too, including autism related issues.

What were some of the "tools" we discovered? First, it must be an issue that sticks with you, not for hours alone, but for days on end. When you are preparing dinner, folding laundry or taking a walk, the topic is on your mind. Continuous

engagement in the issue is often fueled by passion which is just the energy source needed for advocacy. Second, do your research on the topic. There is little worse or more ineffective than an advocate who is ill prepared. One man in the group told about a *Letter to the Editor* he had written regarding unequal access to housing for adults in his community where he had spent many hours researching the facts surrounding the particular incident, laws relating to it and he even sought out his local councilman to get his perspective. The letter was a highly effective piece of advocacy that brought about a town hall

see Effective Advocacy on page 47

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Key Issues in Therapy with Adults with Asperger's

By Irene Brody, PhD
Clinical Psychologist

I have several guiding principles when working with adults with Asperger's Syndrome (AS). First and foremost, people with AS are more like than unlike the rest of us. AS individuals experience the same emotions, thoughts, life situations and challenges as anyone else. Therefore, when working therapeutically, one should not assume that an individual's challenges are all related to his or her having AS. In fact, part of the work is sometimes to help clarify how the AS piece fits into and affects an individual's life, and how it does not, and encouraging the person to not overly identify with the label. At the same time, people with AS have important differences that must be acknowledged, honored, and sometimes remediated. Life's challenges get compounded when a person has AS, and this must be understood and addressed in therapy.

Secondly, all people with AS, like all people in general, are different from one another. Thus the topics I bring up in this article are not a one-size-fits-all list. Rather, the list is an amalgam of issues that many different individual clients have brought to my attention. I am sure there are others I have left out or not yet encountered.

Finally, I believe all clients have the



Irene Brody, PhD

right to take charge of what parts of themselves they would like to improve or change, and what parts they are happy to leave alone. If someone does not want to make a change in order to fit in with mainstream society, that is their business, as long as they are making an informed choice that works for them, rather than simply giving up for lack of skills or confidence. For example, if a client wants to find and keep a girlfriend, I might point out that certain of their behaviors could

possibly alienate them from some potential girlfriends, and then let them decide whether they want to work on those behaviors or not.

The first issue I am on the lookout for is low self-esteem. Most people who are different have been subject to varying degrees of teasing, criticism and ostracism. Social rejection can have profound effects on a person's sense of well-being (Williams, 2009). Ostracism can lead to emotional numbness and also contributes to anger and aggression (Baumesiter, et.al., 2007). People with AS often grow up with a sense that there might be something wrong with them, develop a sense of learned helplessness, and conclude that the safest and best solution is social withdrawal. Thus, a therapeutic goal is to restore a sense of self-worth and confidence. I am quick to point out strengths, and offer a carefully adjusted balance of empathy and encouragement.

The second issue is self-advocacy and assertiveness. When a person has been alienated socially, has low self-esteem, has challenges reading social cues, or all of the above, it may be tough to figure out what one is entitled to, and how to effectively ask for it. Many of the people I work with are unsure and often unskilled, presenting themselves sometimes as too aggressive, too passive, or a combination of both. Assertiveness and self-advocacy skills need to be encouraged through direct instruction and through developing a

positive self image as a person with AS.

Another issue is loneliness. Most of us have varying degrees to which we need and enjoy solitude. At the same time, most of us have some need for human company at least some of the time. This need can range from having others nearby, to having friends to share activities with, to having intimate relationships. This issue should be addressed and explored in therapy. I make suggestions for how to increase social contact, including social skills groups in the area. For some of the individuals I've worked with, I am one of the few people they talk with on a regular basis. For that reason, I make myself more available than a typical therapist might. For example, I allow clients to email me between sessions and will try to respond, if even briefly, to maintain that human connection. This small gesture of responding to an email can serve as a powerful reminder that there is indeed somebody out there who not only acknowledges their existence but truly cares about them as well. I take care of my own needs while at the same time modeling honesty and directness about my own boundaries and needs for space.

Many people, AS or not, bring to therapy past experiences in life that remain a source of suffering. People with AS can be especially sensitive, conscientious, uncertain as to how they or others may

see *Therapy on page 52*

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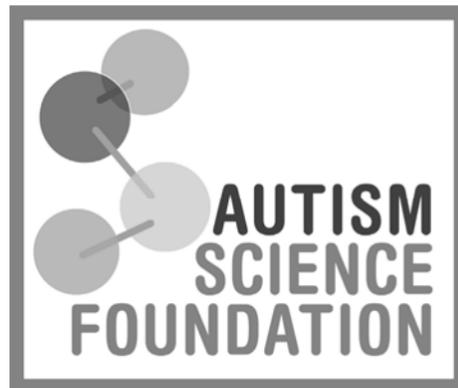
Autism Science Foundation Launches Operations

New Advocacy Group Will Focus on Non-Vaccine-Related Autism Research

Staff Writer
Autism Spectrum News

The Autism Science Foundation, a new not-for-profit organization dedicated to supporting and funding autism research, launched its operations in April, debuting its web site and blog (www.autismsciencefoundation.org and autismsciencefoundation.wordpress.com) and kicking off its "First 100 Days" fundraising drive. The organization is co-founded by Alison Singer, formerly Executive Vice President of Autism Speaks, and Karen London, co-founder of the National Alliance for Autism Research (NAAR). Both Singer and London are parents of children with autism. Singer will serve as President of the new organization.

Singer resigned from Autism Speaks in January of this year, citing disagreement with the group's decision to continue to fund more vaccine research despite multiple scientific studies exonerating vaccines as a cause of autism. "After I left Autism Speaks, I heard over and over from parents who said they needed an organization they could trust to fund nothing but the very best science; science that would open new doors and ask questions that have not yet been answered. That's what we'll do at the Autism Science Foundation."



ASF's mission is to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.

"This organization will adhere to the rigorous scientific standards and values that defined NAAR during its 12 year, pre-merger history," said London. "Outstanding research is the greatest gift we can offer our families. Every research dollar needs to count." Founded in 1994, NAAR was the first nonprofit organization in the world dedicated to advancing autism research. In 2006, NAAR merged with Autism Speaks.

The Autism Science Foundation's mission is premised on the following facts and principles:

- Autism is known to have a strong genetic component. Research must aim to discover the mechanisms of action that trigger autism, as well as safe, effective and novel treatments to enhance the quality of life for children and adults currently affected.
- Early diagnosis and early intervention are critical to helping people with autism reach their potential, but educational, vocational and support services must be applied across the lifespan. Science has a critical role to play in creating evidence-based, effective lifespan interventions.
- Vaccines save lives; they do not cause autism. Numerous studies have failed to show a causal link between vaccines and autism. Vaccine safety research should continue to be conducted by the public health system in order to ensure vaccine safety and maintain confidence in our national vaccine program, but further investment of limited autism research dollars is not warranted at this time.

"We know more about autism than we did just a few years ago. For example, new discoveries in neuroscience, genetics, and epigenetics offer hope for improving the lives of people with autism," said Dr. Edwin Trevathan, Director of CDC's National Center on Birth Defects and Developmental Disabilities. "It is important that we apply these scientific advances to public health research to learn what causes autism spectrum disorders, how to treat autism, and eventually how to prevent autism-associated disability. As we all strive to follow where the science leads, the Autism Science Foundation will play an important role."

"We need the most rigorous science to understand autism and develop new treatments," said Dr. Tom Insel, Director of the National Institute of Mental Health and Chair of the federal Interagency Autism Coordinating Committee (IACC). "I look forward to the Autism Science Foundation joining the public-private partnership described in the new strategic plan for autism research."

"As we attempt to understand the causes of autism, and to develop optimal treatment programs, it is critical that parents have access to information that is based upon the best medical evidence," said David T. Tayloe Jr., MD, FAAP,

see Foundation Launch on page 49



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

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—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.

Your Child is Turning 18 - Now What?

A Primer on Guardianship and Surrogate Decision Making for the Parent of a Special Needs Child

By Raymond J. Falcon, Jr., Esq.
Falcon & Singer PC

You have protected and advocated fiercely for your child with special needs, almost since the day she was born. You fought insurance companies, school systems, you name it; all to get your special child the best possible education and care and to give her the chance to be all that she can be. Time flies, and suddenly your little girl turns 18 and she becomes emancipated as a matter of law.

The law may think that, now that she is 18, she is suddenly ready to take care of herself and make all of her own decisions. You know better. However, suddenly the school can't discuss her education with you and her doctors won't discuss her medical condition. Now that she is legally an adult, you are suddenly cut out. They can't talk to you unless she has given them her consent. What do you do?

You have several options to consider. There are a number of alternatives that are available, ranging from full guardianship to a simple power of attorney and health care proxy. Which option makes sense for you and your special child depends in large part on the degree of disability affecting your special child.



Raymond J. Falcon, Jr., Esq.

Guardianship

If your special child has severe disabilities which affect her mental capacity so that she cannot manage her own affairs, a full legal guardianship may be a good option. A full guardianship, some-

times referred to as guardianship of the person and property or a plenary guardianship, gives the guardian total control over the person and property of another individual, generally called the ward. If you are appointed the full legal guardian for your special child, you control every aspect of that child's life for as long as you are the guardian. You can deal with doctors, government agencies, courts, financial institutions, and others on behalf of your child.

Full legal guardianship is not something that is obtained lightly, since, once you are appointed as full legal guardian of your child, she loses her rights to act independently. In order to protect the rights of a potential ward, a full legal guardianship can only be obtained by going to court and asking a judge to appoint a guardian. The specific procedures vary from state to state; however, there are some common themes that recur in guardianship proceedings throughout the country.

The proceeding is usually commenced by your attorney filing a written request (sometimes called a petition or a complaint depending on your state) to a judge in your area that has authority to appoint you as guardian. The request asks the judge to appoint you as legal guardian of your special child. As part of your initial request, you will usually be required to submit proof to the judge that your special

child is incapable of managing her own affairs on a day to day basis. This is generally done by providing the judge with sworn statements from qualified doctors, detailing the nature and extent of the disability and rendering the opinions of the doctors that the proposed ward is not able to manage her own affairs on a daily basis. You will also provide your own sworn statement, giving the judge your experience in caring for your child, and why you think a full guardianship is needed.

The judge will set the matter down for a hearing, at a date the judge picks. In many states the judge will also appoint an independent third party, often a local attorney, to represent the interests of your child in the proceeding. This person, sometimes called a guardian ad litem, will usually undertake an independent investigation into the situation, meet with your child, review the doctors' statements and talk with you and your attorney. The guardian ad litem will file a written report with the judge giving the guardian ad litem's opinion on whether a full guardianship is appropriate. The guardian ad litem will file a report with the judge at some point before the day of the hearing. This is a good safeguard to protect the proposed ward, since you are in effect asking the court to take away her civil liberties

see Guardianship on page 51

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- ✓ 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.

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ELIJA

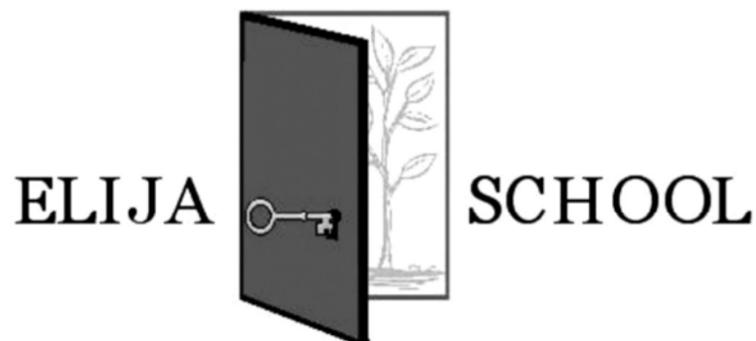
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for Children with Autism*

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To open doors to independent growth for individuals with Autism, creating appropriate opportunities for these individuals to become contributing and interactive members of their mainstream communities

The ELIJA School is a private, non-profit school for children and young adults diagnosed with autistic spectrum disorders that provides an individualized full day 12 month program. The ELIJA School serves the needs of our learners with science-based treatment utilizing the principles of Applied Behavior Analysis. It provides an intensive, one-to-one child to teacher ratio in a comprehensive instructional setting within a classroom environment. The ELIJA School focuses on the development of functional communication, academic and social life skills. The ELIJA School conducts external program evaluations to monitor the quality and effectiveness of our educational and treatment programs.

We are committed to serving individuals with autism and their families with distinctive quality in educational and intervention services. We believe that each individual has a right to services that enhance well being, quality of life and opportunities to learn. The ELIJA School encourages the use of best clinical practices and believes everyone has the right to effective treatment. We are committed in ensuring the most effective, individualized intervention program for each child and to provide the highest quality in teaching and learning that we can possibly achieve.

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The College Internship Program Enhances Curriculum for Students With Learning Differences

By Sarah Williams
Admissions Outreach Coordinator
College Internship Program

The College Internship Program has recently expanded its curriculum to include Wellness and Bookends Programs, which augment their current teaching modules and unique services. CIP has also rolled out six new levels of support at their four campuses across the US.

"We are constantly trying to improve our programs and develop new holistic methods to make sure our students get what they need," stated Dr. Michael McManmon, Founder of the College Internship Program (CIP). "We are working to meld our academic, career, social, wellness and residential curriculum to enhance what has become the most comprehensive college and career program in the US."

The College Internship Program offers academic, internship and independent living experiences for college age students with Asperger's Syndrome and other Learning Differences. CIP serves the growing number of students who are aging out of public school systems and need support after high school. Many of these young adults need to develop self-advocacy skills and learn how to function independently before they can be successful in college or careers.

CIP is continually working to enhance its programs to meet student needs. The new Wellness Program offers individual and group sessions, which help students reduce stress and promote healthy lifestyles. "In addition to being in great shape and strengthening the immune system, exercise and a good diet can increase energy and promote positive social behaviors," stated McManmon. After individual assessments, students receive support in the areas of nutrition, hygiene, sensory issues, weight control and physical fitness.

The Bookends Program consists of executive functioning skills groups in which students come up with organizational strategies for their academics and career internships. Students learn to prioritize tasks, set goals, plan ahead and communicate more effectively. Working in small groups and using visual prompts, students receive instruction on how to carry these skills forward into the workplace and daily life. This program is offered on Mondays and Fridays, serving as "bookends" for each week.

In addition to these two new programs, students at CIP also learn how to deal with social and organizational challenges, which can make the typical college experience overwhelming. "Many of our students went off to a traditional college



Dr. Michael McManmon

but weren't successful because their college did not offer the supports they needed," stated McManmon. "Even though these young adults have great potential, many return home, isolate themselves and lose functioning."

CIP provides a bridge for these young adults, easing the transition to college and independence by offering comprehensive instruction in academics, life skills, social skills and career development. Students live in apartments with residential staff available 24 hours a day. All students have advisors, tutors, therapists and social mentors who help navigate real life situations such as grocery shopping and banking. Many have internships and attend local colleges in conjunction with CIP's classroom modules and services.

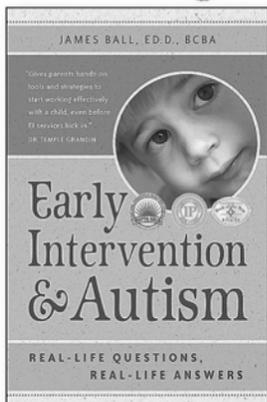
In an effort to further meet the needs of individual students and their families, CIP has developed six new Levels of Support. "Some students who come to us may benefit from Level One services such as executive functioning, social skills, meal planning and hygiene while others may be attending college or employed and need our Level Six services," stated McManmon. "The Levels of Support are also designed to be flexible so students can move into a different level when they are ready," he continued. Year round tuition ranges from \$15,500 for Level Six to \$69,500 for Level One. Students range in age from 18-26 and can enroll in the program for up to five years.

A record number of students recently finished the 2008-2009 school year. Even higher enrollment is anticipated next year at CIP's four centers in Massachusetts, Indiana, Florida and California where the program is currently under expansion to meet growing enrollment. For more information, visit www.collegeinternshipprogram.com or call 1-877-KNOW-CIP.

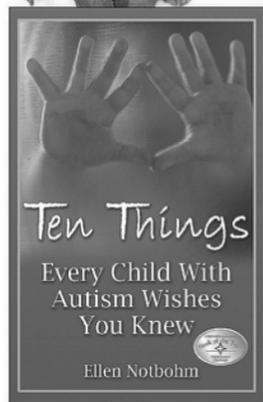
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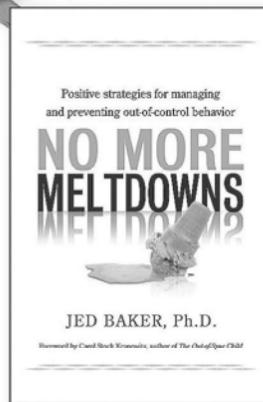
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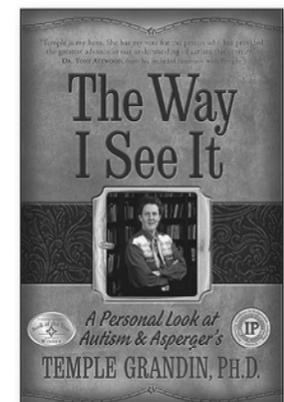
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The most famous person with autism in the world, Dr. Temple Grandin offers helpful do's and don'ts for people with ASD, educators, and caregivers, based on her "insider" perspective and a great deal of research.

If there is one theme in our publications and conferences, it's the focus on the positive and the progress people with ASD can make.



Visit www.FHautism.com to browse through our resources, find a professional in your area, or see which of our outstanding authors will be speaking at a conference near you! Our 8 summer conferences feature Dr. Temple Grandin and/or Dr. Tony Attwood.

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Preparing for Work

By Temple Grandin, PhD
Author of "Thinking In Pictures"

Recently I received a phone call, and the caller asked me if a bright man with Asperger's was capable of having a job. He was in his late teens and his father thought that he was fully capable of working but his mother felt that her son would not be able to live independently. This youth had already completed some college computer science classes and had received good grades. My response was that this youth probably would be fully capable of getting and keeping a job.

The first step is to determine his job skills. Some individuals will be capable of high level careers and others will have to do simple jobs. I have observed that sometimes teachers and parents of smart "Aspie" kids have expectations that are too low. A boy who has received good grades in a computer science class should not be bagging groceries for the rest of his life. However, one summer of bagging groceries would probably be good for learning job skills, such as being polite and being on time. One of my first jobs was hand sewing of hems on dresses. When I was 13, I did this job two afternoons a week for a seamstress who worked out of her home. I liked buying things with the money I earned. When I was 15, mother made arrangements for me to visit my aunt's ranch. Like many people on the autism spectrum, I was afraid to go to the ranch. Fortunately, mother insisted that I go and I ended up loving it. Individuals on the spectrum need to be exposed to new things. My experiences at the ranch became the foundation of my career designing cattle facilities.

Slow Transition to the Work World

The transition from school to a career will be easier if the transition is made slowly. Learning work skills should start in middle school and continue throughout high school and college. Unfortunately, I have seen smart Asperger students who have graduated from college and they have never done a job for somebody else. They had never walked dogs, mowed lawns, worked at McDonalds or bagged groceries. My transition to work started when I was 13. When I was in college, I continued to visit my aunt's ranch, but I also interned at a research lab and a summer program for children with autism. These were very valuable work experiences. I also did freelance sign painting and carpentry projects.



Temple Grandin, PhD

Never Too Late to Start

Parents have said to me, "My son is 35 and he has never worked – it's probably too late to change his life." It is never too late. A person on the spectrum always keeps developing and growing. I was 50 when I learned about how people have little social eye movement signals. Many people have told me that my lectures have improved between the ages of 50 and 60. I always keep learning and I did not even feel like I was an adult until I was in my 40's.

Both Mother and Work Colleagues Pushed Me

I was often reluctant to try new things but mother made me go to the ranch. I had two choices; I could go for two weeks or all summer. It is important to urge people on the spectrum to try new things, but there must be NO surprises. Sudden surprises cause panic. Mother prepared me for the trip to the ranch months in advance. I was given pictures of the ranch and talked to Aunt Ann on the phone.

No Multitasking

There are two things at work that all individuals on the spectrum may have difficulty with. They are multitasking and remembering long strings of verbal instructions. I would have a difficult time being a waitress in a busy restaurant. Learning the social part would be easy, but trying to remember all the orders would be hard. Some entry level jobs would be more difficult for me to perform than my career designing cattle handling facilities. When I design cattle equipment there is no multitasking. A simple accommodation for remembering long strings of verbal instruction is to

ask your boss to email them. Just tell your boss you love email and you will do your best work with written instructions.

Mentors Saved Me

I stopped fooling around in school and started studying when Mr. Carlock, my science teacher, got me interested in science. Now I had a goal of becoming a scientist so I started studying. Parents and teachers often ask me how to find mentors. A good mentor might be a retired engineer who gets a teenager or adult turned on to engineering. One mother taught her son the old fashioned FORTRAN computer language. That was the only language she knew. Teaching something old is perfectly fine because it gets the individual turned on. After this teenager had learned FORTRAN, he was now motivated to learn the more modern programming languages. Mentoring is required to get an interest started that can turn into a career. Learning a higher skill such as computer programming requires discipline and teaching. Very few teenagers will go out and obtain textbooks on high level subjects unless a good teacher turned them on. This teenager developed programming skills and is now employed.

Learning to Do an Assignment

The ability to draw or to write can only be turned into a career when the individual is willing to do an assignment for somebody else. When I painted a sign for a beauty shop, I had to make a sign they would like. Cattle pictures would not have been appropriate. A teenager may want to draw cars over and over. Parents and teachers should work to broaden his art skills by asking for a drawing of a place a car might go to. If the individual is good at writing, encourage him to start doing writing assignments such as writing a neighborhood newsletter. When I first started in the livestock industry, I wrote a single article each month for the Arizona Farmer Ranchman Magazine. My career started one small project at a time.

Sell Your Work

Since I was awkward socially, I sold my work instead of myself. I sold sign painting and cattle design projects by showing a portfolio of my work. Even though people thought I was really weird, they were impressed when they saw my drawings. When I wrote articles for the magazine, I quickly developed a reputation for accurate reporting. When I covered the Arizona Cattle Feeder's meeting, they respected the fact that I never misquoted a speaker at a meeting.

About Dr. Temple Grandin

Temple Grandin, PhD, is inarguably the most accomplished and well-known adult with autism in the world. She has been featured on major television programs, such as "ABC's Primetime Live", the "Today Show", "Larry King Live", "48 Hours" and "20/20" and written up in national publications, such as *Time* magazine, *People* magazine, *Forbes*, *U.S. News and World Report*, and *New York Times*. Among numerous other recognitions by media, Bravo Cable did a half-hour show on her life, and she was one of the "challenged" people featured in the best-selling book, *Anthropologist from Mars*.

Dr. Grandin didn't talk until she was three and a half years old, communicating her frustration instead by screaming, peeping and humming. In 1950, she was labeled "autistic," and her parents were told she should be institutionalized. She tells her story of "groping her way from the far side of darkness" in her book *Emergence: Labeled Autistic*, a book which stunned the world because, until its publication, most professionals and parents assumed being diagnosed "autistic" was virtually a death sentence to achievement or productivity in life.

Dr. Grandin has become a prominent author and speaker on the subject of autism because "I have read enough to know that there are still many parents, and, yes, professionals, too, who believe that 'once autistic, always autistic.' This dictum has meant sad and sorry lives for many children diagnosed, as I was in early life, as autistic. To these people, it is incomprehensible that the characteristics of autism can be modified and controlled. However, I feel strongly that I am living proof that they can." (Taken from *Emergence: Labeled Autistic*)

Even though she was considered "weird" in her young school years, she eventually found a mentor, who recognized her interests and abilities, which she later expanded into becoming a successful livestock handling equipment designer, one of very few in the world. She has designed the facilities in which half the cattle are handled in the United States, consulting for firms such as Burger King, McDonald's, Swift and others.

She presently works as Professor at Colorado State University but also speaks around the world on both autism and cattle handling.

Dr. Grandin's current autism best seller is *The Way I See It*. She also authored - *Animals Make us Human, Animals in Translation, Unwritten Rules of Social Relationships, Thinking in Pictures and Other Reports From My Life With Autism, Emergence: Labeled Autistic* and produced the video -*Dr. Temple Grandin (DVD)*, which can be obtained from Future Horizons. At every Future Horizons conference on autism, the audience rates her presentation as 10++.



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

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Photo by Matthew Septimus, 2008

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

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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

Innovative Programming for Individuals with Autism

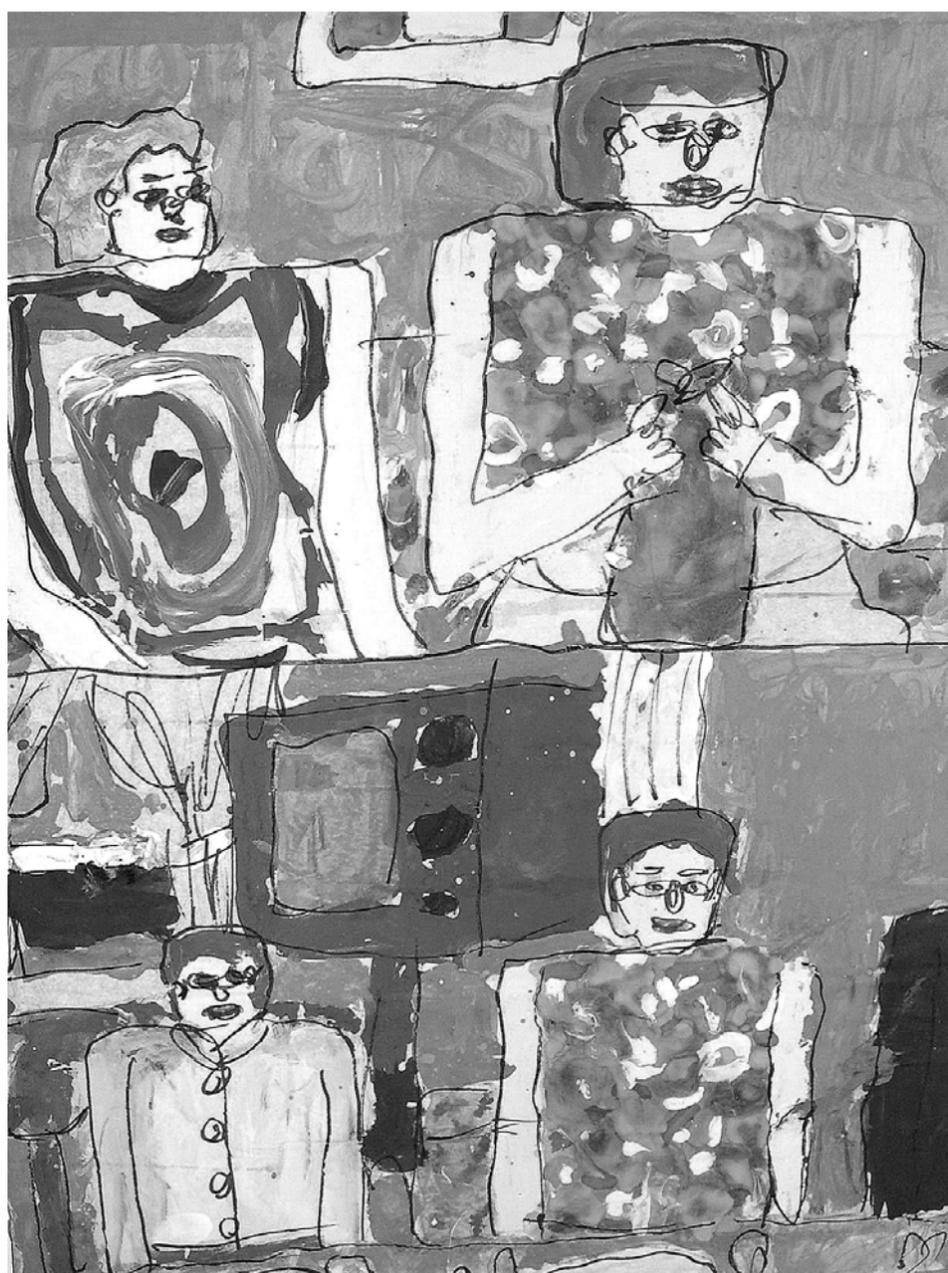
By Suzanne Kucharczyk, MEd,
Mary McKillop, MA, CCC-SLP and
Pamela Rogers, EdD, NCPsyA, LP
The Shield Institute

As children who have autism grow up and transition to adulthood, they demand programs that can attend to their independence, explore their identity in the world and build valued skills. Such innovative programs tap into the talents and gifts of individuals, while appreciating the global needs of people with autism. One such innovative program was developed by The Shield Institute in 2002.

The Shield Institute's Pure Vision Arts (www.purevisionarts.org) is New York's first art studio and exhibition space for adults with autism and other developmental disabilities. Modeled after Creative Growth in California, Pure Vision Arts provides a forum for talent and creativity to flourish by providing a space where people's talents are supported and their art is taken seriously. The mission of PVA is to develop the capacity for creative expression while increasing a sense of personal identity and pride through the creation of art. Dr. Pamela Rogers, Director of PVA, states, "PVA's philosophy begins with the belief that the arts are not a luxury, but a necessity in a civilized society, and that all people regardless of their ability should have the opportunity to express themselves." This philosophy provides a foundation for an innovative studio program.

If you were to take a tour of PVA, you would travel to the heart of Manhattan's art district in Chelsea. You would come to an open studio space rich with the exhibit work of diverse artists. These artists are self-taught and have developed their own unique style over the years. Some were encouraged and supported by friends, family and service providers early on. Others have found art as an important mode of self-expression later in life. They work in a variety of media. Some paint on canvas. Others weave and explore the use of textiles. One artist draws intricate detailed work with the use of pen on paper. One exhibited artist makes high quality wood frames for his internationally respected paintings. On a tour of the studio, you may find as many as twenty-five people ranging from teenagers to senior citizens working on commissioned pieces, works for exhibition and for their sheer enjoyment.

Pure Vision Arts takes a person centered approach with an emphasis on ability rather than disability and process rather than product. PVA views making art as a viable vocation and serves as a representative and agent for its artists. PVA believes that the interests of people who have autism need to be seriously explored and developed. The talents of a person who has



Susan Brown, Family Portrait

a specific interest in creating art need to be cultivated and nourished, not only as a mode of self expression, but as an important value and significant contribution to their community. We will explore the work of two artists, one established and one emerging who highlight the importance of art and innovative programs, which nurture creativity.

Susan Brown, 52, was diagnosed with autism as a young child. She began drawing at five years old before she developed verbal language. Since she was a little girl her drawings have focused on women, trains and cars among a few other preferred subjects. She began working in her characteristic mixed media grids on cardboard in the 1980s while working as a dishwasher for fifteen years at Friendly's Restaurant in Long Island. Cardboard packing material was readily available and she became very attached to working on that particular surface. After commuting for 3 hours, Ms. Brown spends 8 hours at PVA diligently working on her pieces. Her work depicts incredible details from her personal life experiences thanks to her prodigious memory. One painting depicts 64 small images of her mother in different

poses, another shows moments of her sister's life in 144 small images on one canvas. She is an accomplished and mature self-taught artist whose work has brought her considerable attention and is included in numerous private and corporate collections. Her paintings have been featured in many exhibitions including the Outsider Art Fair in New York City, the European Outsider Art Fair in Vienna, Galerie Atelier Herenplaats and Gallery Olof, in the Netherlands, and Ricco Maresca in New York City.

Ms. Brown is an example of an established artist; Pure Vision Arts also provides a forum for young artists. While art may not be their final choice for vocation or recreation, Pure Vision Arts provides a creative space for exploration of what a young adult's gifts and unique talents might be. One such artist is Jonathan, 18, who has attended The Shield Institute's school age program for the last 9 years. JC has an emerging interest in art and geography, which often come together. Over the years this artist's expression has become more sophisticated and a significant aspect of who he is. Over the last year he and other young adults from The Shield Institute's school age pro-

gram have attended the Pure Vision Arts once a week. Dr. Rogers asserts that at PVA "...artists are encouraged to translate their interests and experiences into profoundly personal art that chronicles their inner life. People are free to develop their own 'pure vision' from within and not through formal instruction or copying material from other sources. The work develops organically through gaining a level of comfort with materials and the environment." Jonathan's work this year has culminated in his self-portrait being selected as a winner by the Anne Frank Center, where it will be exhibited this summer.

Although both Ms. Brown and Jonathan have autism, the way that their autism manifests is very different and thus their supports cannot be identical. Pure Vision Arts understands both that people with autism require different supports and also that the similarities of people with autism seem to connect them to art as a vehicle for self-expression. As Dr. Rogers writes in her chapter *Art Education and the Culture of Autism*, "...when a teacher and student gain a comfort level with each other, the arts can be an excellent way to facilitate sensory stimulation, communication, self-expression and social interaction. Art programs can be an effective way to address the deficits in communication and social interaction in a (person)-centered and enjoyable way." Thus art not only provides ways to attend to the challenges or deficits that people with autism experience, but also serves to access the individuality and creativity of a person. Through the vehicle of art we can better appreciate the inherent contributions of a person rather than focusing on their deficits and needs.

Ms. Brown and Jonathan are examples of an established artist and an emerging artist being supported by an innovative program for people who have autism and other developmental disabilities. As the numbers of children who have autism continue to increase, such innovative programs will be that much more critical as these children transition into adulthood. Although funding resources for programs are limited, The Shield Institute has advocated for continued support of a program that highlights the individual gifts, talents, and contributions of people with autism through a vehicle that also addresses the challenges of autism.

Mary McKillop, MA, CCC-SLP, and Suzanne Kucharczyk are with the Shield Institute Staff Development and Training Department. Pamela Rogers, EdD, NCPsyA, LP is Director of The Shield Institute Pure Vision Arts studio. The Shield Institute is a JBFCFS affiliate. For further information, please contact Mary McKillop, Director of Staff Development and Training at 718-269-2044 or mmckillop@shield.org.

The PDD Behavior Inventory (PDDBI)

By Ira L. Cohen, PhD, Chair
Department of Psychology
NYS Institute for Basic Research (IBR)
NYS OMRDD

Autism and the other Pervasive Developmental Disorders (PDD), including Childhood Disintegrative Disorder, Rett's Disorder, Asperger's Disorder, and PDD - Not Otherwise Specified, comprise a set of disorders which share a "triad" of impairments in socialization and communication along with repetitive and ritualistic behaviors (American Psychiatric Association, 2000).

We know there is a great deal of variability in autism at many different levels. At the lowest level there is variability in what is known to cause autism. We know, for example, that the disorder is more likely in certain genetic conditions. For example, autism is highly likely to appear in individuals with Fragile X Syndrome, a disorder linked to a gene at a tip of the X chromosome. It is also more common in individuals with tuberous sclerosis, a genetic disorder that causes non-malignant tumors to develop, and when those appear in the brain, autism is more likely. But these and other similar causes represent a small percentage of the overall numbers of people diagnosed with autism. Although autism is a disorder with a strong genetic basis (Bailey et al., 1995) and progress is being made (Abrahams &



Ira L. Cohen, PhD

Geschwind, 2008), research has yet to identify a single gene or even a set of genes that accounts for the vast majority of the identified cases. Part of the problem is that the genes found to be associated with autism may not actually be linked to the disorder as a whole but, rather, only to certain behaviors which occur more often in autism but which also appear in other disorders. For example,

anxiety and avoidance of social interaction can be common features of autism but these behaviors also occur in other disorders such as social phobia. These social avoidance behaviors also appear more often in children with Fragile X Syndrome, irrespective of whether or not they also have autism, and we found that when autism and Fragile X occur together in the same individual, the severity of the autism is often much worse than in a child with autism who does not have Fragile X (Cohen, Vietze, Sudhalter, Jenkins, & Brown, 1989; Cohen et al., 1991; Cohen, 1992; Cohen, 1995; Cohen, 1996; Cohen et al., 1996). In order to demonstrate this effect, we needed to assess all of the varied behavioral features of autism and associated conditions, not just whether or not autism was present. So it may be that finding the genes that predispose one to develop autism will require researchers to examine more specific behavioral features and not just the syndrome as a whole.

Indeed, at the behavioral level, we know that there is a great deal of variability in presentation. That is, not all people with autism behave in the same manner even though they all have problems with social interaction, communication, and repetitive behaviors. For example, individuals can be diagnosed with autism even when they differ widely in intellectual, language, or social ability. In terms of unusual behaviors, some only show rituals, while others, only repetitive body movements such as hand flapping. Some

are unusually socially withdrawn while others approach other people too often and in an inappropriate manner. Some behaviors, such as eye contact, or pointing, can be very impaired in infancy but may emerge at later ages. Some people with autism are overly aggressive, while others are overly passive and/or aloof.

From both a research and a clinical point of view, it is important to measure as much of this wide variation in behavioral features as possible. Why? Because understanding how a given person is either the same or different from others with autism has implications for understanding causation, designing appropriate interventions, measuring response to intervention, and coping with stress within the family. How should we do this?

Assessment Issues and the PDD Behavior Inventory (PDDBI)

In order for this approach to be successful it is critical to have measures of autism that are reliable, valid, continuous, and standardized in nature; that assess abilities as well as problem behaviors; and that take the age of the person into account. By reliable, I mean that when measurements of behavior are repeated, the scores that are produced are the same or nearly the same as the first score. By valid, I mean that the measures actually assess what they claim to assess.

see Behavior Inventory on page 49

Summer Jobs

By Carole N. Kalvar, Board Member
Asperger Syndrome and High
Functioning Autism Association (AHA)

For most of us a first summer was a kind of rite of passage. Motivated by making some money and by trying on a more adult role way we were ready to take on the responsibilities of work. Knowing we had to commit ourselves to a set work schedule, to learning and performing unfamiliar tasks, to interacting with new people and to meeting the expectations of our employers, we were willing to step away from the familiarity of childhood and over the threshold into young adulthood. Most of us were able to overcome feelings of uncertainty and insecurity in order to seek out a position, be sized up by a potential employer and even risk rejection.

If you are the parent of an adolescent with high-functioning autism, you probably face the prospect of summer without the structure of school with a little angst. Your son or daughter may do their best when their time is structured and certainly a job would provide that sense of organization. In addition, we are so mindful of orienting our children on the spectrum to the wider social world, to foster their independence and self-reliance. We appreciate that getting and working at a job is a wonderful opportunity to learn and prac-



Carole N. Kalvar

tice new social skills but we recognize that those with an ASD will probably require more encouragement and support to achieve this important milestone. If your child attends college they may be interested in summer internships in their specific career area but may still face the social learning challenges and executive function deficits that are associated with their ASD.

I don't know anyone who relishes the prospect of job hunting. It takes lots of energy, motivation, planning and organizing. Those adolescents and young adults with high functioning autism have the

same motivations for attaining the rewards of real work but the tasks involved in finding employment are very likely even more daunting for them. Notwithstanding the significant challenges, getting and keeping a job are among the most important goals for individuals on the spectrum. These goals should be an intrinsic part of any transition plan for students on the spectrum. Realistic employment goals should be set and a specific plan for meeting the goals should be implemented. Find out more at this Department of Labor Site: www.dol.gov/odep/categories/youth.

Working Papers and Employment Regulations

While there are many Federal Laws governing the employment of youth under the age of 18, each state is responsible for implementing the regulations. Therefore, depending upon where you live you may have to obtain working papers (also known as an Employment Certificate or Age Certificate). In the tri-state area, New York, New Jersey and Connecticut require that any individual under the age of 18 obtain an Employment Certificate before beginning to work, only Connecticut requires the commitment of the employer for a specific position before the individual Certificate is granted.

Working papers assure the employer

that the young person has presented proof of age and is in good health. Usually, a proof of a current physical exam is required. To view a sample application for an Employment Certificate go to the following website: jobsearch.about.com/od/employmentlaw/a/employcert.htm. Generally, the certificates are obtained through the student's school guidance office or the local Department of Labor office. When the teen obtains a job, he or she will have to present the Employment Certificate to the employer.

Any advocate for young individuals seeking employment would be wise to learn some basic child labor law. Knowledge is our best protection against the rare exploitative employer. The following comprehensive Department of Labor website details youth labor laws and has presentations directed to parents, students, employers and educators: www.youthrules.dol.gov.

The Job Hunt: Use Those Executive Function Skills

Here's where teaching and practicing executive function skills will pay off. I would strongly suggest that your young job seeker take the time for a self-assessment. They should inventory their skills and interests. What types of environments are comfortable and what environments need

see Summer Jobs on page 44

Post-Secondary Program for Young Adults

Patrick L. Queenan, PhD
Assistant Executive Director, and
Maryann Campbell, MHA
Executive Director
The Glenholme School

An adult's potential is greatly determined by the quality of education and support they received in their early adult years. In response to the growing need for quality supportive services designed for young adults with special needs entering the post-secondary world of college and employment, the Glenholme School developed Glen Ridge College and Post-Secondary Employment Coaching Program. Glen Ridge is dedicated to assisting young adults with Asperger's Disorder and other learning disabilities develop autonomy and the skills needed to succeed in college, work, and social settings while in a safe, supportive, yet challenging environment. Glen Ridge incorporates educational supports for college life and academics, job coaching, a relationship building curriculum, and social development opportunities while fostering an independent lifestyle which leads to a successful career as part of life's journey.

Young adults in the Glen Ridge College Coaching Program, take coursework at local universities and colleges. Our coursework advisor coordinates with the University Disability Services office to ensure that the young adult's needs are



Maryann Campbell, MHA

being met, and that necessary learning accommodations are provided to young adults. Our boarding faculty members teach young adults how to structure their time and schedules so that they are meeting their academic obligations.

For some young adults enrolled in Glen Ridge Post-Secondary Employment Coaching Program, work is a part-time experience, and for others employment is their primary responsibility. The goal of the work experience is to learn employ-

ment skills that will assist them in developing autonomy for the future. These skills include applying and interviewing for jobs, as well as meeting work responsibilities, and maintaining positive colleague and employee-supervisor relationships. For all of the young adults, job coaching will be provided to develop the critical skills needed to function in a work setting.

Our experience and research shows that young adults with Asperger's often need more than individual or group therapy can provide. While social or coping skills can be learned in a controlled environment, such as a therapy office, generalizing these skills to the job, classroom, or social settings where and when they are needed initially requires some support. In order for young adults to use the coping and social skills in the settings where they are most needed, clinicians observe and interact with the young adult in their own environment. While in the young adult's environment, clinicians predict for the young adult the emergence of socialization opportunities or environmental triggers for behaviors that may have caused difficulty in the past, and cue the young adult to utilize the positive skills that have been learned in individual sessions.

The Relationship Building curriculum helps the young adults at Glen Ridge to learn about the various types of social relationships that they will encounter, and the roles, rules, and responsibilities within each of these social relationships. Emphasis is placed on identifying the methods

that they are using to influence these relationships, and on teaching more positive means to do so.

Social growth and instructional opportunities abound at Glen Ridge. A wide array of activities is provided to meet the interests of our young adults, and to broaden their experiences. Our faculty members are present to foster social interaction using our social coaching model. Instruction in the skills required to successfully move toward independence, such as managing a budget, balancing bank accounts, grocery shopping, cooking, paying bills, navigating bus transportation, and independent driving are provided.

Glen Ridge is located on Route 202 in the beautiful New England town of New Milford, CT. Bus routes take young adults from the New Milford green to some of the local Universities. Young adults who have a driver's license and are capable, travel to and from the University or their job by their own car. For others, transportation is available through the school, for a fee.

Recognizing the need for quality supportive services during the early adult years, such as those provided by the Glen Ridge College and Post-Secondary Employment Coaching Programs, are vital to the lifelong success of individuals who struggle with Asperger's Disorder and other learning disabilities. Glen Ridge strives to maximize the potential of young adults and aid in achieving their higher learning goals and ability to live independent lives.



**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?

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- ✓ 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

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Life Coaching for Young Adults with High-Functioning Autism

By Fredda Rosen, Executive Director
Job Path

In the fall of 2006, Job Path launched Life-Coaching for Young Adults with High-Functioning Autism. The program finds innovative ways to help individuals with high-functioning autism, such as Asperger's Syndrome, reach their potential through college attendance, work, volunteer positions and meaningful community activities. The Life-Coaching team offers young adults intensive life planning and assistance to define their goals and develop plans of action. Support is based on the specific needs of each individual.

We were inundated with prospective candidates for the project and had the difficult task of initially selecting ten young people. Now, more than two years into the project we are working with eighteen people - a diverse, accomplished group whose efforts to find their way in the world are complicated by autism. They have strong cognitive abilities, but haven't found outlets for their talents.

The Life-Coaching process begins with an exploration and planning phase in which people consider their total life circumstances and goals, a process they are finding exciting and empowering. The individuals have pretty keen insights into their own lives.

But the best way to understand how



Group members at a recent social understanding session

the project works is to look at the progress being made by individual members of the group.

On The Winning Team

Anthony, a 23-year-old who lives in Chinatown in New York City with his mother, enjoys school and sports equally. As a college student at the Borough of Manhattan Community College, Anthony dives into his school work, whether writ-

ing an essay on the Giants' celebratory parade in Manhattan for English class, or learning how to read text with a critical eye in "Academic and Critical Reading."

While Anthony can talk about his dreams and goals, he sometimes needs help from the Life-Coaching team to make sure he achieves them. Anthony's support workers help him develop social skills both in and out of the classroom, while also making sure that he writes his assignments down and has a full understanding of his

homework and class requirements.

On top of his academic achievements, Anthony is a skilled floor hockey player who plays center position for his Special Olympics team. Currently, Anthony has a paid clerical internship, funded through OMRDD, at AHRC's day habilitation program where he does office work two mornings a week. Anthony also swims at the local YMCA and, in his limited free time, is a singer in the Peace of Heart choir.

Next Steps

In the spring of 2006, Wendela graduated from a special needs high school. The plan was for her to attend a structured residential pre-vocational/college program in Long Island the summer after graduation. Wendela began the program, but after several months, staff recommended that she leave because she was overwhelmed at being away from home and the social demands of school. Wendela retreated into her room at home and rarely left the house.

In the fall of 2006, Wendela began working with a Job Path Life Coach who helped her establish OMRDD eligibility. The Life Coach worked slowly and carefully with Wendela, who was initially reluctant to engage in any activities, to help her figure out her next steps. They visited a number of community colleges,

see Life Coaching on page 50

Our Seizure Nightmare

By Randolph Siegel
President and Publisher
Parade Publications

As a media executive and father of a child whose life has been derailed by uncontrolled seizures, I watched the Jett Travolta tragedy unfold with particular sadness. The Travolta family deserved much better from the media, especially those invasive and sensationalistic TV shows, Web sites and magazines whose feeding frenzy was nothing short of despicable. Yes, even movie stars deserve a zone of privacy when they are in mourning.

The media also wasted an opportunity to educate our country about the relationship between seizures and epilepsy, a devastating neurological disease characterized by abnormal brain activity and recurring seizures, which affects 1 out of every 100 people. That's 3 million Americans and 50 million men, women and children worldwide—more than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined. While some people with epilepsy can lead normal lives and are able to achieve seizure control thanks to effective drugs or brain surgery, most patients do not and suffer debilitating side effects from all the sei-



Randy with his daughter Becca

zures and medications.

Uncontrolled seizures wreak havoc on the brain, causing depression, developmental delays and even death. An estimated 50,000 deaths occur annually in the U.S. from status epilepticus (prolonged seizures), Sudden Unexplained Death in Epilepsy, and other seizure-related causes such as drowning. That's more funerals

from epilepsy than those caused by other terrible diseases such as breast cancer, nearly 140 per day.

In this era of medical breakthroughs, doctors and researchers still struggle to understand what causes seizures. In two-thirds of patients with epilepsy, the cause is never known. Many children with autism also suffer from epilepsy. Thousands

of U.S. soldiers are developing epilepsy after suffering traumatic brain injuries on the battlefields of Iraq and Afghanistan. Despite these numbers and all the lives at stake, epilepsy research is woefully underfunded and the search for a cure has been stymied.

Living with seizures is cruel and unusual punishment for patients and their families, no matter how old they are or how famous they might be. One never knows when the next seizure will strike and whether it will be damaging or even fatal. And for a parent, it is especially heartbreaking.

Our 12-year-old daughter has epilepsy and averages about 1,000 seizures a year. Every night, when we tuck Becca into bed, we hope and pray she will awake the following morning and that one day our nightmare will be over and a cure will have been discovered—for her sake and others, and in honor of those who were not so fortunate.

Randolph Siegel is president and publisher of Parade Publications and a member of the board of CURE, Citizens United for Research in Epilepsy.

This reprinted article originally appeared in the Chicago Tribune on January 13, 2009. You may view it on their website at <http://archives.chicagotribune.com/2009/jan/13/nation/chi-oped0110seizurejan13>.

Planning for the Care of Your Special Needs Loved One

By **Barton P. Levine, Esq.**
Law Offices of Barton P. Levine

We will start out by discussing the rules of eligibility for certain types of assistance programs. Next, we will discuss problems and pitfalls in planning for a Special Needs loved one. This will evolve into a discussion about what are believed to be the best options of planning for special loved ones - the Supplemental Needs Trust.

What Benefits Are Available to Special Needs Loved Ones?

Social Security Disability (SSDI) and Medicare: There are different categories of assistance that your Special Needs loved one might qualify for. The first category is called Entitlement Programs because you don't have to have low income or assets to qualify for them. The two most common Entitlement Programs are Social Security Disability Income (SSDI) and Medicare.

There are different ways to qualify for SSDI, but typically Special Needs persons become eligible under the Childhood Disability Benefits or the Disabled Adult Child Program. To be eligible for this program, the Special Needs person must have first become disabled before age 22. The Special Needs person then qualifies for SSDI, based upon the record or earnings for the Special Needs person's disabled, deceased or retired parent. Once a Special Needs person has received SSDI for two years, he or she will receive federal Medicare benefits. The Special Needs person does not need to wait until he or she attains age 65, as most of us would have to do. Since SSDI and Medicare eligibility is not based on income or assets, these programs usually do not need to be considered when developing an estate plan for Special Needs beneficiaries.

Means-Tested Programs: Means-tested programs include Supplemental Security Income or SSI, Medicaid, In-Home Supportive Services, Subsidized or Section 8 Housing and Temporary Aid to Needy Families. Since these Means-Tested Programs generally do not allow a person participating in the program to have more than \$13,000, the receipt of an inheritance will disqualify a Special Needs loved one until he or she has spent the inheritance down to \$13,000.

Medicaid: The loss of Medicaid can be devastating to a Special Needs person because he or she may not be eligible for any other kind of health insurance coverage.

Supplemental Security Income (SSI): Many Special Needs persons obtain their Medicaid eligibility because they also receive SSI. In order to qualify for SSI, a person must be age 65 or older, blind or disabled, a US citizen, not a resident in a public institution, and have no more than \$13,000 of countable assets. Exempt assets are those that do not count toward the \$13,000 limit. These would include a resi-



Barton P. Levine, Esq.

dence, a car and household goods. An SSI recipient must also meet certain income guidelines.

Once a person is covered under SSI, he or she will receive a monthly benefit. Currently, the monthly benefit for an unmarried New York State recipient is \$761, and \$1,115 for married New York State recipients. These benefits are designed to assist the SSI recipient in paying for shelter and food. If the SSI recipient receives other income, his or her benefit will be reduced.

Income is defined as any cash payments received, except we exclude the first \$20 received every month from the calculation. With regard to earned income, the first \$65 is excluded and one-half of earnings over \$65 are excluded. Based upon this formula, the maximum earned income an unmarried person can have, and still receive SSI, is \$1,587 per month for unmarried persons and \$2,295 for married persons.

The reason most minor Special Needs person cannot receive SSI is because of the deemed income rule. This rule causes the income of a parent or spouse to be attributed to the Special Needs person. Parent's earnings are no longer deemed to a Special Needs person after reaching age 19.

As previously mentioned, SSI benefits are meant to help pay for a Special Needs person's shelter and food. If someone else pays for their shelter and food, it will reduce the Special Needs person's benefit amount. This aid is known as an "In-Kind Support and Maintenance" or "ISM." The first way that ISM is calculated is a one-third reduction in the maximum federal benefit rate. This process is referred to as the "One-Third Reduction Rule" or "VTR," and it applies to Special Needs persons who live with someone else, who provides for their food and shelter. So, if an adult Special Needs person lives with his or her parents, who provide food and shelter, that person's SSI benefit would be reduced by one-third.

Where the Special Needs person does not live with the person and only some of the shelter and food are paid for, the "Presumed Maximum Value Rule" or "PMV" applies. As a result, the monthly benefit is reduced by one-third, plus \$20.

If the actual value of the VTR or PMV received is less than these amounts, then the benefit would only be reduced by the actual value.

Why is all this important? Let's say that a Special Needs person was able to work, and he or she had earned income of \$1,000 per month. This would reduce his or her SSI from \$603 down to \$145 per month. If the Special Needs person then had ISM valued at more than \$144 per month given to him, he or she would lose SSI eligibility, and therefore would be ineligible for Medicaid benefits. This can be a major mistake if the Special Needs person cannot otherwise qualify for health insurance coverage.

Problems and Pitfalls in Planning: So What Are Your Options?

Disinheriting Your Loved One: You could be like some parents, who decide to disinherit their Special Needs child in order to keep her from losing any government assistance. If you disinherit your Special Needs child loved one, you would not need to concern yourself about the loss of her SSI benefits. However, to the extent that the Special Needs child understands he

was disinherited, he may perceive that he was not loved, as much as his siblings who received an inheritance. There would also be no funds set aside to care for the needs or wants of the Special Needs child that are not covered by government assistance.

Leave Everything to Your Healthy Children: You could also be like other parents, who decide to leave everything to their healthy children and disinherit their Special Needs child. They know that their healthy children love their Special Needs brother or sister, and they expect their healthy children to use their inheritances to care for Special Needs brother or sister. The good thing is that this strategy would not cause the Special Needs child to lose his or her government assistance. The bad thing is that the inheritance that is supposed to be set aside for the Special Needs child would be subject to the creditors of the healthy children. The inheritance could also be claimed by a divorcing spouse. Moreover, the healthy children could use their entire inheritance for themselves, or mismanage their inheritances. Even if none of these possibilities

see *Planning on page 52*

To obtain a complimentary copy of our special handbook entitled, "Estate Planning for Special Needs," please contact us at www.bartonlevine.com.

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Panel discussion will follow.

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Establishing Integrated Family & Community Services for Young Adults with Autism Spectrum Disorder Transitioning to Adulthood

By Virginia Cover MSW, MBA, John Pomeroy MBBS, MRCPsych, and Ellen Woodward LMSW, EdD
The Cody Center for Autism and Developmental Disabilities



John Pomeroy MBBS, MRCPsych

This edition of Autism Spectrum News is focused on issues related to adult service needs. This is timely as evidence mounts that multiple systems are attempting to deal with an easily predicted, but not always prepared for, crisis in adult services. The demand for housing, physical and mental health services, vocational training and job placement, social opportunities, supported education, all constitute the legacy of increased identification, recognition and diagnosis of ASD – both in children and now in late diagnosed young adults. Centers like the Cody Center must evaluate the needs of young adults with ASD from a much broader perspective than that of a medical or mental health clinic. The problems that most impact on these individuals are those of community integration and ability to live a full and functional life with the greatest degree of independence that can be achieved. Ginnie Cover, at the Cody Center, anticipated this trend and has been systematically broadening our services for young adults and their families. Each of the programs

developed has addressed areas of concern identified in our clinical practice and, through numerous funding opportunities, the center has created important and innovative programs that are beginning to address the needs of the full cognitive and behavioral range of individuals with ASD at minimal cost. This article describes

those programs that are fully functional at present.

Transition to Adulthood Conference and Individual Consultation

An annual full day conference covers topics such as applying for SSI and Medicaid, person-centered transition planning, post-secondary education options, vocational programming, residential placements, life skills training, medical services, guardianship and special needs trusts. The conference is open to parents of 14 to 20 year olds with any neurodevelopmental disability.

For families requiring more individualized consultation there is an hourly, fee-based, transition planning and information meeting for parents of young adults with Autism Spectrum Disorders, who are preparing to enter adulthood. Specific concerns about adult transition issues which affect the entire family are addressed, using a family centered approach. Individually specific information and guidance is provided about accessing and applying for: government benefits (SSI, SSDI), government health insurance (Medicaid, Medicare, etc.), guardianship (when appropriate), private and government sponsored services, higher education, adult programs, and adult health care. Information and guidance is also

provided to help in understanding eligibility requirements for different OMRDD and OMH programs and answering questions specific to their child's changing adult needs.

Young Adult Social Group

The Young Adult Group is a social group for young people in college or working in the community that meets approximately twice a month for activities in the local area. Members must be aged 18 and have graduated from high school. This group is for young people with autism spectrum and related disorders who can function independently. The Cody Center provides social skills coaching.

Sex Education and Reproductive Health Program

This unique program is funded by the NY State Department of Health. The *sex education component* is offered to individuals with developmental disabilities, aged 11 years and up. Education is primarily provided in short term groups, with parents or significant caregivers assisting in determining each group's educational content. Depending on the age, needs, and functioning level of the participants, as

see *Integrated Services on page 47*



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Incorporating Exercise in a Healthy Lifestyle for Adults on the Autism Spectrum

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

Addressing the needs of adults on the autism spectrum would be remiss if it failed to include the adoption of a healthy lifestyle. The United States is faced with an obesity epidemic that affects people of all ethnic backgrounds and types of disabilities. Currently 2/3 of the population of the United States is either overweight or obese (CDC, 2009). People on the autism spectrum may even be more susceptible to obesity than their neurotypical counterparts due to a number of factors. First, many people on the autism spectrum take medications to deal with co-morbid disorders. One side effect of some of these medications is weight gain. Second, some individuals on the spectrum have very restrictive self imposed diets that are high in fat and have little nutritional value. In fact, anecdotal stories of individuals with ASDs eating only "white foods" such as breads and plain pasta suggest that they have a diet replete with carbohydrates that are associated with weight gain. Third, there is some research to suggest that individuals with Asperger Syndrome may have coordination problems (Siapras, Holland, & Ring, 2008) or difficulties with proprioception (Weimer, Schatz, Lincoln,



Ernst O. VanBergeijk, PhD, MSW

& Ballantyne, 2001), which might discourage an individual from participating in sports requiring a high degree of coordination or a good sense of where their body is in space. And finally, many forms of exercise are team sports oriented. Many team sports require a high degree of sociability and the ability to anticipate the intention of others (e.g. whether a runner in baseball intends to steal a base). The

stressors associated with team sports would discourage many adults with ASDs from participating in team sports and enjoying the benefits of exercise. A lack of regular exercise is associated with obesity, diabetes, orthopedic problems, loss of bone density and heart disease (Pangrazi, Beighle, & Sidman, 2007).

A positive relationship exists between exercise and longevity. Individuals who exercise regularly have reduced mortality from all causes (Paffenbarger, Hyde, Wing, & Hsieh, 1986; Blair & Brodney, 1999). One form of exercise that is available to the majority of individuals on the autism spectrum is walking. Walking requires no training, little equipment, and can be done almost anywhere. Walking 10,000 steps a day is associated with better cardiac health, reduced stress, better moods, reduced risk of diabetes, lower blood pressure, and improvements in sleep quality. A sedentary person walks between 1,000 and 3,000 steps a day (www.walkingsite.com). Walking 10,000 steps is equivalent to almost 5 miles a day.

Aside from having a comfortable pair of walking or running shoes, a person wishing to begin a walking program should purchase a pedometer. Pedometers can range in price from \$24 for one pedometer to as low as \$8-\$12 a pedometer if you buy in bulk. The more features a pedometer has, the more costly the pedometer will be. For individuals on the autism spectrum, the functions should be

kept to a minimum to avoid frustration and confusion. The pedometer should have a belt clip as the primary way to secure the device to the hip area of the walker and a back up alligator clip that will prevent the device from getting lost in the event it becomes dislodged. Two other features to look for are a cover and a simple one touch reset button. The cover will prevent the individual from accidentally resetting the pedometer and "losing" all of the steps the individual has accumulated. The loss of the data can easily frustrate a new walker and discourage him or her from exercising. A simple one touch reset button, likewise helps prevent frustration.

A second important piece of "equipment" for adults on the autism spectrum is graph paper. The graph paper is used to document and monitor the progress the walker has made to date. In group settings, the graph paper can be used to compare walkers side by side to instill a little healthy competition. It is important to reward the daily wearing of the pedometer early and often so the person gets into the habit of wearing the pedometer. Then rewards should be set up based upon reaching certain milestones. In the beginning of the pedometer program these rewards so come more frequently than in the later stages of the pedometer program. Weekly updates and award ceremonies

see *Exercise on page 52*

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Autism Spectrum and the Clinical Geneticist: An Approach to the Family

By Robert W. Marion, MD
Director, Children's Evaluation
and Rehabilitation Center
Albert Einstein College of Medicine

More than any other condition, autism spectrum disorders (ASDs) are a group of diseases that affects families. They have profound effects on the individual with the disorder, and significantly alter the lives of parents, siblings, the family, and the community. The extended nature of ASDs has special significance to the geneticist, the medical specialist whose role is to identify causes of inherited conditions and provide counseling and guidance to the patient and family. To the geneticist, ASDs are a symptom complex in which impairments in socialization and communication occur in association with stereotypic behaviors. This symptom complex is a "final common pathway", the result that multiple causes have on the brain. The goal of performing a genetic evaluation in an individual with ASD is: (1) to identify one of these underlying causes so that the family can learn more about the individual's likely future functioning and potential medical problems, (2) to provide genetic counseling, which will inform the family about the likely recurrence risk of an ASD in future progeny, and (3) to provide an explanation of "why this happened." For



Robert W. Marion, MD

these reasons, evaluation by a geneticist should be offered as part of the work-up of all individuals diagnosed with ASD.

The fact that genetic factors clearly play an important role in the etiology of most cases of ASD is supported by multiple lines of evidence (Muhle R, Trentacoste SV, Rapin I. The genetics of autism.

Pediatrics 2004;113:e472-e486). For instance, according to the Centers for Disease Control, in 2007, the prevalence of autism at age 8 in 6 areas of the United States was approximately 1 in 150 (MMWR, February 9, 2007 / 56SS01; 1-11). However, after the birth of a child with an ASD, the empiric recurrence risk (based on observation of thousands of families) for full siblings is between 4 and 7%, much higher than would be expected in the general population. Further, if a second child has autism, the recurrence risk rises to 25-35%. These increases point to the role genetic factors play in the etiology of ASD.

The geneticist does not make the diagnosis of an ASD. Rather, this specialist is part of the interdisciplinary team of health care professionals who are involved in the diagnosis and management of such individuals. Ideally, a referral is made to the geneticist after the diagnosis has been confirmed. The geneticist's evaluation should occur while other evaluations are being performed and a therapeutic plan is being developed.

The Genetic Evaluation

What can a family expect when their child is referred for a genetic evaluation? What does the clinical geneticist actually do? In most cases, the genetic evaluation begins with a complete history, focusing on issues that might have contributed to

the affected individual's (or proband's) condition. Although, as previously stated, genetic factors play a role in most cases of ASD, in some cases, environmental exposures occurring prior to birth have been implicated. Specifically, the geneticist is concerned about exposure to intrauterine infections such as Rubella (German measles) or cytomegalovirus, prenatal exposure to certain drugs and chemicals, such as the anti-seizure medication Valproic Acid and alcohol. Information about the proband's general health, age at onset of symptoms, presence or absence of language and developmental regression and of seizures, and the age at which the diagnosis was made is also obtained.

Next, a complete family history is taken. Assembled as a pedigree, a pictorial representation of the family history, information about at least three generations is recorded. The family history includes details about the presence of ASDs, as well as other conditions causing developmental and behavioral disabilities; also information about the diagnosis of any genetic disorder, number of miscarriages and of childhood deaths in these related individuals is also obtained.

This is followed by a complete physical exam. When examining the proband, the geneticist searches for subtle clues that suggest the presence of a genetic disorder known to be associated with ASD (a

see Geneticist on page 46

Meeting the Needs from page 1

adulthood begins during the person's childhood, but it intensifies during adolescence. Efforts need to be made to consider future placements, to equip students with skills they will need in those settings, and to include the individual's preferences and choices into the development of the plan.

Schall & Wehman (2009) identify several key elements in transition planning. One critical aspect of transition planning involves the development of specific goals. It is important that the goals identified match the vision that has been developed for the individual. It is also important that increased choices are offered to students as they age, with a strong emphasis on choice beginning during the middle school years. This parallels the increased level of choices available to typically developing students. This process should involve the student as much as possible, and should reflect the student's preferences that are expressed directly and that have been observed by members of the educational team.

Another aspect of planning identified by Schall & Wehman (2009) is the provision of a wide variety of community-based employment and life experiences. There are specific behaviors that are context-specific, and work behaviors are best taught in real-life work contexts. Examples of such work-related behaviors or rules best taught at work include the rules involved in customer service and the deference expected by supervisors. Examples of community-based activities include buying food in a grocery store or waiting in line at the post office. While some of



Cecelia M. McCarton, MD

this preparation can be done in analog situations, it is best to train in the natural environment. Training in schools should include immersion and practice in the broader community.

Schall & Wehman also discuss the need for effective transition across service providers and other resources. When possible, current service providers should communicate with service providers in the next setting. Goals that are important for the next setting can be included in the current IEP, and the expertise of the educational team members who have known the student for many years can help the new team get to know the person with autism as quickly as possible.

Assessment and Treatment of Challenging Behaviors: The assessment and management of challenging behaviors is an area that has experienced tremendous attention

in recent years. Positive Behavior Support services are becoming more commonly available to individuals with autism. PBS services use the principles and procedures of applied behavior analysis (ABA) to identify problem behaviors, to discover why an individual is engaging in those behaviors, and to teach alternate skills (Heineman, Childs, & Serry, 2006; Smith, 2009). Behavior analysts have helped highlight the importance of understanding the functions of behavior, of matching interventions to those functions, and of teaching the individual alternative ways to get their needs met.

Individuals with autism present with many unusual and disruptive behaviors, and it is sometimes difficult for teams to select the first behaviors to target. In making that decision for an adolescent or adult with autism, the team considers whether the behavior poses a danger to the person or to others in the environment, whether the behavior curtails independence, and whether it negatively affects social or employment possibilities (Smith, 2009). The functional behavior assessment process involves identifying the purpose of the behavior (Carr et al., 2002; Carr et al., 1999; Machalicek, O'Reilly, Beretvas, Sigafoos, & Lancioni, 2007). The idea is that behaviors persist because they work in producing an outcome that is valued by that person. Understanding the motivation/reason behind the behavior is necessary for developing a plan to reduce it. The process also helps to set goals for what the person might need to learn to do differently. For example, if the behavior is motivated by the desire to escape difficult demands, it may be appropriate to

teach the person to request a break. The identification of the purpose of behaviors also helps in developing prevention techniques. It may be that the person would benefit from more choice in selecting tasks to work on, shorter work periods, or more frequent scheduled breaks. The environment can be changed to reduce the likelihood of difficulties.

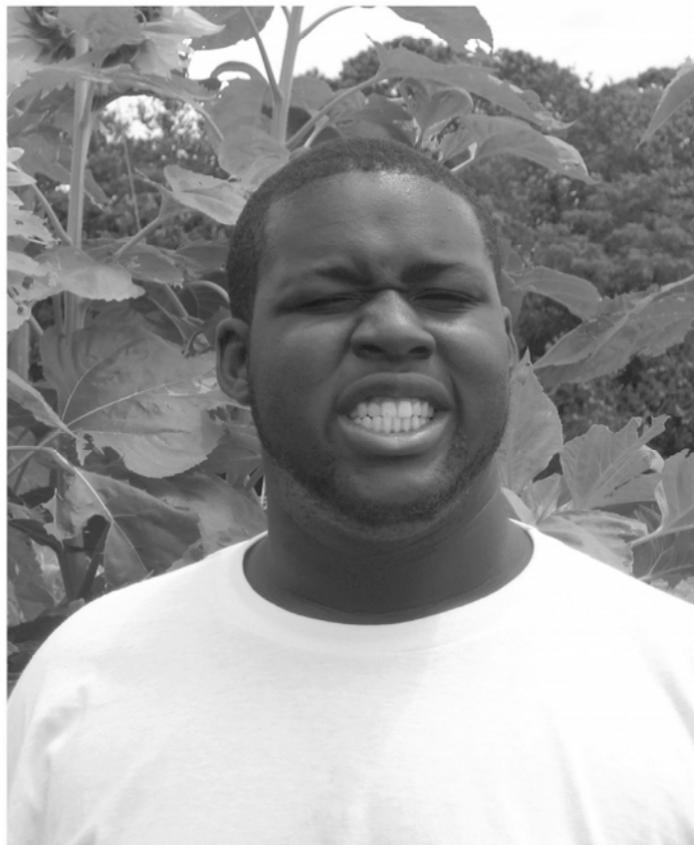
Teaching the individual with autism new ways to get their needs met is another essential component of addressing challenging behaviors in an ABA approach. The person with autism must learn to communicate their needs in more socially acceptable and effective ways (Heineman et al, 2006; Mancil, Conroy, Nakao, & Alter, 2006). It is also sometimes helpful to provide incentives to the individual to engage in the new target skill. For example, if an individual is being taught to request a break instead of throwing chairs, they can be given rewards for engaging in the new response of requesting a break (Heineman et al., 2006; Mancil et al., 2006).

Challenging behaviors may be the most important focus of attention in working with adolescents and adults. The social consequences of behavioral outbursts are severe, and can severely limit vocational options and social integration. Approaching challenging behaviors from an ABA perspective ensures that challenging behaviors are understood and that treatments match those functions. Furthermore, the individual is helped to develop alternative adaptive skills that are socially acceptable.

see Meeting the Needs on page 50

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- 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.

Get to the POINT - A New and Unique Program for Independent Living

By Kevin Gorrasi, Program Director
WJCS POINT Program

In 2008 the Jewish Child Care Association (JCCA) and Westchester Jewish Community Services (WJCS) began the POINT (Pursuing Our Independence Together) Program in White Plains with initial funding from UJA-Federation of NY. The program aims to enable participants to live, work and recreate independently in the community.

The program grew out of the work of a committed parent group concerned for the future of their young adult children with special needs including autism spectrum disorders. In the fall of 2007, these parents reached out to JCCA and WJCS to help develop a program design to operationalize their vision. The family group, known as FFIL (Families for Independent Living) ultimately identified White Plains as the ideal location.

Eager to move forward, the parents located an apartment complex in downtown White Plains within walking distance to services, medical providers, stores, employment opportunities, colleges and public transportation including the train station.

By August 2008, the first group of young adults moved in to their new apartments. The program accepted and is currently serving 15 young adults who have an autistic spectrum disorder, a develop-



Members of the WJCS POINT program on a trip to Gramercy park in NYC

mental disability or other special need. They occupy eight units of the building and are responsible, with some assistance from parents and staff, for all aspects of their lives. They are required to seek employment, pay bills, maintain their apartments, prepare meals and integrate into the community as contributing members of society.

A full-time director and part-time program assistant, both Masters level social workers, staff the program and are available 24 hours a day for emergencies. They visit participants on at least a bi-weekly

basis to assist with individual personal goals. Group activities are held to enhance socialization and help participants learn basic skills. Monthly meetings provide additional opportunities for socialization and skills training. Several Life Skills Trainers assist members with their daily living activities such as cleaning, laundry, budgeting and travel training and time management. In addition, the program's Service Coordinator assures that all participants receive benefits and supports available from OMRDD and other governmental entities.

All POINT Program members are expected to be employed or involved in some type of activity during the day. VE-SID has linked the participants with a vocational agency that assigns a job coach to help participants with resumes, applications, identifying potential employers, and interview preparation. Once a position is secured, the job coach shifts to working with the participant to help maintain the job. Currently more than half of the participants have secured employment – five full-time and four part-time.

The POINT Program also focuses on getting members fully ensconced in the community. Currently, they are involved in the Special Olympics, local softball and hockey teams, political campaigns, volunteering at soup kitchens, the Red Cross and retirement homes. Monthly activities include miniature golf, bowling and minor league baseball games. Trips have also been organized to Times Square, Rockefeller Center and Broadway. The families continue to be an integral part of the POINT Program, forming the JCCA and WJCS FFIL Steering Committee which meets regularly.

Presently, there is little government funding for the program, although many individuals have applied and their materials are under review. If approved, OMRDD funding will cover the Life Skills training and assist with various living

see Point Program on page 50



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Music Therapy for Individuals with Autism Spectrum Disorders

By Dr. Alan Turry
 Managing Director
 Nordoff-Robbins Center for
 Music Therapy at NYU Steinhardt

The Therapeutic Power of Music - Music occupies a significant place in human activity across cultures, reflecting its deeply rooted biological origins. A growing body of evidence indicates that the physiology of the human brain is specialized for musical perception and activity. Our sensitivity to music is lifelong, beginning even before birth. Musicality appears to survive considerable cognitive and neurological impairment. The therapeutic power of music lies in this innate responsiveness to music, which is found in all people regardless of developmental level or extent of musical training.

In music therapy, this power is harnessed to bring about the fulfillment of specific, individualized clinical goals. The American Music Therapy Association states: "Music therapy is an established healthcare profession that uses music to address physical, emotional, cognitive, and social needs of individuals of all ages. Music therapy improves the quality of life for persons who are well and meets the needs of children and adults with disabilities or illnesses."



Dr. Alan Turry

Music and Development

Music contributes to all areas of development. Because music is processed in both hemispheres of the brain, musical experiences promote neurological and perceptual integration. Active engagement in musical play allows participants to learn through doing—acting upon their environment and discovering the consequences.

Cognitive development is stimulated by rhythmic and melodic patterns within music. This reinforces mathematical concepts, such as counting, and the perception of contrasts: differences between high and low pitches, fast and slow tempos, and loud and soft dynamics. Songs support children's learning of classroom material, allowing for repetition in a playfully varied manner. By anticipating the form of a musical phrase, a child builds the capacity to focus for longer periods of time. The combination of order and freedom in music is conducive to the development of flexibility, both inside and outside the music room.

Perhaps most importantly, successful participation in creative musical activity builds self-confidence and self-esteem. Emotional development is encouraged through self-expression in singing and instrument playing, or role-playing in musical dramas. A vast range of emotional experience and expression is possible through music.

The basic elements of music—rhythm, tempo or pulse, melody, and intensity—are intimately connected with the production of speech; hence, music serves to highlight the stress patterns and contours of speech. Singing enhances auditory perception and processing, vocal quality, production of speech sounds, and the learning and retention of language.

Musical exchanges—the call-and-response of singing or playing melodic or

rhythmic phrases—help develop the elements of reciprocal interaction that are necessary for communication. Especially in group sessions, music therapy provides opportunities for engaging in cooperative activity, taking turns, appreciating others' contributions, and building a sense of belonging and community.

Music in the Treatment of Autism

Core features of autism spectrum disorders (ASD) include difficulties in communication and social interaction. As described above, these are significant goal areas in music therapy. For individuals with ASD, non-verbal elements of communication may be "hard to read," including speech inflection, eye contact, facial expression, and body language. Even for people with very limited verbal skills, meaningful communication can occur through music.

Music therapy calls upon the innate musical responsiveness of those with ASD as a basis for developing curiosity and interest in their peers. While they may face considerable challenges in classrooms and other social settings, music can be an exciting way of motivating people with ASD to relate to others.

Music is a creative medium that can be tailored to the needs of each individual. Many with ASD demonstrate unusual

see *Music Therapy* on page 45

Web Site from page 8

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 lifelong 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 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. "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 opportu-

nities to make meaningful contributions."

About Autism

Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships, and is often accompanied by 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.

About Advancing Futures 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 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.

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Robin's Voice

A Resilient Mom's Commentary on Autism



Society's Role in Autism Acceptance - Teaching and Learning About Autism

By Robin Morris
Freelance Writer

Parents of autism are forever in search of "the missing piece" that will help their child. One step toward independence is a universal goal. The dangers in misunderstanding people with autism are multifaceted. Sadly, many of our children are deer in the headlights, hardly understanding reactions to their actions. However, they can be taught consequence and that is the operative word.

I had the privilege of attending an autism conference recently. Its focus was *Promoting Inclusion: Best Practices for Education, Vocation, and Socialization Across the Age Continuum*. The keynote speaker was Dr. Peter Gerhardt, President and Chair of the Scientific Council at the Organization for Autism Research. He is a remarkable and most importantly a practical man. Dr. Gerhardt is a behaviorist who speaks of the "Ultimate Transition Strategy":

- If you can teach the skill, teach it
- If you can't teach the skill, adapt it
- If you can't adapt it, figure out some way around it



Robin H. Morris

- If you can't figure out some way around it, teach the neuro-typicals to deal.

Given that Dr. Gerhardt does not believe that teaching skills in the confines of a classroom is particularly effective, he suggests a "hands-on" approach. The best example given is an anecdote he shared about a trip to Wal-Mart with a young man who was non-

verbal and sometimes aggressive. The lights and noise and strangers were overwhelming at best, yet Dr. Gerhardt encouraged the young man to focus on what he wanted, which was a candy bar. He immediately guided the young man to the register, paying the bill, counting the change, engaging the clerk to respond to the young man (and not Dr. Gerhardt). Then Dr. Gerhardt allowed the boy to eat the candy, before he even left the store. Brilliant. Why? Because the next time the young man went to Wal-Mart, he was allowed to get the candy—but had to pick up some milk first, then to the cash register, then paid, counted the change from the clerk, and then got to eat the candy bar. Teachable moment? Yes, not only for the young man, but for the neuro-typical clerk as well.

Gerhardt created another scenario to induce independence by utilizing blue tooth technology. The young adult with autism wore an ear piece, and direction was delivered by a therapist outside the visual range. It enabled the young man to navigate alone, without a "bodyguard." The Rite Aid cashier who participated in the transaction responded, "I thought something wasn't quite right with him, but I didn't think it was as bad as that autism thing."

I have always supported the applica-

tion of behavioral therapy. Common sense tells us that if behavior can be observed, data can be analyzed and given outside stimuli so we can modify behavior by applying different strategies. It doesn't take a genius to recognize the benefits of such work. However, what it does take is tenacity, incredible resourcefulness, and sometimes Herculean strength to be responsible for children with autism. The benefits far outweigh any pitfalls along the way.

Finally, and most significantly, Dr. Gerhardt cautions that, "Nobody, it seems, goes to college to work with adults with autism. Kids with autism? Sure. Adults with autism? Not so much." Newsflash! Our children grow up. There is very little research or data on the outcomes for adults with autism. Certainly the happy endings are far and few between. The only option is to change the focus from what autism cannot do to what it can do. That task is one for a group effort.

You can reach Dr. Peter Gerhardt at www.researchautism.org.

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.

Addressing the Needs of Adults on the Spectrum

By Robin Morris
Freelance Writer

When I consider "Addressing the Needs of Adults on the Spectrum," it nearly suffocates me. A therapist once noted that, "These kids are cute at three, but what happens when they grow up?" Those are hardly threatening words, but the significance can suck the air out of a room.

Compliance is the operative word when trying to reach our children of autism. We insist on invading their space, procuring language and appropriate behaviors. These are the keys to assimilation and acceptance. However, what happens when that very same acquiescence is used against them?

Reported by Planned Parenthood of Connecticut, an astounding 75% of young women with developmental disabilities under the age of 18 have been abused, while 65% of disabled young men suffer similar assaults. The perpetrators in most cases are family members or staff.

When we address the needs of our adult children we are compelled to be proactive. We are not going to live forever. Harsh as that sounds our obligation is to give them a voice, when they don't have one. We are also obliged to partner with government agencies, insisting on guidelines and programs for our children.

- Sexual orientation classes are essential. What is appropriate and inappropriate touching is a start.

- Our children are often isolated and depend on aides and caregivers. That does not mean unconditional trust is a given.
- Whatever their living or school situation, we cannot be with them 24/7. Give your children the tools to speak out (pictures, prompts, words).
- Given their disability, their voice often lacks credibility. We have to read between the lines and notice change in their behaviors, fears and regression.

Our children are victims over and over again. There is another piece to the puzzle that is more vague, yet devastating in nature. Sometimes, when personal space

is not recognized by adults with developmental disabilities, their actions may be misinterpreted. Accusations and false conceptions are perpetuated by poor eye contact and monosyllabic responses. The court system does not automatically recognize all of the language issues and poor communication skills that is in the nomenclature regarding developmental disorders. Various arrests and law enforcement badgering for confessions render these adult-children willing to admit guilt, simply to comply. Oftentimes they don't even understand the charges.

It is a learning process, often at our children's expense. We have no choice. Enlighten and enforce. It is the future for addressing the needs of our adult children.

Dear President Obama,

My name is Paul Morris and I am a 21 year old guy who is high-functioning autistic. I was non-verbal until the age of 5. Now that I am looking for work and living with roommates, I am worried about my life. It's going poorly for autistic adults because the fund-

ing is over. I want you to create programs for autism spectrum disorders. Today, you donate lots of money to autism.

From,
Paul Morris

Paul has a way about him. His truth tran-

sends life's minutia and cuts to the core. We are worried too. Sadly, the hiring "freeze" for disabled individuals resonated prior to the economic downturn. Job discrimination is a "pre-existing condition." People fear what they do not understand. Our plea to President Obama is that he take the opportunity to face the nation and say

"look to your neighbor with differences and say something kind, or learn about their disability....today!" He can change thinking by example. We ask Paul's friends and family to donate your time and resources to change the face of autism. We remain hopeful for a cure. Ghandi said: "You must be the change you wish to see in this world"



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Director of the Yale Child Study Center

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College Coaching from page 13

- Social: how are the student's basic social skills and relationship development skills? Does the student have a social network upon which he or she can depend?
- Independent living: is it realistic to expect the student to be able to function independently in basic life skills or is it necessary for that student to receive support services in order to live successfully at college?
- Family life: how much support has the family been giving the student and is it realistic to assume that that student can be successful living away from home? (Geller & Greenberg, in press)

One very important method of support, that is just beginning to be more widely implemented, is that of college coaching. The significant advantages of this kind of approach are that the coaching can be more or less intense depending on specific need and that coaching can occur for students attending any college of their choice, not only those with special programs. The critical elements of coaching are an excellent fit with the very disabilities that students with Asperger Syndrome manifest.

What is Coaching?

The field of coaching originated in the business world where individuals within an organization coached others in the group toward successful achievement. Since those beginnings several decades

ago, coaching has grown to include helping a wide variety of individuals with all sorts of disparate needs meet individual or organizational goals. Further contributions from the fields of psychology, business, and education have enriched the conceptualization of what coaching can be to a diverse clientele.

The general field of coaching assumes an equal relationship exists between two adults the purpose of which is to meet the client's self-determined goals. Coaching assumes that the client is competent and resourceful and that the client is capable of developing the agenda. Coaching can address a narrow focus or broaden to address larger life issues. The coach is responsible for developing appropriate supports based on client need and to spontaneously adjust the approach whenever needed. For college students with Asperger Syndrome, the approach must be adjusted to assume that the client is a developing young adult and may not yet have reached the maturity level coaching typically assumes. The coaching relationship supports that developing maturity by engaging the client in creating and investing in goals that are achievable and specific to individual need. The coach who engages in supporting college students with autism spectrum conditions must have a fundamental understanding of the condition and a full knowledge of the specific characteristics of the client to be effective.

Coaching for these students on the spectrum can very successfully address a wide range of common issues. A critical element of coaching is creating goals and systems of accountability. For the college student, the coach helps develop feelings

of internal drive and mechanisms for setting and meeting interim goals. Often our students need a feeling of urgency and anxiety to complete any long term work, yet are also incapacitated by these feelings. Coaching can help create a healthier balance between motivation and planning. For many students on the spectrum, feelings of inadequacy and self defeat have arisen from failure experiences or quickly arise for the first time when college feels overwhelming in its multiple demands. Coaching can help by encouraging and reinforcing competent behaviors that lead to feelings of competency. Students sometimes cannot self motivate, especially when they are not prepared to handle college stressors. A coach can provide positive reinforcement while teaching how to develop individual methods of reinforcement. Lastly, a coach does not solve problems, but helps the student become a problem solver by increasing self awareness and accepting personal responsibility for outcomes.

How Can Coaching Be a Useful Approach for Students with Asperger Syndrome?

A coach who has a strong understanding of the general neurobiological issues inherent in the condition and the individual's particular profile of strengths and challenges is in the best position to be truly helpful. Understanding specific neuropsychological differences and their effect on function is a very important beginning to developing a useful coaching relationship. Testing data should be shared so that this knowledge is part of the relationship. The coach and the stu-

dent together examine this information and incorporate it into the overall plan, developing effective coping strategies. As the student comes to make proper attribution to causes of problems and learns how to find the right coping mechanisms, this awareness will help in solving other life issues. The student practices concretely how to address individual challenges rather than to endlessly experience blame. Many students have had their confidence destroyed by years of blame from themselves and others. Sometimes not trying has become a defense mechanism for those who have tried too often without success. Slowly, coaching can give the student positive experiences in handling problems effectively.

As we know, the experience of creating solutions and learning actually changes neural pathways in the brain, just as not having these experiences changes nothing. When students work together with a coach who is encouraging brain-based solutions, they may be experiencing for the first time someone who has a thorough understanding of their condition. Unlike family members, who may understand, coaches can support students without the emotional baggage that years of joint struggle may have created at home.

Individuals with Asperger Syndrome are frequently notoriously poor problem solvers and need to be supported to learn how to do so if they are to have an independent adulthood. Creating effective problem solvers is a prime goal for all coaching. The coach considers the entire

see *College Coaching* on page 53

LAW AND THE AUTISM COMMUNITY



The Autism Spectrum Justice Project

A Proposition to Centralize Legal Education and Guidance for the Autism Community

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

Neurodiversity – This concept asserts that atypical, neurodivergent development is a normal human difference that is to be recognized and respected as any other human variation (This term is believed to be first made public by Judy Singer and published by Harvey Blume in a September, 1998, New York Magazine Article).

Individuals on the Autism Spectrum, their loved ones and supporters are experiencing a dynamic shift in the way society responds to the multitude of issues that touch most every aspect of their lives. This response includes greater public awareness, increased access to educational and vocational opportunities and growing funding for research, clinical programs and other support services. However, there is much work to be done. Economic pressures, bureaucracy, competition for research and funding dollars and societal biases and stigmatization cause great challenges to the “normalization” of lives for individuals on the spectrum. For many, every day is a struggle to secure access to funding, treatment and support services at the community level. Addi-



Douglas K. Stern, Esq.

tionally, there is a great disparity in authoritative responses to individuals on the spectrum who are alleged to violate the law or educational or vocational rules and regulations when compared to the general public. Whatever the challenge, legal issues usually arise. Unfortunately, there are scant reliable, centralized resources

available to the Autism Spectrum community for legal education, guidance, and discussions. I have, for many years, envisioned an environment created and dedicated to provide legal education, discourse and support, in one location, to the Autism Spectrum community. With my gratitude, the publishers of the Autism Spectrum News have allowed me to use this column space to make this call for interest.

You, the readers of the Autism Spectrum News, form the most concentrated gathering of individuals with intense, personal and professional knowledge of the issues of the day relevant to individuals on the Autism Spectrum. Undoubtedly, all of you at one time or another have been challenged by an issue that needed to be resolved with legal intervention or in hindsight would have been aided by a comprehensive understanding of a particular law or regulation or from old fashioned advocacy. I am equally sure that many of you have either experienced or heard of individuals on the spectrum being treated in disparate ways. Whether the issues relate to equal access to treatment and education, criminal justice, funding, provision of services, etc., there are no meaningful centralized places where one can find a community dedicated to justice for those on the Autism Spectrum. I hope to create such a place. With your help, I am optimistic that

this idea can come to fruition. The following is my vision for the Autism Spectrum Justice Project:

- To provide the Autism Spectrum community with a single, web-based environment for legal education, reference and discourse.
- To provide the Autism Spectrum community with an annual educational and informational conference on legal issues and related topics.
- To provide the Autism Spectrum community with the ability to gather like-minded individuals in furtherance of advocacy and support in relation to legislative and other bureaucratic actions and initiatives.

I believe the possibilities are limitless but I need your help. I cannot find a better group of people to tell me whether or not such an endeavor has any value. Furthermore, I would like to establish the actual needs and wishes of you; the consumers, supporters, families and care-providers. I ask that you all let me know what you think. I can be reached via e-mail at dstern@abramslaw.com or by telephone at (516) 592-5857. Thank you for your interest and assistance.

Acceleration Act from page 6

general public audience or specific audiences such as medical, criminal justice, or emergency professionals.

Interdepartmental Coordinating Committee - Establishes an Interdepartmental Coordinating Committee to coordinate and advise on government activities relating to research, services, and programs for individuals with autism spectrum disorders. Members will include representatives from relevant governmental agencies (Dept. of Health and Human Services, Dept. of Education, etc) and members representing individuals with autism, parents, service providers, and advocacy groups.

National Network for Autism Spectrum Disorders Research and Services - Establishes a National Network in order to strengthen linkages between research and service initiatives at the federal, regional, state and local levels, and facilitate the translation of research on autism into services and treatments that will improve the

quality of life for individuals with autism and their families. A national data repository will be created to share emerging data, findings, and treatment models.

National Training Initiative - Creates a national training initiative on autism and a technical assistance center to develop and expand interdisciplinary training and continuing education on autism spectrum disorders.

Insurance Coverage - Requires that health insurers cover the diagnosis and treatment of autism spectrum disorders, including Applied Behavioral Analysis therapy and assistive communication devices.

Please contact Kim Musheno (kmusheno@aucd.org) at AUCD with your comments and suggestions for further advocacy on this bill. Material for this article was reprinted with permission from the AUCD website. You may view it on their website at www.aucd.org/itac/detail/news.cfm?news_id=3796&parent=654&parent_title=ITAC:%20ASD%20News.

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

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Fostering Successful Social Skill Development in Young Adulthood

By Shana Nichols, PhD,
Laurie Perlis, PsyD,
Stacey Kanin, CCC-SLP, and
Samara Pulver Tetenbaum, MA
Fay J. Lindner Center for
Autism and Developmental Disabilities

A parent recently came to us to ask whether it is important to include social skills goals as part of her son's high school Individualized Education Plan (IEP). He is a bright young man who has one friend who shares similar interests. He would like to go to college, pursue a professional career, and have a relationship ("maybe someday"). Though he is friendly, keeping conversations going is challenging for him and he quickly becomes anxious and flustered, resorting to talking about his interest in solar systems. Our response to his parents, as it has been to all parents and educators who ask this question, was an emphatic "yes": ongoing social skills programming throughout late adolescence and young adulthood is essential for everyone with an autism spectrum disorder (ASD) diagnosis, even for conversationally verbal individuals. Most importantly though, the kinds of social skills goals and approaches to programming can and should look very different for older teens and adults than for elementary school-aged children.



Why is Social Skills Programming Essential in Young Adulthood?

Social skills development is a life-long process of learning and practice for everyone. Though it would be nice, we don't turn twenty-one having fully mastered all the social interaction, communication, and problem-solving skills we will use throughout adulthood. If we did, there would be no need for the self-help sections at bookstores that shelve titles including *Dealing with Difficult People*, *Crucial Confrontations: Tools for Resolving Broken Promises, Violated Expectations, and Bad Behavior*, and *Cru-*

cial Conversations: Tools for Talking When the Stakes are High. Many individuals with ASDs, just like their typical peers, look forward with both excitement and trepidation to developing significant adult relationships and perhaps even getting married and having a family. Consider all the trials and tribulations that most individuals experience as they navigate the path to a satisfying adult relationship, then add the social difficulties and anxiety associated with ASDs. Young adulthood is a particularly critical time to emphasize the development and maintenance of social learning and skill development.

For individuals with ASDs, continued social skills development throughout the lifespan is essential for a number of reasons:

- The social world expands dramatically towards the end of high school: dating and relationships; interactions with college professors, teaching assistants and classmates; exchanges with co-workers and bosses; community interactions including store clerks, wait staff at restaurants
- An expanding social world introduces new skills and contexts (e.g. interviewing, landlords, reservations, dates)
- Skill development moves beyond mastery of the basics and emphasizes subtleties and nuances of interactions while at the same time facilitating fluency and feeling more natural and confident during interactions
- Continued learning of any skill requires repetition and practice. Once individuals are no longer in school, they can distance themselves from social contact, thus preventing achievement of goals that require continued social learning. In addition to purposefully distancing themselves, individuals no longer have the

see *Young Adulthood* on page 54

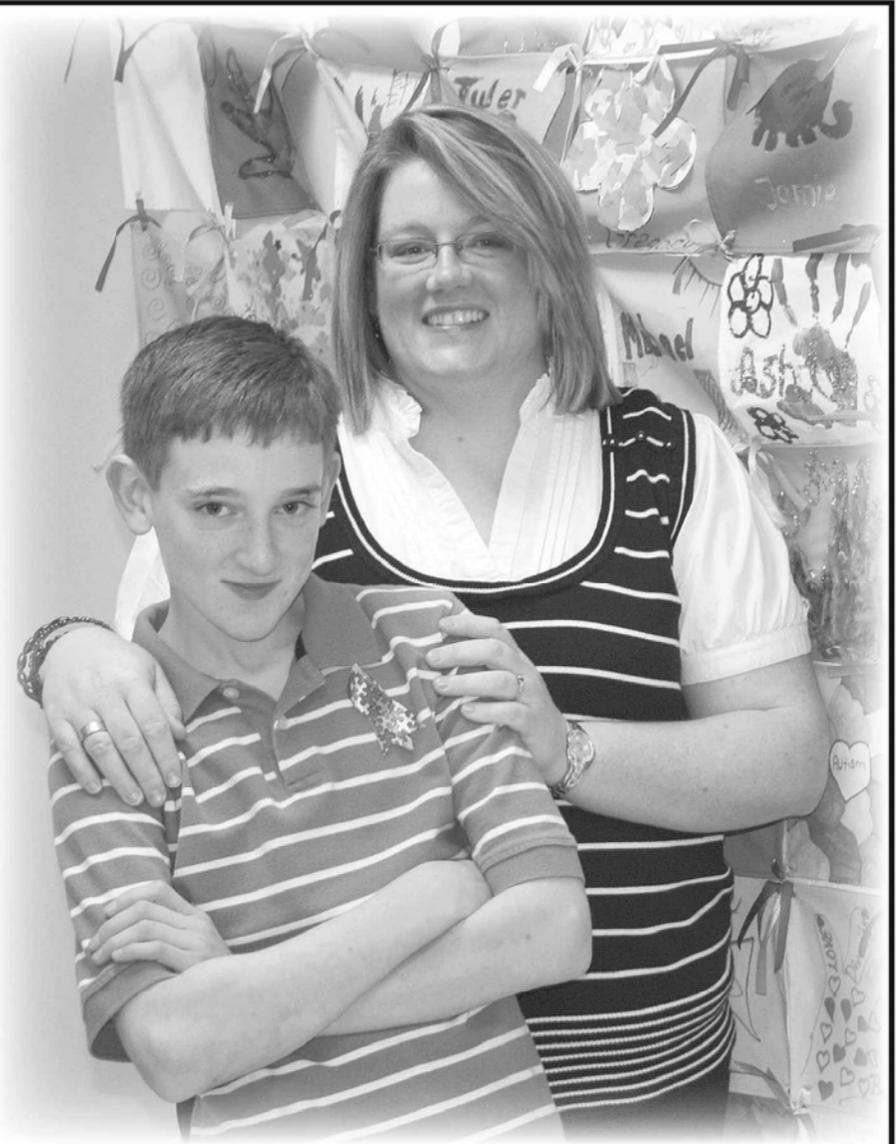
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Can Children with Autism Recover? And if So, How?

By Ruth Nass, MD, Pediatric Neurologist,
Professor of Child Neurology
and Child and Adolescent Psychiatry
NYU Medical Center

Autism is thought to be a life-long biological condition. However, a number of investigators have reported on subgroups of children with autistic spectrum disorders (ASD) who lose their diagnosis/“recover” or have what is termed an optimal outcome. This has been reported to occur in anywhere from 3% to 25% of subjects in group studies of school aged children and adults.

What Counts as Recovery?

In the following studies, recovery was defined as a child that is functioning in a regular classroom without an aide, although he/she may be receiving remediation for attention, organization issues or specific academic subjects. IQ must be with the normal range. Social skills must be adequate, i.e., normal based on clinical assessment and on standardized measures like the Autism Diagnostic Observation Scale (ADOS) and Vineland Scales. Investigators in this area note, however, that recovery does not necessarily mean that cognitive, social, and emotional functioning are completely normal.

Fein’s group (Helt et al, Neuropsy-



Ruth Nass, MD

chology Review, 2008) recently reported on a follow-up study of children, currently of middle school age, who had been assessed 3 years prior and determined to have had an optimal outcome (OO). Their OO group still had above average intelligence, but nonetheless scored significantly less well than age and socioeconomically matched controls on measures of pragmatic language (talk intended to communicate feelings, ideas,

etc. in a reciprocal way with another person). Their parents’ ratings, although within the average range, indicated more attention problems, atypical behaviors, and depression than the control group. The high functioning autism (HFA) control group, despite normal intelligence, scored in the impaired range on tests of pragmatic language, verbal memory, expressive language, and parents’ reports of communication, socialization and daily living skills.

Thus, despite “recovery” residual vulnerabilities – problems with higher-order language (like discourse) and social cognition (understanding subtle mental states), social awkwardness, perseverative interests, attention issues and ADHD, tic disorders, depression, phobias, social anxiety, and worries – are relatively common.

What are the Predictors of Recovery?

The most consistent predictor of recovery is good early communication and language ability, the sooner the better, optimally by age 3 and definitely before age 5 years. The presence of joint attention (a child drawing his/her parents’ attention to something which they look at together) early on is also a good predictor. Other predictors of OO include relatively high intelligence, good receptive language, the ability to imitate both verbal and motor cues, and normal motor development. Severe

ASD does not preclude recovery, but children with PDD-NOS are more likely to have an OO than those with autistic disorder. This difference could mean that restricted and repetitive behaviors herald a poor prognosis – present in autism disorder but not in PDD-NOS. Alternatively, children with autistic disorder may have lower IQs than those with PDD-NOS. Indeed, significantly above average IQ may turn out to be another predictor of optimal outcome. Recovery is less likely in children with neurological or other disabilities, like problems with vision or hearing.

What are the Mechanisms of Recovery?

Dawson (Development and Psychopathology, 2008) suggests that risk factors (like a genetic tendency) lead to risk processes, behaviors like early abnormalities in social interactions, which precede full blown ASD. The risk processes can prevent exposure to the normal social and language inputs that are necessary for normal brain development. Without the right exposures and interests, “expertise” does not develop. For example, infants learn to recognize facial emotions when they spend time looking at faces rather than away from them. The necessary brain structures and circuits may be there, but they need to be used to develop properly.

see *Recover on page 53*

Coping with Asperger’s in the Home

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

Andrew returned home after four years away at school this past December. My husband and I considered what it would be like to have Andrew living at home again; it had been difficult in the past. Andrew has his own agenda, isn’t interested in participating in household activities, and is not great at housekeeping.

I discussed how to handle Andrew’s reintegration into our home with our psychiatrist and took detailed notes of his suggestions, mostly aimed at reining in my nagging and scolding. My husband and I also talked about Andrew’s return and decided to start by giving him a grace period in which to unwind and adjust to being home again.

We started on a high note since Andrew had successfully completed his Associates Degree and came home a very happy young man. We delighted in his upbeat mood and enjoyed his increased conversation. At 22, Andrew had grown from the withdrawn teenager we had sent off to school.

January and February rolled by. Andrew showed no initiative in looking for a job. My husband and I would



Betsy Ern and her son Andrew

point out job postings that we thought might be good for him to no avail. My husband set up an appointment for Andrew to tour Guiding Eyes for the Blind since he loves dogs and had volunteered at a shelter while he was in school. Andrew went on the tour but didn’t seem interested in taking that a step further.

I had some computer work I thought Andrew could do at my coffee shop. Using the doctor’s suggestions, I first mentioned it, giving advance notice. I asked him a few times if he’d like to do

that; he wouldn’t. Finally, I set a start date thinking that might work; it didn’t. All Andrew wanted to do was stay home and play video games. He’d occasionally go out to dinner with us or to a movie, but even getting cleaned up and dressed was too big a chore. Still, he’d assure us, he was very happy with his life.

In March we went on a family vacation. Andrew wanted to stay in the room for the most part, although he seemed content to do so. I became frustrated with his seeming inability to just get with the program and felt that familiar banging-my-head-against-the-wall feeling of dealing with Andrew.

Then it hit me. I had always prided myself on not having expectations for my boys, including Andrew with his special needs. But I obviously did expect that by now, Andrew would have changed. I sat with that for a whole day, realizing that I had to change how I interacted with him. I saw that my approach and tone conveyed judgment and disappointment rather than acceptance, love and encouragement. Not only did this not work but caused Andrew to withdraw and likely feel bad, even if he didn’t show it.

My husband had been noticeably more patient with Andrew than I had since his return home, an interesting role reversal from Andrew’s younger

years when I had been the one more in tune with our son. Now I needed to adopt my husband’s perspective, that Andrew may have grown, but he still has a lot more growing up to do. And, as his doctor points out, he’s still Andrew.

Adjusting how I talk to Andrew has resulted in a marked improvement in his responsiveness. I have taken to “dropping in” on him in his room. I just sit down on the floor or on his bed and start paying attention to one of our dogs keeping him company. Andrew stops what he’s doing and talks to me. I only have a few minutes of his attention before he goes back to his world, yet we accomplish a lot. Sometimes I have something specific to report or to ask him to do, but sometimes it’s just a visit.

When spring arrived and the roads cleared, we encouraged Andrew to practice driving and he’s progressing nicely. I respect that he’s not willing to drive every time we go out and that he’s on his own timeframe. He has started to talk about looking for some type of work, even if it’s not a “real” job for which he has been trained (computer drafting).

I wouldn’t have expected Andrew to take six months before developing a life outside the house, but that’s who he is. I’m learning to expect and respect that.

The Asperger's Difference

A Film For and About Young People with Asperger Syndrome

By Jamey Wolff, MA, SDA
Program Director and
Courtney Scott, Development Coordinator
The Children's Annex

Difficulty communicating and social isolation have come to be seen as hallmarks of Asperger Syndrome (AS), and while many with AS display average or above average intelligence, they face obstacles in their daily life with peers. At no time is this loneliness and isolation more heightened than when beginning the already complicated emotional and physical transition into adolescence and adulthood. While Asperger Syndrome has become a more commonly known and understood condition, many teens embarking on their middle, high school and college years require help in understanding their disability and need support to build self-esteem and develop self-advocacy skills.

It was with this group of adolescents and young adults in mind that *The Asperger's Difference: A film for and about young people with AS* was conceived and executed. "The idea for the film came to me 5 years ago when I was starting to see increased numbers of children with Asperger Syndrome reach their young adult years," says Children's Annex Program Director and co-founder, Jamey Wolff.



The Asperger's Difference writer Dr. Jane Nofer and Producer/Director Jamey Wolff view the film stars Annie, Jeff and Noah

"This is a time when they have the growing ability to understand what AS is and begin to learn to advocate for themselves." Since individuals with AS are generally visual learners and respond well to visual content in videos and films, it was a surprising that there have been few films about AS expressly created for this population.

For more than 30 years, The Children's Annex, a not-for-profit center, has specialized in education, evaluation and treatment of Autism Spectrum Disorders. Two New York State approved day school programs serve students throughout the Hudson Valley at campuses in Kingston and Ellenville, New York.

The Children's Annex also provides diagnostic evaluations for Autism Spectrum Disorders for people of all ages, consultations and trainings to schools and agencies on best practices, and groups for children and teens focusing on social skills and self-advocacy.

Jamey Wolff worked in collaboration with Dr. Jane Nofer, Clinical Director for The Children's Annex Center for Diagnostic & Consultation Services and a nationally known expert on Asperger Syndrome to establish the film's guiding principles and write the script. The film, presented in documentary style, spotlights young people with AS as they talk about their experiences, challenges, and hopes for the future. The content is designed to help young people with AS understand their diagnosis, the positive aspects that accompany it, as well as think about when to disclose their diagnosis to others. Finally, the film seeks to build self-esteem and help viewers to understand they are not alone.

The resulting 30 minute film, *The Asperger's Difference*, stars three young people with Asperger's as they navigate the waters of their daily life and articulate their experiences to the target audience. Annie, a middle school student, Noah, a high school student, and Jeffrey, a college

see *Asperger's Difference* on page 47

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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

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For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 - patrowan@bestweb.net
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This physical synchrony — dots colliding to produce a clapping sound — only existed on the upright side of the screen, because the inverted figure played in reverse and its motions weren't in sync with the soundtrack. The children with ASD chose the upright figure 66 percent of the time, a strong preference.

This clue led the researchers to suspect that what initially appeared to be random viewing by the ASD toddlers might actually reflect preference for audiovisual synchronies that were less obvious than the clapping. So they re-analyzed the data, factoring in more subtle synchronous changes in motion and sound.

"Audio-visual synchronies accounted for about 90 percent of the preferred viewing patterns of toddlers with ASD and none of unaffected toddlers," said Jones. "Typically-developing children focused instead on the most socially relevant information."

A follow-up experiment using new animations optimized for audiovisual synchrony confirmed these results.

Klin, Jones, and colleagues also recently reported (www.nimh.nih.gov/science-news/2008/lack-of-eye-contact-may-predict-level-of-social-disability-in-two-year-olds-with-autism.shtml) that children with autism look more at people's mouths than eyes as early as age 2. Since the mouth is the facial feature with most audiovisual synchrony — lip motion with speech sound — the researchers propose that their new findings offer a likely explanation for this phenomenon.

"Our results suggest that, in autism, genetic predispositions are exacerbated by atypical experience from a very early age, altering brain development," said Klin. "Attention to biological motion is a fundamental mechanism of social engagement, and in the future, we need to understand how this process is derailed in autism, starting still earlier, in the first weeks and months of life."

NIMH is funding a related research project of Klin and Jones' that explores related behaviors in infants who have

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Autism and Developmental Disorders, that found a higher incidence of autism among children whose mothers had been exposed to hurricanes and tropical storms during pregnancy. Maternal exposure to severe storms at mid-gestation resulted in the highest prevalence of autism.

Drs. Purpura and Mehler believe that, in autistic children, fever stimulates the LC-NA system, temporarily restoring its normal regulatory function. "This could not happen if autism was caused by a lesion or some structural abnormality of the brain," says Dr. Purpura.

"This gives us hope that we will eventually be able to do something for people with autism," he adds.

The researchers do not advocate fever therapy (fever induced by artificial means), which would be an overly broad, and perhaps even dangerous, remedy. Instead, they say, the future of autism treatment probably lies in drugs that selectively target certain types of noradrenergic brain receptors or, more likely, in epigenetic therapies targeting

older siblings already diagnosed with ASD and who, because of the genetic heritability risk in autism, have greater risk of also developing the condition.

Also participating in the research were: David Lin, now at Harvard Medical School; Phillip Gorrindo, now at Vanderbilt University; Gordon Ramsay, Ph.D., Haskins Laboratories. The study was funded through the NIH's STAART Program (Studies To Advance Autism Research & Treatment).

Eye-tracking data shows where toddlers in each of three groups were looking during the Pat-a-Cake animation. It plays upright and forward on the left side of screens, upside down and in reverse on the right side. Red cross indicates where the child was looking. Toddler with autism is focused on audiovisual synchrony of hands clapping, while typically developing and developmentally delayed toddlers focus on face.

Pat-a-cake animation, with audio playing at half-speed and color scale indicating levels of audiovisual synchrony in child with autism. The hands clapping show the highest levels of audiovisual synchrony (red) in the figure on the right, which played upright and forward. Motion was out of sync with the sound track in the figure on the left, because it played upside down and in reverse.

The National Institute of Mental Health (NIMH) mission is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. More information is available at the NIMH website, <http://www.nimh.nih.gov>.

The National Institutes of Health (NIH), the Nation's Medical Research Agency, includes 27 Institutes and Centers and is a component of the US Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

genes of the LC-NA system.

"If the locus coeruleus is impaired in autism, it is probably because tens or hundreds, maybe even thousands, of genes are dysregulated in subtle and complex ways," says Dr. Mehler. "The only way you can reverse this process is with epigenetic therapies, which, we are beginning to learn, have the ability to coordinate very large integrated gene networks."

"The message here is one of hope but also one of caution," Dr. Mehler adds. "You can't take a complex neuropsychiatric disease that has escaped our understanding for 50 years and in one fell swoop have a therapy that is going to reverse it — that's folly. On the other hand, we now have clues to the neurobiology, the genetics, and the epigenetics of autism. To move forward, we need to invest more money in basic science to look at the genome and the epigenome in a more focused way."

The paper by Drs. Mehler and Purpura, "Autism, fever, epigenetics and the locus coeruleus," was published in the March issue of Brain Research Reviews.

Adults, Autism, Asperger's and Social Skills - All the World is a Stage

By B. Madeleine Goldfarb, MA
Director of Outreach and Education
The Autism Center of NJMS UMDNJ

The ever growing number of children with autism spectrum disorder aging out into adult systems of care should give us pause. Finding the constellation of services for this population will be one of the great challenges any of us working the field today will be faced with. Whether talking about housing, medical care, employment and vocational opportunities or recreational outlets, the limited availability of services will be an unequivocal challenge for every community. Through the many therapeutic interventions and advances in early diagnosis of autism, many adults on "the spectrum" will be able to fully participate in community life with proper supports. For the purposes of this article I will focus on the recreational aspects of adult life.

When we speak about recreational programs it is important to remember that as a society we place great value not only on the structure and functionality of social living, but also on the development and expression of recreational activities of all forms. Not to sound too pedantic I will quote the Declaration of Independence's famous lines from the second section: "We hold these Truths to be self-evident, that all Men are created equal, that they are



endowed by their Creator with certain inalienable Rights that among these are Life, Liberty and the pursuit of Happiness."

The idea that we all have a right to pursue happiness should not be lost upon individuals with autism or other developmental disabilities. This idea should be incorporated into all IHP's (Individual Health Plans) as an integral part of life planning. The IHP is the document which follows an individual who has aged out the school age entitlement, IEP Individual Education Plan (3-21 years of age) and is part of the transition planning following school into adulthood.

Around the state of New Jersey we can find what I like to term "pockets of excellence" in recreational programs. The challenge can be found in funding as well as information sharing and human resource development.

So far there are individual programs which are springing up to address these needs, but they are funded on a pilot, experimental basis, as opposed to being considered core to overall programmatic processes.

Systemic change in thinking inches along and is enhanced through unique collaboration which is cross disciplinary.

The Autism Center at New Jersey Medical School UMDNJ has had the unique opportunity to partner with excellent organizations such as The Daniel Jordan Fiddle Foundation as well as other institutions of higher learning including Montclair State University and The Garage Theatre Group at Fairleigh Dickinson University.

By recognizing the innate passions and strong interests individuals on the autism spectrum possess, we are able to create vibrant programs which validate their passions while working on the profound skill deficits core to this disability.

Why theater workshops as a starting point? Simply put, because there was consensus in the community of individuals on the spectrum, when we bothered to ask... this was an interest and indeed a passion of many of our participants.

Theater workshops are not new. Autism is not new. Putting them together, however, is very new.

Haven't we all had a socially difficult experience? Haven't we all felt socially awkward on occasion? For us it is the fleeting uncomfortable moment of anxiety, nervousness or shyness. For adults with Asperger's Syndrome or Autism Spectrum Disorder it is their way of life. What if every day we were faced with that social anxiety, nervousness or shyness? What would we do? We would do exactly what they do. Struggle to come to

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Still Overlooking Autistic Adults

By Linda H. Davis, President
and Chuck Yanikoski, Treasurer
The SAGE Crossing Foundation

Question: What coming social expenditure will cost more than a third of this year's budget for the Department of Health and Human Services and be larger than the entire current budget of the Energy Department?

Answer: The bill for the tide of autistic children entering adulthood over the next 15 years, an estimated \$27 billion annually in current, non-inflation-adjusted dollars by the end of that period. The number of autistic children expected to need extensive adult services by 2023 -- more than 380,000 people -- is roughly equal to the population of Minneapolis. If a town were created to house this group of people and their caregivers -- for you can't separate the two -- it would exceed the population of all but six U.S. cities. If they formed a state, it would have four electoral votes.

But most of these cognitively impaired citizens don't vote. Most of them can't live alone or work in public places. Many can't even take public transportation by themselves.

Yet as World Autism Awareness Day (www.worldautismawarenessday.org) passed this year, with the wrecking ball swinging at all levels of social services in this devastated economy, the challenges

of adult autism continue to be overlooked. Many news reports focus on whether vaccines cause autism, the need for a cure or the education of autistic children. Autistic adults are relegated to the sidelines. Even the Obama administration, which has pledged better care for disabled Americans, including those with autism, has not been specific enough about its plans for those who will probably never be able to live independently or be part of the traditional workforce. "Improving life-long services for people with ASD," as autism spectrum disorder is known, is a worryingly broad, detail-free promise in the White House agenda published online (www.whitehouse.gov/agenda/disabilities).

I understand that no one wants to look at a child and imagine the clunky, in-your-face adult he or she will become or think about the stares he or she will induce. When I look at my pudgy 22-year-old son, Randy, still sweet-faced but so obviously disabled, I cannot locate the blond cherub he used to be, gripping his stuffed brown bear. While writing this, I listened to Randy getting into the refrigerator (he's home again from his supervised job -- two mornings a week -- because of another problem with the overwhelmed human services provider funded by the Commonwealth of Massachusetts), and wonder who will love or at least protect him when he ends up in a group home run by an underpaid, overworked staff.

Randy's father and I are keeping him at home as long as possible, even as I'm battling an incurable cancer. The inadequate state services and perilously thin funding have seriously hampered our ability to work while caring for our son. I feel as though we're playing Russian roulette with Randy's future, yet I cling to my gentle son, unwilling to entrust him to a system that grows more fragile than I do.

Randy is just one of hundreds of thousands of autistic adults to whom society pays frighteningly little attention. The price of their care will affect all Americans, not only those who have autistic children. Along with housing, day programs, transportation to those programs or jobs, and higher-than-average medical costs, adults with autism require steady supervision and support. Consider: A well-behaved, relatively high-functioning person such as my son could manage in an environment that has a ratio of three clients per staff member. But many autistic people require a one-to-one ratio. This is a serious hurdle, not least because of the high turnover rate among those who provide direct care, which stems in part from their low wages. Not everyone is temperamentally suited to this work. People with autism present myriad challenges: They can sometimes be violent, sometimes are self-abusive, suffer psychological meltdowns, or behave in many socially unacceptable ways, to say the least. Women, traditionally cast in the caregiver role, are

at risk of greater physical harm when caring for autistic adults than for children. At expected rates, we will need to find an additional million caregivers, people who must have the right personal qualities to work with autistic individuals but who are willing and able to work for low wages. This is no small challenge. We not only must train people but also show that we value this work by paying them better.

In 15 years, the cost of care just for the autistic children entering adulthood over that time will be about equal to the current state budget of Tennessee. Meanwhile, services are dangerously strained, and the influx of autistic adults is underway. This country urgently needs to focus on adult autism, new models of care and new sources of funding. Before the looming tidal wave delivers another crushing blow to our economy, we should have a national discussion. It should begin today.

Linda H. Davis is the author, most recently, of "Charles Addams: A Cartoonist's Life" and is president of the nonprofit SAGE Crossing Foundation, formed to create a farmstead for autistic adults. Her husband, Chuck Yanikoski, who is treasurer of SAGE, contributed to this piece.

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to be avoided. Are noise levels a problem? Would he or she prefer to work indoors or outdoors. Will she/he be looking for summer placement in their future career area? These questions will narrow the search and go a long way to assure that the job experience will be a pleasant one. A self-assessment course for those with developmental disabilities can be found at: www.partnersinpolicymaking.com/employment.

As the job hunt gets underway, encourage your youngster to keep records of who he has contacted about jobs and what their responses were. He/she should note when follow-up is required. If interviews are scheduled, record the date, time and place. What will they need to bring to the interview: Social security cards, working papers, resume etc.

If interviews are scheduled, ask or encourage your youngster to practice interviewing skills. Share your own interview experiences and give them lots of support.

Where Are the Summer Jobs?

Given our current economic hard times, summer jobs may be harder to find this year. It's good to remember that looking for a job is a job in itself. Many executive functions and social skills need to be used to obtain employment. Definitely reward your young job seeker for going through the job seeking steps even if they do not result in employment. Here are a

few suggestions for finding summer employment:

The career placement office or guidance office: Don't pass up the obvious; this should be the 1st stop on any student's job hunt. This is certainly the place to inquire about summer internships for college students.

Summer camps: If your child has attended camp and has now aged out, consider asking the camp administration if they would consider summer employment for your child. These are people who are already familiar with your child's strengths and challenges. A counselor position may or may not be a good fit but there are many other jobs at camp which would be appropriate for your child. Help with taking care of the grounds for instance, help in the dining room, help in the office. Consider asking for positions at other special needs camps. After all, these are organizations that foster independence for their campers and what better way to prove that independence is an attainable goal than to hire those with special needs.

The friends and family network: The 1st rule of job hunting is to tell everyone you know that you are looking for a job. Our individuals on the spectrum may have to be taught to use some discretion but they should be encouraged to share their job hunting activities with friends and family. Networking is

the most important tool for the job seeker.

Hotels, restaurants, beaches, parks, baseball stadiums: If you are fortunate to live near a resort or vacation area look into jobs at local hotels, beaches, parks and other recreational facilities. Contact the recreation departments in your area for their list of summer jobs. For instance, the Town of Hempstead, in Nassau County, Long Island is currently seeking lifeguards and ticket takers. (Personal note: My son worked for the City of Long Beach for several summers as a beach ticket taker and beach cleaner. He will start his fourth year as the fry chef at the Long Island Duck's City Field. My daughter worked at local restaurants, as delivery person and counter clerk)

Newspapers, employment agencies, state unemployment offices: The employment offices may even have specialists who work with special needs job seekers.

Creating Jobs and Volunteering: Creating a schedule for your youngster to do extra chores or volunteering can bring the same benefits as regular paid employment. It must be understood however that the job be approached with the same level of responsibility as a salaried job. If your youngster has special interest and is motivated to work in a specific environment but paid employment is not a possibility ask if an internship or volunteer position would be considered

Other Job Hunting Tips

You'll find a slew of websites offering job listings and opportunities. Be very selective. However, I did find some good advice and tips for young job seekers and their parents at the following sites: jobsearch.about.com/od/teenstudentgrad/a/parentguide.htm and www.myfirstpaycheck.com/advice.

GOOD LUCK!

A Summer Job and Much More

For young adults 16 years of age or older whose special needs require a more supportive environment the Introduction to Independence Program, located on the New York Institute of Technology's campus in Central Islip, New York offers a very comprehensive residential summer program. This work-study-recreation program focuses on social skills, vocational skills and independent living skills with classes that support these areas. Each participant is placed in an appropriate summer position and will work several hours per week for a small salary with the benefit of job coaching and vocational counseling. The program also prepares young adults who are headed for college to live, study and socialize in an independent setting. Call the program at 631-348-3139 and visit their website at www.nyit.edu/vip/UniquePrograms_01.html.

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terms and find a way to make it all work.

We have heard the descriptions: They have a hard time understanding body language; they have difficulty reading facial expressions; they are clumsy and awkward; they avoid physical contact, or they stand too close for comfort; they cannot make eye contact; they don't fit in socially; they have trouble making friends; they misunderstand the behavior of others; they act out in unusual and often unpredictable ways; they have trouble taking the listener's perspective; they are eccentric. They... They... They are us...only more so.

"You are using theater as therapy?" "No." We are using theater as theater. That may just be why it is so successful. The problems for individuals on the autism spectrum are manifold. First, let's isolate and breakdown one area we can work on. If we deal with the area of social skills and target that area to focus upon we can tailor a program which works on those skills. The dilemma with many social skill classes is that of functionality. When I say that, I mean that the participants are incredibly adept at learning the "scripts" in the confines of the

social skills class.

"Hey, it's been awhile since I've seen you." "What's up?" "What are you doing later?" So on and so forth.

Individuals on the spectrum can role play with the best. Unfortunately, life comes at you from left field and ultimately the context of that social situation is not experienced in the same context the participant learned in the social skills class. This often leads to a failure of generalized learning into the natural environment.

We live in a very fast paced and ever evolving social society. There is speed dating, instant messaging and Facebook, not to mention Twitter, to contend with. The innate ability to maneuver through this very complex and nuanced social world can be daunting for anyone. Overlay the inability to correctly "read" social situations into that equation and it is not difficult to understand and feel extremely empathic at this breakdown of social ability.

Solutions...beyond the social skills class. Solutions need buy in by participants. If the program is not of interest to the participants the exercises and skills those exercises build will be diminished and the chance that they will be generalized into the greater social world is also uncertain.

Theater has, if not universal ap-

peal, I would say it has near universal appeal. Participants may have an interest in, even an intense interest in, if not acting, individual actors or movies or movie genres. There is half the battle. Find that interest and find what leads to buy in. Buy in leads to participation. Participation leads to skill acquisition, shared learning, experiential activities, team building and the sky is the limit.

I think the other important aspect of this has to be process over product. The discussion whether or not to do a final performance has always been left to the group. The process of discovery always outweighs the product at the end. Also, a thoughtful examination of general theater course curriculum without accommodation based upon the goals of the group is also very important. Think about the skills you may work on in a performance group for example. You may spend time working on voice modulation and porosity. You may devote time to role playing character emotions. You may dissect the motivation for a character's actions. You may work on spatial relations on a stage.

I have been struck at how the craft of acting works on so many of the areas that typically individuals on the autism spectrum have difficulty with. I have also been amazed at the quality

and enthusiasm of the work ethic everyone has brought to the classes. The camaraderie and fellowship amongst the participants and the teaching actors has been rewarding on so many levels.

The challenge is, as always, finding the funding needed to incorporate this type of programming into more areas and for a greater range of students. I would encourage advocacy on the part of families and communities to start regional groups where individuals with ASD can access this type of program. I feel the benefits are so compelling that this should be a priority for families and communities to pursue.

The synergy of the connection between theater and autism is an embrace of acceptance and community building which lasts far beyond the theater workshop. Who is the teacher? Who is the student? When the roles become melded and the lines become indistinct, there is growth, mutual respect and admiration. In short, there is success.

I will leave you with one quote I quite think sums it all up:

"The thing about performance, even if it's only an illusion, is that it is a celebration of the fact that we do contain within ourselves infinite possibilities." -Daniel Day Lewis

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Intensive Behavioral Plan. The provider will then implement the strategies and interventions described in the plan.

An important outcome of Intensive Behavioral Services is that the behavioral intervention strategies are maintained on a long-term basis. To this end, the provider will work with family and caregivers to ensure they are able to implement the behavioral interventions. If necessary, the Intensive Behavioral Service provider will work with the individual and family to establish a transition plan so that the behavioral strategies can be supported on a long-term basis by another community provider such as a day service provider.

An Intensive Treatment
Facility for Adults

Another key component of OMRDD's Autism Platform is the development of a

transitional center that will provide intensive treatment and stabilization services to adults with ASD statewide. That center is taking shape at OMRDD's centrally located Capital District Developmental Disabilities Services Office (DDSO) in Niskayuna, NY.

"The Transitional Program for Adults is designed as a specialized program to assist people with autism who are experiencing crisis and need behavioral stabilization through intensive behavioral supports, sensory integration and medication management," said DDSO Director David Slingerland. "This program will give them the intensive, individualized supports they need to be more successful, and the clinical team will then work with home districts to ensure that the needed level of support is established."

Staff at the center have received additional autism-related training, and will use proactive, behavioral strategies and intensive clinical and medical monitoring and

intervention to ensure ongoing and effective treatment for those in crisis. While the program will serve adults from anywhere in New York State, it recognizes that people ultimately need to thrive and contribute in their home communities, in the company of family and friends. With intensive person-centered intervention and treatment, the Transitional Program for Adults will enable people to succeed, some for perhaps the first time, and it will coordinate the necessary level of support for individuals with their home districts.

Forward Momentum - The Autism
Platform and the Inter-Agency Task Force

OMRDD's Autism Platform contains numerous other initiatives, each focused on particular aspects of New York's response to the needs of those with ASD. They relate to making information more readily available to those who need it, elevating the competency of our commu-

nities, our schools and service providers to support people with ASD, advancing our understanding of ASD and its treatment, and ensuring that state government – all its service providing systems – focus on meeting needs rather than the constraining dictates of program bureaucracies.

Currently OMRDD and the New York State Education Department are leading the Inter-Agency Task Force on Autism, a group of 10 state agency leaders, in a thorough examination of the needs of individuals with ASD and their families and the systems in place to serve them. The Task Force's final report, due in December 2009, will provide a blueprint for further action, further advancement in the support New York provides its citizens with ASD.

For more information on the work of the Task Force and specific initiatives within the Autism Platform, visit the new Autism Platform page on OMRDD's homepage (www.omr.state.ny.us).

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that recognize the need to focus on programs and services beyond childhood. *The Autism Treatment Acceleration Act of 2009*, a bill, recently introduced in the Senate and House of Representatives, includes language that would create a demonstration project to provide a full array of services to adults with ASD to improve their quality of life and enable them to live as independently as possible. This important inclusion of adult issues in a multi-faceted bill aimed at improving the lives of individuals with ASD is a major step forward in promoting awareness that autism is a life span challenge.

In many states, legislators are also beginning to realize that the growing population of children with ASD is rapidly aging to adulthood and that it is imperative to identify and address the issues that not only affect their lives but will have an enormous impact on society at large. The fact that adult ASD will incredibly impact all citizens should be apparent by the numbers of those currently diagnosed; it is well reported that 1 in 150 children have ASD, and in our organization's home state, New Jersey, 1 in 94 are on the autism spectrum. New Jersey legislators like Assembly Speaker, Joseph J. Roberts, Jr., State Senators,

Loretta Weinberg and Joseph Vitale and Assemblywoman, Joan Voss have spearheaded important legislation that created *The Adults with Autism Task Force* that was signed into law by Governor Corzine. The Task Force, on which I am a member, was convened last year with the mandate to provide an actionable plan to address the needs of adults.

The report that was presented to Governor Corzine and legislators in June of 2009 outlined the major issues that think tanks around the country have also identified, illustrating that many are thinking along the same lines.

Some of the key needs relating to adults with ASD that were put forth by the New Jersey Task Force and other task forces, think tanks and symposia relating to adults include:

- The need for effective and coordinated transition planning guided by the individual with ASD, their parents/caregivers and autism trained professionals; this must begin early in the education process.
- The need for a variety of day programs that provide person centered training, autism specific support systems and intensive life skills curriculum that fosters independence

- The need for college support and opportunities for those pursuing that path
- The need for a variety of safe and sustainable residential options that enhance participation in community life
- The need for a variety of employment opportunities that focus on the strengths and talents of adults with ASD and the availability of a support system to assure their sustainability and success
- The need to enhance the health and wellness of adults through fulfilling and varied recreational endeavors
- The need to educate the community about the diversity of the adult ASD population so as to create more awareness, opportunities and support for them
- The need to address issues relating to community life and the safety of adults with ASD such as transportation, sexuality, marriage, legal matters, faith-community participation, aging

These issues are ones that The Daniel Jordan Fiddle Foundation has been addressing and will continue to address in

the days and years to come. It is essential that in the process we listen to the ideas and guidance from adults with ASD. Organizations like the Autism Society of America have been doing so for many years and others should follow their lead. Self-advocates must have a platform and voice in the national and statewide agendas that affect their lives. The issues mentioned are ones you will be hearing more about in the future and the more discussion the better as we engage our country in creating the best futures possible for adults with ASD. This is the dream I had for my son Danny and I am confident that we are moving in the right direction towards its realization.

Linda Walder Fiddle, Esq. is the founder and executive director of The Daniel Jordan Fiddle Foundation, a national 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.

For more information visit: www.djfiddlefoundation.org. For more information on Advancing Futures for Adults with Autism visit: www.affaa-us.org.

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perceptiveness of pitch, melody, or rhythm. Music therapy builds on these strengths and enables those with ASD to share their private worlds.

Nordoff-Robbins Music Therapy

Nordoff-Robbins music therapy has become internationally recognized over the past four decades. The approach grew from the pioneering collaboration of Dr. Paul Nordoff, American pianist and composer, and Dr. Clive Robbins, British special educator. They used music as a means for engaging children with autism, developmental delays, emotional disturbances, and physical challenges, many of whom were unable to communicate verbally. Through drawing children into active mu-

sic making, they found that music effectively accessed the healthy core potential for growth and development within each child—what they called the "music child"—beneath the barriers imposed by the child's condition.

Nordoff-Robbins music therapists employ both spontaneously improvised and pre-composed music, using a variety of conventional and specialized instruments. Clients do not need to have prior musical skill or training. With children and adolescents, a team of two therapists work together, with one providing the music on piano or guitar while the other facilitates the client's participation when necessary.

To initially engage the client, the therapist plays music to reflect the client's physical presence and mood. When the client initiates the music, the therapist

joins in and together they enter into shared creative musical activity, both instrumental and vocal. Within this musical interaction, the therapeutic relationship develops, and clinical goals for the client are continually addressed.

The Nordoff-Robbins Center for
Music Therapy at NYU Steinhardt

The Nordoff-Robbins Center for Music Therapy at New York University, founded in 1989, offers individual and group music therapy sessions to clients of all ages. The work is funded by foundations, corporations, and individuals. The Center also provides advanced training to music therapists, holds workshops, publishes musical and instructional materials, and conducts research.

Current research at the Center is fo-

cused on the effects of Nordoff-Robbins music therapy on the development of communication and social interaction in young children with developmental disabilities, particularly those with ASD. A long-term project is underway to establish research partnerships with therapeutic preschools in New York City. The ultimate aim of this project is to enhance the quality and scope of music therapy services to children with autism and other developmental disabilities.

Thanks in part to NYU's ongoing support of Nordoff-Robbins music therapy, the Center is entering its twentieth year of service. We are currently conducting intake sessions for September enrollment. Placement in individual and/or group music therapy is available Monday through Saturday. Please call 212-998-5151 to begin the enrollment process.

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partial list appears in Table 1). For instance, does the proband have café-au-lait macules, pigmented spots on the skin known to be associated with neurofibromatosis, or hypopigmented spots in the shape of ash leaves, which suggest tuberous sclerosis (the search for ash leaf spots is aided by the use of a Woods lamp)? Are there unusual facial features such as a prominent forehead or jaw, or large ears that point to fragile X syndrome? Is the head circumference larger (suggesting Sotos syndrome or the *PTEN*-associated disorders) or smaller (supporting the effects of a teratogen) than would be expected for a child of that age? Are the joints lax or, in boys, are the testes large (both features of fragile X)? Does the proband have unusual hand movements such as flapping (associated with fragile X), ataxic, puppet-like movements (seen in Angelman syndrome) or “hand washing” movements (noted in girls with Rett syndrome)?

The Genetic Work-Up

Following completion of the history and physical exam, an assessment is made about the likely cause of the proband's condition. Specifically, in order to direct the laboratory evaluation and counseling, the geneticist must decide whether the proband has a *primary* ASD (an ASD not

associated with an underlying genetic disorder or environmental teratogen), or an ASD that is *secondary* to a prenatal exposure (such as congenital rubella syndrome or fetal alcohol spectrum disorder) or to the presence of a genetic disorder, such as neurofibromatosis, fragile X or Rett syndrome. Between 80 and 90% will be judged to have a primary ASD, while 10-20% will have a secondary ASD.

Based on the outcome of the assessment, the geneticist will decide the laboratory tests, if any, that should be performed. As noted in Table 2 (and described in Schaefer GB, Mendelsohn NJ. Genetics evaluation for the etiologic diagnosis of ASDs. *Genet Med* 2008;10:4-12.), the testing should be done in stages or tiers, in which tests are ordered in sequence, based on results of previous evaluations. If an ASD is due to an underlying genetic disorder, direct DNA testing should be performed (or, in the case of neurofibromatosis, the diagnosis should be confirmed using the scoring system described by Riccardi [Ferner RE. Neurofibromatosis 1 and neurofibromatosis 2: a twenty first century perspective. *Lancet Neurol.* 2007;6:340-351.]). If a congenital infection is suspected, serologic testing or polymerase chain reaction may be helpful in confirming the etiology, while the diagnosis of a teratogenic syndrome, such as fetal alcohol spectrum disorder or valproic acid embryopathy, is confirmed on the basis of the history of exposure and

the presence of characteristic features.

As already noted, the majority of probands will have primary ASD, with no features suggestive of an accompanying genetic disorder. It is this population that presents the greatest challenge to the geneticist. In these cases, discovering information that will prove helpful to the family is often difficult and elusive. However, new tools, such as microarray comparative genomic hybridization, have offered hope that the cause will be identified in more individuals with a primary ASD

“Silent” inborn errors of metabolism have been postulated to be a cause of primary ASDs. In 1994, Laszlo et al. reported that 43% of children who met the DSM III criteria for ASD had elevated levels of lactic acid, a non-specific biochemical marker of underlying abnormalities in glucose metabolism (Laszlo A, Horvath E, et al.: Serum serotonin, lactate and pyruvate levels in infantile autistic children. *Clinica Chimica Acta* 1994; 229:205-207). Although subsequent studies have identified a smaller percentage of probands with elevated lactate levels, routine testing for lactate and pyruvate should be part of first tier testing. If levels are normal, no further evaluation is indicated; if abnormal, a series of tier 2 tests should be performed.

The need for analysis of chromosomes has been well established in the evaluation of the cause of an ASD. Numerous small (submicroscopic) deletions and du-

plications, called copy number variants (CNVs), have been associated, including duplication of a portion of chromosome 15 (15q11.2), seen in 3% of cases, and a deletion in the short arm of chromosome 16 (16p11.2), seen in 1%. In the past, the approach to identify these errors has always included high resolution chromosome analysis accompanied by fluorescent *in situ* hybridization (FISH) looking for errors at the end of the chromosomes (subtelomeres). More recently, microarray comparative genomic hybridization, a powerful technique 4 to 5 times more sensitive at identifying CNVs, has begun to supplant these previously used techniques. Recent studies have indicated that using array CGH, CNVs can be identified in 10% of individuals with sporadic autism beyond what would be identified by standard chromosomal testing (Bejjani BA, Shaffer LG: Clinical Utility of Contemporary Molecular Cytogenetics. *Annual Review of Genomics and Human Genetics* 2008, 9:71-86).

Although array CGH has the potential to identify CNVs, the technique cannot identify mutations within genes. As such, even in the absence of clinical features that suggest the diagnosis, because of the high yield in this population and the implications to other members of the family, all probands should have DNA testing for fragile X, and all females

see Geneticist on page 53

Table 1: Partial list of “common” genetic syndromes associated with autism

SYNDROME	GENE OR CHROM INVOLVED/ETIOLOGY/TEST
Angelman syndrome	<i>UBE3</i> / absence of maternal copy / FISH, methylation
CHARGE syndrome	<i>CHD7</i> / mutation / direct DNA analysis
Down syndrome	Trisomy 21/ nondisjunction/ chromosome analysis
Fragile X syndrome	<i>FMR-1</i> / Trinucleotide (CGG) expansion/ Direct DNA
Neurofibromatosis	<i>NF1</i> / mutation / direct DNA analysis
Prader-Willi syndrome	<i>SNRPN</i> / absence of paternal copy/FISH, methylation
PTEN associated disorders (Cowden syndrome, Bannayan-Riley-Ruvalcaba syndrome)	<i>PTEN</i> / mutation/ direct DNA analysis
Rett syndrome	<i>MECP2</i> / mutation, deletion/ Direct DNA analysis
Smith-Lemli-Opitz synd	<i>DHCR7</i> / mutation / Direct DNA analysis
Sotos syndrome	<i>NSD1</i> / mutation / direct DNA analysis
Tuberous sclerosis	<i>TSC1</i> (20%), <i>TSC2</i> (60%)/mutations/direct DNA analysis
Velo-Cardio-Facial syndrome (aka diGeorge, Shprintzen)	deletion 22q11.2 / deletion / FISH
Williams syndrome	deletion 7q11.23/ deletion of 26 genes/ FISH

Adapted from Schaefer GB and Mendelsohn NJ. Genetics evaluation for the etiologic diagnosis of autism spectrum disorders. 2008; *Genet Med* 2008;10:4-12.

Table 2: Template for the clinical genetic diagnostic evaluation of ASDs

Pre-evaluation: Before referral to the geneticist, the following should be accomplished:

- 1) Confirmation of diagnosis of ASD by trained professional (using objective criteria)
- 2) Cognitive testing
- 3) Sensory screening (complete audiogram)
- 4) If clinical suspicion of seizures/regression: Electroencephalogram

Evaluation: Following referral, pt should have:

- 1) History
- 2) Pedigree including information on at least three generations
- 3) Physical Exam with special attention to dysmorphic features (should include Woods lamp evaluation for hypopigmented macules)
- 4) Assessment: Using information from above, decide if patient has ASD as part of a genetic syndrome or as the result of exposure to a teratogen (*secondary ASD*) or is an isolated finding (*primary ASD*)

Work-up: Dependent on results of assessment:

- 1) If ASD is secondary, and specific diagnosis is suspected, proceed with targeted testing:
 - a) Rubella titers—if clinical indicators present
 - b) DNA analysis if single gene disorder is suspected (see Table 1); also family members should be examined to determine if they have similar features
 - c) High resolution chromosome analysis if chromosomal anomaly is suspected
- 2) If ASD is primary, proceed with tier one of generalized work-up:

Tier 1 Work Up should include:

 - a) Metabolic screening—check newborn screen results; serum lactate and pyruvate. If normal, no need to continue; if abnormal, proceed to tier 2
 - b) Microarray comparative genomic hybridization (array CGH)
 - c) DNA for Fragile X
 - d) DNA for *MECP2* associated disorder (Rett syndrome) in female
 - e) *PTEN* gene testing (if head circumference is 2.5 SD greater than the mean)

Tier 2 Work Up:

- a) If metabolic screen abnormal, complete metabolic work-up (serum and/or urine amino acids, organic acids, mucopolysaccharides)
- b) Array CGH of parents if copy number variant identified
- c) Appropriate DNA testing for first degree relatives (if mutation is found)

Tier 3 Work-Up

- a) Brain magnetic resonance imaging
- b) Serum and urine uric acid
- c) If elevated, Hypoxanthine-guanine phosphoribosyl transferase (*HgPRT*) and Phosphoribosylpyrophosphate (*PRPP*) synthetase superactivity testing
- d) If low, purine/pyrimidine panel (uracil excretion, xanthine, hypoxanthine)

Adapted from Schaefer GB and Mendelsohn NJ. Genetics evaluation for the etiologic diagnosis of autism spectrum disorders. *Genet Med* 2008;10:4-12.

Autism Spectrum News - Fall Issue**“Understanding the Assessment Process:****What Parents Should Know”****Deadline: September 15, 2009****We Invite You to Contact Us****About Your Interest in Submitting an Article****And Advertising Your Vital Programs and Services****Phone: (508) 533-4053 Email: dminot@mhnews.org**

Effective Advocacy from page 14

meeting and opened up conversation in the community. Good research that yields a fact-based argument more times than not results in successful advocacy. Nothing beats it.

Along with engagement, passion and research, constructing a plan of action is a key component of any effective advocacy effort. In developing a plan of action or "advocacy strategy" there are several basic questions to ask. Who is my audience? What is the most efficient and impactful way to reach my audience? What result(s) do I wish to achieve through my advocacy or put another way, what do I want my audience to do about it? There are other questions too, but these three are what I would call threshold questions in developing an effective advocacy strategy.

The answers to these threshold questions will be important on many levels. They will help you determine whether you are going to spearhead a letter writing campaign, testify before a legislative committee or organize a protest rally on the steps of city hall. If this sounds too

lofty, time consuming and labor intensive, then this is not a strategy you would choose. How about starting more simply, like joining an on-line petition, writing a letter to a local official or newspaper, attending a meeting on the topic to share ideas with others? All of these are effective ways to advocate.

The point is to develop a strategy that is comfortable for you. Realize too, that no effort is too small or insignificant to matter. Attendance at a meeting, even if you say nothing when there, shows your recognition that the topic is of value by virtue of the fact that you took the time out of your busy schedule to show up. There may be only one person expressing the collective voice of the group at the meeting but never underestimate the power of the numbers behind that proponent, applauding their support or booing their disapproval.

What comes next after the "advocacy moment?" You've made the speech, written the letter, made a few key phone calls—now what? The next step is as important to effective advocacy as any other and that is what I call, "the follow-

up." Now that you made some noise, presented your plan, how will you follow-up to get the sought after result? This may be the most challenging aspect of any advocacy effort, or at least the part that requires the most persistence. It is what I often call, "persistence against resistance." There is no easy answer or way around it. Here is again where the fuel of passion can continue to nurture the flame you ignited, or not.

I have seen many effective advocates and advocacy organizations raise important questions on the issues, creating excellent awareness, only to drop the ball before the desired result is achieved. On the other hand, I have seen exactly the opposite happen. Sometimes effective advocacy requires a "chain reaction effect" whereby one person or group begins the work, say by creating awareness about an issue, and then another person or group takes on the issue and continues the fight. And yes, advocacy is a sort of fight—at its core; it is a fight for what you believe in.

In speeches we have all heard from politicians to pundits, we have been counseled that one voice can make a difference.

Although it sounds good and even inspires us, is this really the case? I believe, from my experience that it is true. Some advocates get more exposure than others because of their celebrity or connections but all advocates make a difference if they affect one person's life. In the end, effective advocacy, driven by passion, fostered by knowledge and perpetuated by persistence begins one person at a time.

Linda Walder Fiddle, Esq. is the founder and executive director of The Daniel Jordan Fiddle Foundation, a national 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. Ms. Walder Fiddle is an advocate on the state and national levels for issues relating to adults on the spectrum and works closely with legislators in developing public policy initiatives aimed at improving the lives of those affected by ASD. For more information visit: www.djfiddlefoundation.org.

Integrated Services from page 29

well as the concerns of caregivers, topics may include: modesty; getting ready for and/or dealing with puberty; grooming and hygiene; social judgment and responsibility; dating; love and intimacy; menstrual hygiene; masturbation; reproduction; sexually transmitted diseases and their prevention; sexual decision making skills; birth control; lifestyle choices; parenting; and sexual health.

Short-term individual counseling is offered to persons recovering from traumatic experiences, as well as individuals exhibiting socially or sexually maladaptive behaviors. Parents of children with significant cognitive impairment can also receive education in teaching their children about sexuality, particularly emphasizing protection against coercive sexual activity, pregnancy and STDs. Services offered within the sexuality education component of the program are free of charge.

The *reproductive health* component offers adolescents and adults with developmental disabilities education, prevention and screening for sexually transmitted infections. Services include gynecological examinations, and testicular examinations. Family planning services are

also offered, including an overview of current contraceptive choices, and assistance in selecting the method best for each individual. Medical services are charged to the patient's insurance or Medicaid coverage. No patient is turned away for inability to pay for services.

Mentor Supported Employment for Individuals with Developmental Disability

The Cody Center has collaborated with Community Enterprises on a program funded by OMRDD to develop mentor-supported employment for clients with developmental disabilities, including Autism Spectrum Disorders, who manifest behavioral barriers to successful job acquisition and maintenance. The program develops job placements in workplaces that specifically volunteer to accommodate job candidates whose primary challenges to successful employment are social skill deficits and unusual behaviors, such as rocking, other repetitive movements, or compulsions. These workplaces appoint an internal mentor for the employee, to act as on-site liaison to the job coach and behavior consultant. The centerpiece of the program is a behavioral plan that breaks down problematic em-

ployee responses into components that can be addressed systematically to improve the employee's retention in the job, and specific training for both job coach and mentor in applying the behavior plan in the workplace. Ongoing consultation provides for adjustments to the behavior plan as the employee learns new skills and takes on additional duties.

College Support Programs at Suffolk County Community College

Summer Pre-College Experience: This program provides high school students in 11th or 12th grade with the opportunity to audit a college class for three weeks, and to develop study, organizational and social skills necessary for success in college. It also provides students with an opportunity to take the college placement test. A post-program assessment is given to students and their families at the conclusion of the program. The program is supported through a grant provided by Eastern Suffolk BOCES, and is provided without charge to families or to school districts.

Cody Center College Support Program: The Center also initiated a pilot college support program with a start-up grant

from Autism Speaks, in fall of 2008. This program is now offered on an ongoing fee for service basis. It provides on site social skills training and academic coaching services to college students with autism spectrum and related disorders. Students attend weekly group sessions and have access to academic and organizational coaching 12 hours per week. Assistance is also provided with vocational planning and support, including help with obtaining internships and services provided by VESID. Students must meet all admission requirements at SCCC, and maintain adequate academic standards, to participate in the Cody Center program. They may attend classes full-time or part-time.

Like many centers across the country, the Cody Center has always provided service to individuals of all ages. Early detection and educational intervention has improved the outlook for many young children with ASD, but these disorders are essentially life-long, and it is important that we turn our skills to addressing the needs of adults, as well as endeavoring to ensure that targeted interventions have prepared the family and individual for a successful transition from school to adult life.

Asperger's Difference from page 41

student, represent a range of ages and circumstances but share many of the common challenges and strengths of individuals living with AS.

The film is presented as a series of visual chapters. This format allows its stars to address typical difficulties such as struggles with social and communication skills, controlling thoughts and behaviors, and experiencing sensory sensitivity. The viewer easily identifies with 13 year old Annie, who speaks convincingly of the pain and isolation experienced as the result of bullying and teasing which leaves her feeling like "the odd one out." 16 year old Noah shares the frustration caused by his need for perfection as he shows us the reminder sign posted in his room reading "Perfection and procrastination are the enemy." And 18 year old college fresh-

man Jeffrey helps the audience to understand the challenges faced in daily conversation which he refers to as "foot in mouth syndrome."

And yet, these remarkable young people also provide a window into the often overlooked strengths that can accompany Asperger's Syndrome. Individuals with AS often have heightened language and memory skills which are manifested in Noah's exemplary academic performance. The sensory sensitivity which can prove so challenging, also lends Annie musical talents and perfect pitch. The intense concentration that requires Jeffrey to employ an egg timer to limit his computer use conversely provides him the focus to compose poetry. Each of these young people bring a poise, self-awareness and sense of humor which help the audience to see the full picture of what it means to live with AS.

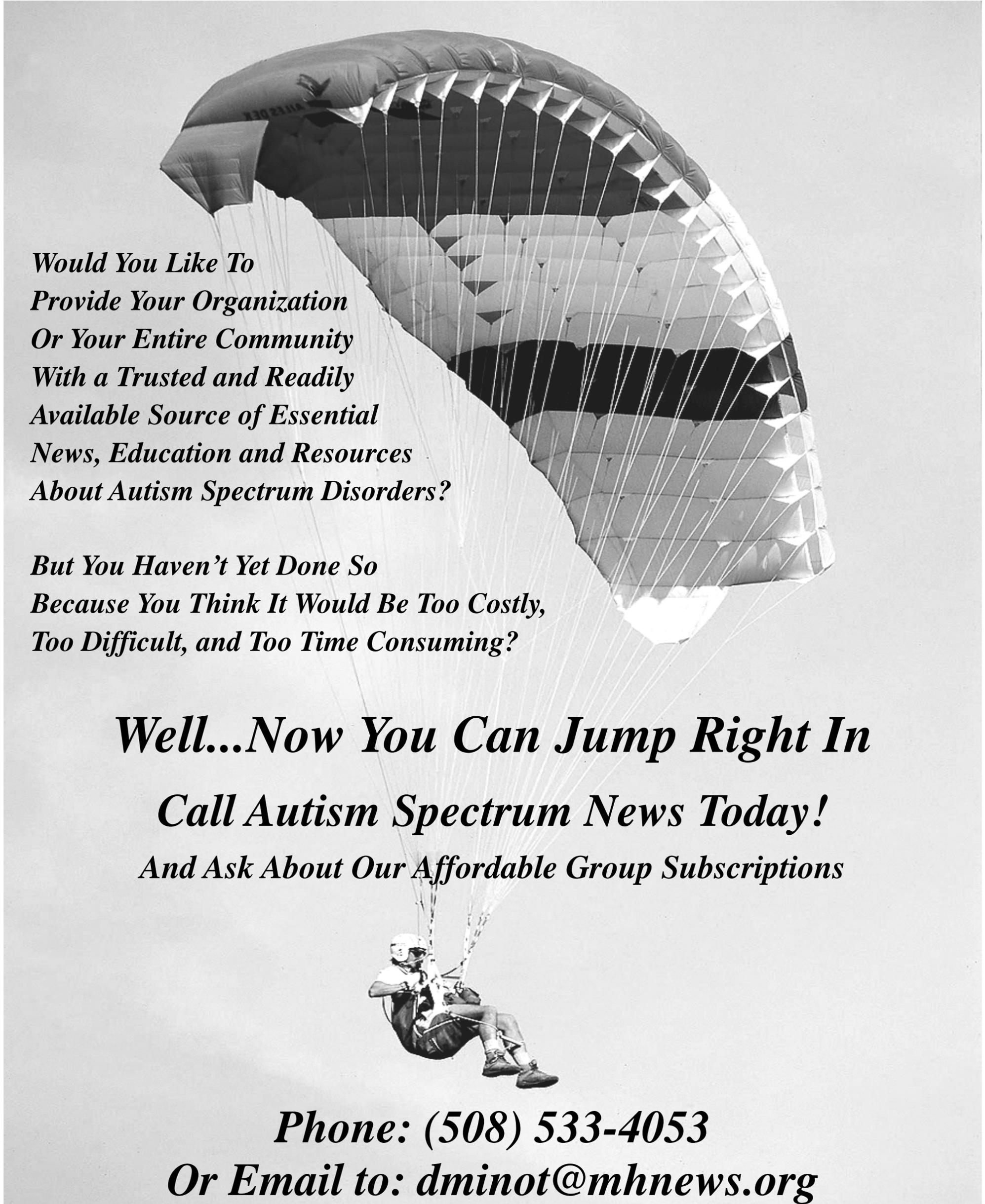
The final chapter of *The Asperger's Difference* is designed to help young adults with AS to develop self-advocacy by thinking about when to share their diagnosis with others. Viewers are invited to consider aspects of disclosure, such as the length and nature of a relationship, and the outcomes which may occur.

The Asperger's Difference can be watched by individuals with AS alone, in classrooms, with clinicians or family groups in its entirety, or discretely by stopping and starting chapters with the support of an instructor or therapist. The film, presented in a documentary format, has value for peers, siblings and others who are touched by autism. The accompanying discussion guide is intended to allow the viewer to personalize the information and experiences seen in the film. As many individuals with AS are strong visual learners, the film also plays to this

learning style through its graphic design, presented clearly and employing a series of Picture Communication Symbols (PCS) ©1981–2008 Mayer-Johnson, LLC.

The film is scheduled to be released this fall. A trailer for the film was recently shown at the New York State Regional Forum on Autism Awareness and generated considerable excitement in New York's autism community. Jamey Wolff credits the generous support of The Daniel Jordan Fiddle Foundation, The Hudson Foundation for Youth Health, Inc, and The Michael & Murtrude Hancouski Foundation for their support in the production of *The Asperger's Difference*.

Several regional screenings of the film are planned for the fall. For more information about the film screening schedule and purchasing *The Asperger's Difference* with its accompanying resource guide, call The Children's Annex at 845-336-2616.



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Foundation Launch from page 16

President of the American Academy of Pediatrics, an organization of more than 60,000 pediatricians dedicated to the health, safety and well being of infants, children, adolescents and young adults. "We welcome the chance to work closely with the Autism Science Foundation to improve the

lives of children diagnosed with autism."

Joining London and Singer on the Autism Science Foundation Board of Directors are Dr. Paul Offit, Chief of Infectious Diseases at Children's Hospital of Philadelphia and author of the critically acclaimed *Autism's False Prophets*; Bad Science, Risky Medicine and the Search for a Cure, and Michael Lewis, attorney,

mediator and grandfather of a child with autism. ASF's Scientific Advisory Board, still in formation, includes Dr. Emanuel DiCicco-Bloom (UMDNJ-Robert Wood Johnson Medical School; past program chair of the International Society for Autism Research); Dr. Ami Klin (Yale Child Study Center); Dr. Harold Koplewicz (NYU Child Study Center); Dr. Sharon

Humiston (University of Rochester); Dr. Eric London (NYS Institute for Basic Research in Developmental Disabilities and co-founder of NAAR); Dr. Catherine Lord (University of Michigan); and Dr. Matthew State (Yale Medical School).

To learn more about the Autism Science Foundation or to make a donation, visit www.autismsciencefoundation.org

Behavior Inventory from page 24

Practically, this means that if I have two different measurement instruments that both assess eye contact, for example, the scores from one instrument should be similar to the scores on the other.

So what is a continuous measure? Many clinical diagnoses are categorical (i.e., binary, or yes/no) classifications such as "normal" or "abnormal." But these classifications are often not very productive from a research perspective, can be difficult to interpret, and do not readily map onto the way behaviors occur in the natural environment, i.e., in a continuously varied manner. For example, impairments in social interaction can manifest themselves as varying degrees of shyness, aloofness, avoidance, or aggressiveness or a combination of these behaviors. Thus, our measures should also be continuous, providing a score, for example, that would be very low for shy people and very high for aggressive people.

What do I mean by standardization? Continuous measures used in a clinical context can only be interpreted if there is a reference against which the meaningfulness of the size of the scores can be interpreted. For example, IQ scores are easily understood because they are standardized against the "typical" population. Therefore, if two people receive IQ scores of 95 and 100, it tells us that they are actually quite similar to each other as well as to most people in the population (since most IQ tests are standardized such that "average" people will score somewhere between 85 and 115 but most will score 100). A person with a score of 145, however, is clearly not typical. IQ scores are also standardized for different age groups because adults can understand and do more things than children.

Many tools for assessing autism yield continuous measures of the severity of the disorder. However, most of them do not provide "standardized scores." Thus, there is no way to know, for example, if raw scores of 10 and 15 in two different people on an autism measure such as the Autism Diagnostic Interview-Revised [(ADI-R); (Lord, Rutter, & Le Couteur, 1994)] represent "normal" variation or an actual meaningful difference in severity. Related to this, such assessment tools are not age standardized. This is a critical issue since children with autism at age two do not behaviorally look the same as children with autism at age twelve.

Finally, most assessment tools for autism exclusively assess problem behaviors. These tools do not measure the person's abilities in socialization, communication, and play. There are several problems with this approach. First, there is no way to measure actual improvement or worsening in skills over time; only a change in problem behaviors can be assessed. Second, there is no way to differentiate sub-groups within the autism spectrum that differ mainly in their relative assets (e.g., Asper-

ger's cases that have intact language but poor social skills). Third, there is no way of identifying cases that differ on the basis of a relative lack of appropriate skills, and not the presence of unusual behaviors (e.g., language-impaired children).

For the above reasons, we developed the PDD Behavior Inventory (PDDBI) (Cohen, Schmidt-Lackner, Romanczyk, & Sudhalter, 2003; Cohen, 2003; Cohen & Sudhalter, 2005), a reliable and valid informant-based assessment tool standardized on a large, well-diagnosed sample of children, ages 2 to 12.5 years, with PDD. Informants can be parents or teachers, allowing the clinician to assess how these different informants, who have different life experiences with the child in different environments, perceive that child's strengths and weaknesses. Filling out the PDDBI is relatively straightforward (items are between the fifth- and eighth-grade reading level) and can be completed by most informants in about 30 to 45 minutes. Scores on the PDDBI are highly associated with other diagnostic measures of autism, such as the ADI-R.

PDDBI scores are standardized, taking the age of the child into account, and are continuous in nature, allowing the clinician to determine how similar a child is relative to others with autism of the same age, much like an IQ score. Structurally, the PDDBI measures problem behaviors typically seen in children with autism. It also measures assets that should be present in children with autism but often are not, specifically, their social communication skills. These measures of social communication skills are actually highly associated with IQ and provide information to the clinician as to how the child is likely to score on an IQ test.

Our studies indicate that the PDDBI provides both reliable (repeatable) and valid (it measures what it is supposed to measure) information on problem behaviors seen in autism, problem behaviors that appear in other disorders but can complicate the picture (e.g., anxiety, aggression, hyperactivity, sleeping problems), and social communication skills (e.g., social play, eye contact, shared attention, language and conversational skills). Thus, a "behavioral profile," rather than an all-or-none diagnosis, is provided.

Because the PDDBI assesses assets as well as deficits, it provides the clinician with information on existing skills and on skills that need to be developed. It also allows the psychiatrist or neurologist who may be administering medication to control behaviors or seizures, to assess whether or not the medication is causing a specific improvement in behavior problems and not just an overall decrease in behavior, including declines in social communication skills. As a result of the "No Child Left Behind Act" of 2001 and the "Individuals with Disabilities Education Improvement Act (IDEA)" of 2004, school psychologists need to monitor the child as part of the "Response to Interven-

tion" process. The PDDBI can be used for this purpose and is also useful in monitoring outcomes in clinical interventions (Ozonoff, Goodlin-Jones, & Solomon, 2005).

Additionally, since the PDDBI assesses behavior problems seen in other disorders as well as in autism, and because it is standardized on an autism sample, it is possible for the clinician to determine if these behavior problems are to be expected because the child has autism or whether the problems are unusually severe, even for a child with autism. The latter instance may indicate a need for further studies to diagnose possible medical problems (e.g., dental problems) causing an unusual increase in agitation, or may indicate that another behavioral disorder is present, e.g., a mood disorder.

At the New York State Institute for Research in Developmental Disabilities, we have found the PDDBI to be very helpful for research purposes. Using information provided by parents and teachers, for example, we have been able to confirm that a common variant of a gene on the X chromosome appears to modify the severity of autism in males (Cohen et al., 2003), and that children on the autism spectrum who have mothers with a lifetime history of two or more episodes of major depression tend to have better social communication skills than similar children whose mothers do not have this history. Interestingly, teachers see these same children as more anxious and inhibited than their peers (Cohen & Tsiouris, 2006). We suspect that this unanticipated observation is related to the first study because the gene variant we studied is more common in women who have recurrent depression. We would not have known of these effects of gene and depression on autism severity, however, had we not had an assessment tool like the PDDBI.

In short, the PDDBI is increasingly being accepted as a useful clinical and research tool that provides information not currently available from other assessment instruments.

The Asperger's Disorder Behavior Inventory

The company that publishes the PDDBI, Psychological Assessment Resources, Inc. (PAR), has reported increasing demand from school psychologists for an assessment tool that would be useful for "higher functioning" people with PDD, specifically those with the features of so-called Asperger's Disorder. As currently defined, these are people who have the characteristics of Autism but without the delay in language development and without the intellectual delay usually present in Autism. At the request of the publisher, I have developed a new assessment instrument explicitly designed for this type of individual. The current working title for this new measure is the Asperger's Disorder Behavior Inventory

(ADBI), and it is a modification of the PDDBI adapted for a more verbal group, assessing additional behavioral assets and deficits that can only be reported in such a group. PAR and I are gathering information on this new instrument in order to determine its reliability and validity.

We are looking for volunteers (parents and teachers) to participate in development of this assessment tool. Volunteers will receive a small monetary compensation for their time and effort. Information provided by these informants will be used to standardize the ADBI. Specifically, we are looking for parents and teachers of individuals, ages 5 to 21 years, who have been diagnosed by a clinical psychologist, school psychologist, or other health professional as having Asperger's, PDD-Not Otherwise Specified, or High Functioning Autism and have scores in the average to above average range on standardized tests of language ability. Participants will need to fill out the ADBI either in pencil and paper format or online. Parents will need to be willing to be interviewed about their child's behavior and developmental history.

We are also looking to administer the ADBI to the following clinical comparison groups - Attention Deficit Hyperactivity Disorder, Conduct Disorder, Social Phobia, Obsessive Compulsive Disorder, Reading Disability, and Nonverbal Learning Disability - so that we will be able to see how these groups are the same or different from our "Asperger's" group.

If you are a parent or professional interested in collaborating with us on this project, please send an e-mail to ADBI@parinc.com.

Summary

We have developed a new assessment tool for children on the autism spectrum, the PDDBI, which provides important information not available from other instruments. It is being used with increasing frequency by both clinicians and researchers to assist in diagnosis, plan interventions, monitor outcomes, and make treatment decisions. It should never, however, be used to make such decisions without observing the child, obtaining information from parents and other informants, and reviewing pertinent medical and psychological information. PDDBI profiles should provide guidance to the clinician as to what the presenting problems are as perceived by the informants, whether these profiles match the standardization sample, and whether the profiles and diagnostic predictions are consistent with those expected, on the basis of direct observation of the child.

Ira L. Cohen, PhD is the Chair of the Department of Psychology at the New York State Institute for Basic Research in Developmental Disabilities - New York State Office of Mental Retardation and Developmental Disabilities.

Life Coaching from page 26

looking at class offerings and requirements. They talked about finding a volunteer job that would help get Wendela out of the house. Within six months, she was volunteering for a small theatre arts organization, first going with the Life Coach and eventually going by herself. In the fall of 2007, Wendela enrolled in Empire State College, taking one course without credit. By spring she was taking a course for credit, and now she is taking two courses a semester working toward her associate's degree. Wendela decided she did not want mentors accompanying her to class but needed their support to encourage her to work through assignments.

Wendela now works two days a week at Job Path - paid for through an OMRDD funded internship - learning a range of clerical and data entry skills and developing social skills in the process. At each step, her Life Coaches have gently encouraged her to take the next step.

Meet Jon

Jon is a recent high school graduate and passionate collector of miniature fantasy figures. He is also a savvy seller on eBay, where he ac-

tions items from his collection to make room for new additions. Consistent with his Asperger's diagnosis, Jon had a narrow interest in pursuing these fantasy figures. Working with him required taking into account this preoccupation. We helped Jon look for ways to leverage his hobby into a paid position while trying to make more meaningful social and community connections. The Life-Coaching team worked with Jon, contacting gaming stores in New York about possible employment opportunities. Jon landed a job handling all aspects of eBay sales for one of New York's top gaming stores - from listing items to communicating with buyers to shipping merchandise. Jon worked with his coach, who helped him understand the social dynamics of the workplace, while assisting him with the technical side of the job. Jon has become a master with a tape gun! Jon worked at the store part-time for two years until recently when the store closed during the economic downturn. Currently, a Job Path Employment Specialist is following up on some promising leads at comic book stores that have shown an interest in hiring Jon for inventory and sales. Jon has also been exploring Goth culture while working on social skills and moving out into the community with the help of a Life Coach fa-

miliar with the world of Goth.

Finding His Place

"It honestly feels weird to finally be on a path of MY choosing," says Evan, a Life-Coaching participant. After struggling for years to find a place where he could further his education in his chosen field of graphic design, Evan has found the perfect environment at the New York City College of Technology in Brooklyn.

Job Path works with the faculty at the Advertising Design and Graphic Arts Department to ensure that Evan receives the support required for his success. This assistance has included finding internship opportunities for Evan, extra coaching and guidance in choosing courses and software. A Life-Coaching mentor attends classes with Evan and helps him navigate different aspects of college life. Evan says of the experience, "I think this is cool. As a differently-abled student, it is amazing to be accepted and valued."

Evan's mother Harriet says, "Job Path's Life-Coaching program has been transformative for Evan. Evan has a career goal, a stronger identity of himself as an artist and a growing sense of confidence and self satisfaction." During rare down time, Evan and his mentors visit galleries and

museums.

The driving mission in Evan's life is to develop his already prodigious art skills. Job Path linked him up with Pure Vision Arts studio in Manhattan, where Evan has had the opportunity to work in a variety of media and to showcase his work in their gallery. He also takes brush classes in the Japanese style of Sumi art, to which he is particularly drawn. In summing up his current life, Evan explains, "For the first time, I'm with people who just get it. Job Path has turned *me* into an artistic creation."

We anticipate the Life Coaching project will be able to sustain itself on government funding by the end of 2010. We expect to expand into a full scale project with ongoing enrollment of at least 30 adults. As individuals gain independence, we will be able to reduce their level of support and counseling and add new people, creating the individualized supports that allow them to participate in community and educational activities. Currently, four of our eighteen participants have paid jobs, three are in internships and seven are attending college or other classes. We agree with the assessment of one of our participants who summed up his life over the last 24 months in Life-Coaching by declaring: "Outstanding!"

Meeting the Needs from page 31

Social Skills: Individuals with autism spectrum disorders have well-documented deficits in social skills (e.g., Bellini, 2006; Matson, Matson, & River, 2007). Social skills can also have a large impact on how the individual is perceived and on the success of his or her integration into all types of settings.

Smith (2009) lists several skills that can be helpful to teach individuals with autism that may ease their entry into social settings. These include using social expressions such as please and thank you. It is also helpful to prepare individuals with autism for social expectations. For example, people will expect greetings to be reciprocated. Skills important in work settings include the ability to terminate conversations, the ability to graciously accept suggestions and corrections, and the ability to engage in basic daily social skills such as waiting and turn-taking. Another relevant skill is asking for help. While it may not be necessary for the person with autism to be competent in all aspects of their job assignments, it is essential that they can recruit assistance when they can not manage a task or situation independently. In addition, it is im-

portant to ensure that the individual has basic assertiveness skills. In schools, there is often a focus on ensuring that students can manage bullying or teasing. Similarly, it is important to ensure that an adult with autism can identify and navigate such circumstances.

The social skills to work on should be developed individually for the particular learner. As mentioned above, every environment will have unique social expectations and rules. A thorough assessment of the social expectations in the work environment should be done to guide the creation of goals. Instruction should occur in the targeted environment (Smith & Targett, 2009).

Furthermore, the individual with autism has to learn the hierarchical structure at work, and needs to be taught appropriate behaviors associated with degrees of power within the organization. These kinds of nuances are extremely important. Violations of these types of rules are not well tolerated in most environments.

Other behaviors are also influenced by degree of familiarity and workplace policies. In particular, behavior towards individuals of the other gender must fall within the boundaries of acceptable behavior within that organization. Individuals

with autism need to understand that certain behaviors may make people uncomfortable, that many messages are communicated nonverbally, and that people's preferences must be respected.

Attention to these issues is immensely important. It is more likely that individuals with autism will get into difficulties at work for interpersonal difficulties than they will for performance issues. Navigating the social world is essential to positive performance evaluations and retention.

Of course, part of what we need to do is help the broader community understand the special challenges faced by individuals with autism. Educating employers about autism increases the likelihood that they will understand behavioral difficulties and attribute behaviors to the disability. This will increase their tolerance and enable the employer and employee to work together to address issues.

Summary

People with autism require lifelong services. As adolescents and adults, they experience challenging behaviors that may occur at a higher or more dangerous level than during childhood. Difficulties in adoles-

cence and adulthood are intensified by a paucity of appropriate and individualized services and poor transition planning. The careful attention to programming and to transitioning that is available in childhood is less available to adolescents and adults. Furthermore, the social environment is more complex and there is less tolerance for socially aberrant behaviors in older learners.

Programming for adolescents and adults needs to take these factors into account. Attention must be paid to effective transition planning, the development of critical social survival skills, and the management of challenging behaviors. Efforts must also be made to educate the broader community about the needs and potential contributions of people with autism spectrum disorders.

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Point Program from page 33

expenses. In order to cover the program services, an annual fee has been established for all participants.

JCCA and WJCS also are working

with the parent group to seek additional funding to keep the costs as low as possible. The agencies and parents will continue to develop and enhance the program design and secure participant benefits and funding - always

focused on enhancing the independence of each participant, building community among the members, and integrating the participants in all aspects of society.

Recently POINT has begun recruit-

ment efforts for additional members. Anyone interested in finding out more about the POINT Program can contact Kevin Gorrasi, Program Director at kgorrasi@wjcs.com or 914-761-0600 ext. 175.

Can Do from page 1

much tragedy in our autism/asperger world, alarmist campaigns citing only said tragedy cause psychological harm to a population already psychologically challenged enough as it is. Messages of hope, acceptance, and accommodation are not only nicer to the adults (and children) being discussed, such affirmations will be of far greater spiritual benefit to the messenger as well.

I have the privilege of running GRASP—The Global and Regional Asperger Syndrome Partnership—the largest organization in the world composed of, and run by, adults on the spectrum diagnosed with Asperger Syndrome (AS), Autism, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Before both I and my then four year-old son were diagnosed with AS in late 2000, I was a starving playwright by night, and a minor, minor-league diplomat at the U.N. by day, working on projects in places like Bosnia and pre-invasion Iraq. I was lucky. I had proof, not the faith-based



Michael John Carley

words of self-help spin, telling me that I'd enjoyed something close to "a life" before that life-changing diagnosis at age 36.

Mine was the gift of conviction, not hope.

Quickly after making such a dramatic career change, I started to hear the plethora of stories coming from the adults that visited our nationwide network of peer-run support groups. Yes, there were stories of misfortune that paralyzed the listener. Stories of misdiagnosis leading to misprescribed pharmaceuticals, stories of consistently misinterpreted intentions... stories of giant mistakes made over the years that had irreparable consequences. One quickly could see that the depression, anxiety, and sometimes anger that existed now didn't need to be there; and wouldn't have, given a world that knew what it was doing.

But there were also tales of unbelievable heroism and resilience that taught me more than the most exhilarating war stories heard abroad in my earlier life. There were stories about learning how to trust, stories telling of smart choices concerning when to assimilate to the rest of the world's way of doing things, and stories about when not to.

I, and everyone else at GRASP, have consequently developed a rather large,

and sometimes overwhelming, sense of purpose. And yet, that sense of purpose is not to be interpreted as mired in sympathy. Given the talents, and the sometimes unreal abilities of people on the spectrum, of all the marginalized populations there are on this earth, *this* one can benefit greater society the most if better understood, if better accommodated, and thereafter more respected. Working on behalf of adults on the spectrum is clearly akin to working on behalf of everyone.

Let's be real: who in their right mind *wants* to be ignorant, scared, or in fewer cases, prejudiced against people with neurological differences? Think of the loss of anxiety we'd *all* enjoy in such a world. Binding those on the spectrum, and those off, is that we all fear the unknown.

*In addition to his duties as the Executive Director of GRASP (www.grasp.org), Michael John Carley is also the author of *Asperger's From the Inside-Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* (Penguin/Perigee).*

Guardianship from page 17

when you ask the court to appoint you as full guardian over your special child.

When the hearing date comes, you and your attorney will attend the hearing, as will the guardian ad litem. At that hearing, the judge will listen to your evidence. In most cases, your doctors do not have come in and testify. The judge will accept their sworn statements. You will likely have to testify as to why you think you should be appointed guardian. You will also have to satisfy the judge that you understand the full impact of the role you will undertake. This is normally not difficult; after all, you have been acting as your child's guardian all her life. The only real difference is that she is now 18.

The judge will ask the guardian ad litem to confirm that full guardianship is appropriate. Assuming there are no new developments since the guardian ad litem filed the report, the guardian ad litem will generally confirm the appropriateness of the appointment. If the judge is satisfied, then an order appointing you as full guardian will be issued. You will have to report back to the court (usually annually) regarding the status of your child/ward, including providing a report on how you have handled the child's financial matters. While this may seem a bit of a nuisance, this is an important protection for your child. You only have to read the papers to see incidents where a guardian abused the ward to know that such protection is very valuable for your child. After all, you may not be around forever. Someday, someone else may have to step up to act as guardian for your child. You would certainly want the court to be looking over that person's shoulder, watching out for your child!

Sometimes, the special child may not be so incapacitated as to require a full guardianship. For example, if your child is able to attend a regular school, then a full guardianship may not be available to you since a child that can handle school activities may not be so disabled as to be unable to handle any of her own affairs. She may only have a mild disability, and be able to make some decisions for herself but, for

example, cannot manage her own assets. In that case, a more limited guardianship over only her assets, but not her person, may be appropriate.

Many states allow for such partial or limited guardianships. In those states, you may be able to request more limited authority over your child. Courts in those states that allow limited guardianships try to create a guardianship that gives you authority over areas where your special child needs protection, but allows her to retain as much autonomy and control over her affairs as is possible. The procedures for seeking limited guardianship are much the same as in a full guardianship, except that the scope of authority you request is more specifically crafted for the abilities of your special child.

Alternatives to Guardianship

Just because a child has disabilities does not automatically make her a candidate for guardianship. A judge will not appoint a guardian for a special child with disabilities who otherwise has sufficient mental capacity to manage her own affairs. However, if your child has enough mental capacity that a guardianship is not appropriate, but still needs help in managing her affairs, there are several alternatives.

Some states have a procedure, sometimes referred to as a conservatorship where a conservator is appointed to manage the financial affairs of an otherwise legally competent adult who by reason of advanced age, illness or physical infirmity, is unable to manage his or her own financial affairs (such a person is sometimes called a conservatee).

The process for seeking appointment as a conservator is similar to the process for seeking appointment as a guardian of the property, with one key difference: unlike in a guardianship proceeding, in a conservatorship, there is no requirement that the conservatee be found legally incompetent, only that she is unable to manage her financial affairs due to advanced age, illness or infirmity. As a result, the conservatee does not lose any of her civil rights, since there has been no determina-

tion of legal incompetency. The conservatee may consent to the appointment of a conservator to manage her financial affairs. In fact, the conservatee may actually start the conservatorship process herself. A conservatorship may be a good alternative to guardianship of the property where the child is mentally competent but there are concerns regarding his/her ability to manage money.

Another alternative to consider once she turns 18 is for her to sign a Durable Financial Power of Attorney authorizing you to handle her financial affairs. A Durable Financial Power of Attorney is a document that gives another person the right to manage and dispose of your property in the same manner as you could. The recipient of the Power is called the "attorney-in-fact." If the child with special needs has sufficient mental capacity, she can grant power of attorney to one or both of her parents. This will allow the parents to handle the child's financial affairs without the need to appoint a guardian or a conservator.

Keep in mind that, even if the special child grants her parents the authority to act as her attorneys-in-fact, this does not prevent her from taking actions on her own behalf. In addition, since she has sufficient mental competence to grant a Durable Power of Attorney, she can also revoke the Power it at any time. Thus, it is important that parents and child maintain a good and trusting working relationship.

The situation differs when dealing with medical decision making. As a general rule, if a person has the mental capacity to make medical decisions on her own behalf, the person will make her own decisions. This is equally true for the child with special needs. If she has sufficient mental capacity to make her own decisions regarding matters of health, the call will be hers. This does not mean that the parents cannot participate in medical decisions. However, in order to do so, the parents must have the child's permission to discuss her medical matters with doctors and other health care providers. The child can simply sign a consent allowing the child's medical caregivers to give

medical information to the parents.

The child with special needs should also appoint one or both of her parents as her health care representatives to give them the clear right to make medical decisions for her if she becomes incapacitated. She does this by signing a Health Care Proxy, a document similar in concept to the Durable Financial Power of Attorney, except that it relates solely to health care. The person to whom the decision-making power is given is sometimes called the "health care representative" or "health care proxy."

In similar fashion, the special child can grant her parents permission to interact with her teachers and other persons involved in her education in connection with her individual education plan and transition planning. Most schools have forms available for the child to sign upon turning 18.

A note of caution about seeking guardianship or conservatorship: although you can go to court without an attorney, the rules and procedures for obtaining guardianship or conservatorship can be quite complex. This is not a good area for the uninitiated. However, if your child is developmentally disabled, your state or local office serving persons with developmental disabilities may assist you in obtaining guardianship for your child. A developmental disability is generally defined as a severe disability which started at birth or developed during childhood, which the disability will continue indefinitely and seriously adversely affect the child's ability to function in life.

Summary

In summary, as your special child approaches 18, you should: (1) evaluate what level of independence she can achieve in her lifetime, (2) consider to what extent a full or partial guardianship may be needed and begin the process, and (3) if a guardianship is not appropriate, make the necessary arrangements for your special child to give you her power of attorney and appoint you as her health care representative. In this way, you can continue to support and protect your special child.

Planning from page 27

materialize, there is always the question of what happens if one of the healthy children becomes disabled or predeceases the Special Needs child. Who takes over then, and how does a Special Needs child get any money if that were to occur?

Create a Supplemental Needs Trust: The good news is that parents of Special Needs children have a third option to consider. They can establish a Supplemental Needs Trust. A Supplemental Needs Trust holds the inheritance for the Special Needs person, but it doesn't result in a loss of benefits. Any benefits paid by Medicaid do not need to be reimbursed at the death of the Special Needs person. The trust assets are not subject to the creditors or divorcing spouses of the Special Needs person, of his or her siblings. A Supplemental Needs Trust also allows for the professional management of the trust assets.

The Supplemental Needs Trust: There are two kinds of Supplemental Needs Trusts. They are known as First Party Trusts and Third Party Trusts.

First Party Trust: One kind of First Party Trust is known as (d)(4)(A) Supplemental Needs Trust. We use this kind of trust in situations where parents have failed to plan, and we now need to try to prevent the Special Needs child from losing his government assistance. These trusts are created to hold inheritances or the proceeds from litigation where a disabled person is compensated for injuries. These kinds of trusts must be created by the parent, grandparent, a guardian of the Special Needs child or by the court. The major

disadvantage of a (d)(4)(A) Trust is that Medicaid must be reimbursed from whatever is left in the trust upon the death of the Special Needs child.

Another type of First Party Special Needs Trust is known as a (d)(4)(C) Trust or "Pooled Special Needs Trust." These trusts are also formed to hold inheritances or litigation proceeds. They are formed by charities that work with disabled people. The charity manages the funds for the benefit of the Special Needs person. When the disabled person dies, the charity gets to keep at least some of what is left in the trust.

Third Party Supplemental Needs Trust: Third Party Special Needs Trusts are created by parents, grandparents or other interested parties, as part of their estate plan. These trusts are not considered available for SSI purposes because they are fully discretionary, meaning that the trustee has the choice of whether or not to use the funds to assist the Special Needs person. Since these trusts are not First Party Trusts, none of the trust remainder needs to be used to repay Medicaid.

A Third Party Trust can be a part of your Will or Revocable Living Trust. It can also be created as a separate "Stand Alone" Trust. Many clients like to have the trust drafted as a "Stand Alone Trust" because then it allows for more than one person to make donations to it, such as parents, grandparents, uncles, aunts, brothers, sisters and others. A "Stand Alone" Trust can be funded during life or at death. If it is to be funded at death, some parents and grandparents use their life insurance or retirement assets as the means of providing for the funding of the Supplemental Needs Trust.

Problems and Pitfalls of Administering Supplemental Needs Trusts

Distributions: As we learned previously, distributions of cash to a Special Needs child can cause him or her to lose government assistance or have the amount of their government assistance reduced. As a result, the trustee of a Supplemental Needs Trust must be aware of what distributions can or cannot be made. Sometimes credit cards can help in the administration of a Supplemental Needs Trust. For example, if the Special Needs person can qualify for a credit card with a \$500-\$1,000 limit, it may be possible to have the trust payoff the card on a monthly basis. Since the card balance is a debt of the Special Needs person, we don't have to worry about the ISM penalty, and the Special Needs person doesn't have to be making requests for distribution to the trustee on a frequent basis.

As mentioned previously, payment of housing expenses and groceries would be considered ISM, and would result in a reduction in the Special Needs person's SSI benefit and possible disqualification from Medicaid and other benefits. Does this mean that a trustee should never pay for housing costs from a Special Needs Trust? No. There are many circumstances where the payment of housing costs is of greater benefit than the reduction in benefits that result from it.

Selecting Your Trustee: One of the most important decisions in creating a Special Needs Trust is selecting the Trustee: (a) Do you make the Special Needs person's siblings or other trusted relatives the trustee? (b) Will the trustee

have knowledge of these rules or the time and patience to learn them? (c) What happens if they become unavailable to serve as trustee? One consideration when naming family trustees is to name a special Co-Trustee, such as the drafting attorney or other knowledgeable professional to advise these trustees. What about naming an attorney or a CPA, or a financial Planner or other professional to serve as trustee? This can often be a good idea.

However, just because these persons are professionals doesn't mean they have the special knowledge to manage a Supplemental Needs Trust. And even if they do, who will serve if they are not able to do so? As with family members serving as trustees, it might make sense to name a Special Co-Trustee to serve as an advisor to the professional fiduciary.

A third alternative to serve as trustee is a bank or trust company. These institutions have experience managing money and sometimes have employees experienced in administering Supplemental Needs Trusts. As with the other options, you can always name a Special Co-Trustee to assist the bank or trust company with technical questions.

Mr. Levine received his B.S. degree from New York University and his J.D. degree from St. John's University School of Law. Mr. Levine was an Editor of the Law Review. Mr. Levine has been a member of the New York Bar since 1973, and is admitted to practice law before the federal courts of the Southern and Eastern Districts of New York. Mr. Levine is a member of the American Academy of Estate Planning Attorneys and the New York City Bar Association.

Therapy from page 15

have gone wrong, or uncertain as to what is okay to accept in one's own behaviors. Their minds tend to work overtime, re-playing and rethinking past interactions. I call it "flypaper brain." Thus forgiving oneself and others is frequently a challenging task that might need to be addressed. Sometimes, simply listening patiently to the play-by-play of a troublesome past experience eventually reduces the energy attached to that story and thus it fades away. Other times, I may help a person lessen their personal suffering by a combination of teaching methods for controlling mind chatter and reframing past experience so that it can be understood and viewed from a different perspective.

Sometimes an important issue is coming to terms with the diagnosis itself: understanding what AS is, and what it

means for understanding and accepting one's self and one's relationships with others. One of my clients was recently diagnosed as an older adult. His wife, however, refused to accept the diagnosis as a way of understanding some of his different behaviors, saying: "You don't have Asperger's. You're just an ass!" Helping this client understand that some of his behaviors were shared among many on the spectrum allowed him to become more self-confident in dealing with his challenging spouse despite her resistance.

Another area to address is learning to cope with stress and anxiety. I offer a variety of cognitive and behavioral strategies including breathing, relaxation, movement and physical activity. I also help a person create and maintain a sustainable lifestyle that honors the individual's interests, pleasures, and source of meaning, whether it be a sense of belong-

ing or contributing to society, expressing their connection to and gratitude for the earth upon which we all depend, or pursuing a deeply felt passion.

Although perhaps obvious, it is still important to mention that understanding social relationships, recognizing and expressing emotions, dealing with typical people, and developing a workable orientation to social norms and customs are usually important components of doing therapy with people with AS. In this area I do my best to offer honest, direct and sensitive feedback. I give concrete suggestions, specific explanations, help decode language and customs that may be perceived as alien, and offer opportunities to practice through role-playing.

Sadly, there are still insufficient numbers of therapists well versed in working with AS, leaving too many individuals with AS with limited options for support. I urge other therapists to consider this

work. I am currently writing a book on the topic in the hopes that the little I know can be shared and help remedy for the lack of trained, sensitive and caring providers for adults with Asperger's Syndrome.

Dr. Irene Brody is a psychologist in private practice specializing in children, adolescents, and adults with Asperger's Syndrome and High Functioning Autism. Dr. Brody has been leading social skills groups since 2000. She developed the clinical and social skills program for the ASPIE Program, an innovative model school for high-functioning autistic teens. Dr. Brody has consulted for the NYU Child Study Center's Asperger Institute, as well as for numerous public schools. Dr. Brody also offers training and supervision to professionals, teachers, and para-professionals. Dr. Brody received her PhD in clinical psychology from City University of New York in 1989.

Exercise from page 30

are key to maintaining motivation.

The pedometers can be incorporated in other activities such as using a tread mill or other exercise equipment. Even video games such as Wii games, Wii Fit and Dance, Dance, Revolution can be used to motivate pedometer users to exercise in a fun way. In inclement weather, stair climbing contests can be used not only to get the pedometer numbers up, but also

the heart rates of the participants.

At New York Institute of Technology Vocational Independence Program we began a pedometer program this academic year. The students were involved in the planning and selection of incentives. Each class, (Freshmen, Sophomores, and Juniors), were competing against each other and the staff as well as competing individually. Class prizes included parties and trips. Individual prizes included t-shirts, sweatshirts, free movie passes, and

I-Tune gift cards. The grand prize for the student body upon reaching their ultimate goal was the opportunity to shave the head of the dean of the program. In less than two semesters the students and staff walked over 48 million steps which was approximately 21,000 miles. This was the equivalent of walking due east from our Central Islip campus to Australia for a rest stop and then proceeding to Los Angeles, CA. Participants in the program were in better shape and lost weight as a result

walking 10,000 steps a day.

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).

College Coaching from page 36

life picture and helps the student grapple with whatever parts need support. While there may be many aspects that need support, the coach helps the student learn how to prioritize and choose goals, creating an achievable plan with incremental steps appropriate to the student's current level of functioning. Most importantly, coaches teach students new ways of behaving through the joint effort of problem solving, systematic goal creation and personal monitoring and responsibility. These skills are critical to independent functioning, yet are often not taught through any past experiences. A coach

may help a student develop organizational strategies, role play appropriate classroom behavior, or brainstorm about how to choose a social activity, but the underlying learning that occurs through the relationship paves the way to independence.

How Can Families Access Coaching?

It is important that college coaches have knowledge of autism spectrum conditions, the demands of college, and the field of coaching. Families should not assume that someone has this knowledge and need to remember that coaching is not a regulated profession and anyone may advertise as a coach. Recommendations

from those who have utilized a specific coach may be helpful or a family may want to sponsor an appropriate individual to take additional training. Some college disability offices may be able to recommend someone who has worked in this capacity or who is willing to be trained. This search needs to begin before the college year starts and perhaps before the college selection process begins to insure a smooth transition. Many coaches work only by telephone and internet, but face to face meetings, especially at first, are an important aspect for students with Asperger Syndrome. It is important to remember that coaching is not therapy but is a personal relationship and a learning ex-

perience. The need for this service is increasing and we hope the field will expand to meet the demand.

Lynda Geller, PhD, is Director of the Institute for Cognitive Diversity at the Bank Street College of Education. Dr. Geller is also working on developing the Asperger Center for Education and Training, a collaborative effort designed to provide evidence-based, practical, current information about Asperger Syndrome and related conditions and appropriate treatments and to develop and provide innovative services to the community of children and adults with Asperger Syndrome and their families.

Recover from page 40**What Effect does Treatment Have?**

Earlier diagnosis and treatment are also favorable factors for OO, and most recovery

is reported in the context of intensive behavioral intervention. Behavior therapy, ABA being the best studied to date, is the most evidence-based and most likely to produce OO. Theoretically, treatment could facilitate recovery by forcing a child's attention out-

ward or by enriching the environment, promoting the value of social stimuli, preventing interfering behaviors (like stimming), and/or practicing of weak skills.

Overall, there is evidence for recovery in a subgroup of the ASD population.

While subtle problems often persist they do not interfere with normal life. We know a bit about who is most likely to have an optimum outcome and how to facilitate it, but clearly there is much to be done to improve the odds.

Geneticist from page 46

should be tested for *MECP2* associated disorder (Rett syndrome).

According to Schaefer and Mendelsohn, the aggregate result of tier 1 testing is that between 22 and 33% of individuals with primary ASD would have an identifiable cause of their condition. This includes between 10 and 15% with CNVs, 5% with fragile X, 2 to 3% with *MECP2*-related disorders, and 5 to 10% with other causes.

Based on results received, following this first tier, a second tier of testing should be performed. As noted in Table

2, if the results of metabolic testing are abnormal, a more complete evaluation is needed to pinpoint the specific error in metabolism. If a CNV or genetic mutation is identified in the proband, the parents should be tested to see if this is inherited or occurred *de novo* (spontaneously).

Finally, depending on the results of the tier 2 testing, a group of tests in the third tier might be performed. This includes the performance of an MRI to identify an underlying structural brain anomaly, more complete metabolic testing, and, as indicated, DNA testing of additional members of the proband's family.

Counseling

Following completion of this work-up, the family is invited back for genetic counseling. If a specific etiology, such as fragile X, has been identified, counseling is provided for that condition. If the proband has primary autism and work-up has revealed a genetic cause, such as a CNV that is not present in either parent, a low recurrence risk, on the order of 1%, can be cited. If the work-up has failed to reveal any genetic cause, an empiric recurrence risk for full siblings of 4% if the proband is female, and 7% if the proband is male, can be given. If it has been found

that two children in the family are affected, the empiric recurrence risk rises to between 25 to 35%. This visit is also an opportunity for the family to ask questions of the geneticist.

Follow-up with the geneticist is necessary, especially when no underlying etiology has been identified. Because technology in the field of clinical genetics is advancing so rapidly, it is possible that new tests will become available that will identify an etiology in children in whom currently no etiology is identifiable. For this reason, periodic reevaluation on an annual or biannual basis is important.

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Research Initiative from page 8

for individuals with which abilities? Are adults with ASD facing discrimination in the workplace? How much assistance from caregivers is needed with functional daily living skills – everything from toileting to balancing check books? Are adults with ASD content with their living situations?

Social Settings: What type of support do adults with ASD receive in social set-

Young Adulthood from page 39

regular opportunity for interaction and social learning that a high school environment provides. Less structured college and occupational programs often require individuals to be proactive and independently seek out social contact, which can be very challenging for individuals with ASDs.

- Generalization of skills into a variety of settings and with a variety of people is essential for success in everyday tasks. There is a whole new “hidden curriculum” for adulthood that includes social norms that individuals with ASDs may not be familiar with. For example, a young adult who decides to live independently may not know what to do if there is a flood in his bathroom because this is not something he or she has been explicitly taught. While typical young adults may have learned how to handle such a situation by observing parents or others with a similar issue, individuals with ASDs are less likely to have benefitted from this form of social learning. We need to teach these individuals specific life skills such as how to call and interact with a plumber.

The Many Domains of Social Skills

There are many aspects of social skills and social communication that are important, and each individual may present with relative strengths and weaknesses across the various areas. For youth, there are many standardized assessments that professionals can use to evaluate an individual’s current social skills set and generate a “social profile” (e.g., *Social Responsiveness Scale*, *Social Skills Improvement System*) to determine what areas to target in social skills programming. However, there are limited resources for assessing social skills in adulthood. Some of the aspects of social skills that are important to evaluate include: *social awareness* (ability to pick up on social cues), *social cognition* (ability to interpret social cues once they are detected), *social communication* (expressive and receptive social communication including turn-taking, inference, perspective taking, conversation skills), *social motivation* (extent to which individual is motivated to engage in interpersonal behaviour), and *social problem solving* (individual’s ability to generate and carry out effective solutions to social situations that arise). Goals you may choose to work on would be very different for an individual who is socially aware and motivated than for an individual who is also socially aware, but is not at all interested in engaging with others.

tings? Are they content with their relationships?

Financial/Health Care: What type of financial support are adults with ASD receiving (e.g., Medicaid and Supplemental Security Income)? Do they have access to medical, dental, and mental health care?

Newly armed with information provided by adults with ASD from all across the nation, researchers will gain a better understanding of ASDs across the life span. At the same time, advocates and

Related skills that are part of social functioning are also critical to evaluate including hygiene and grooming, coping skills, organization and time management, emotional understanding, and behavioral regulation. For bright conversationally verbal adults, many of these skills will need to be assessed informally as part of a session with a speech-language pathologist or a psychologist.

**We Know it’s Important,
So How Do We Make it Happen?**

There are a number of obstacles to creating and participating in effective social skills programming for young adults with ASDs. For example, we hear from many parents that their son or daughter often experiences group “burn out”; they participated in many groups when they were younger and are now feeling “done with groups.” These feelings are also often associated with a desire to be independent, to be seen as capable, and as such, teens and young adults may be left feeling reluctant to continue in formalized group programs that emphasize deficits rather than strengths. Young adults with ASDs may also be reluctant to engage in social skills programming as a result of years of unsuccessful and often emotionally painful social experiences.

In our experience, social skills for teens and adults must be taught within the context of appreciating and understanding the interests and goals of the individual with ASD. Related to this, emphasis on “why” social skills are critical, and not just presenting the “how to do them” or “what to do” is very important. For example, we saw an older adolescent in individual therapy who did not want to leave his house or socialize with anyone; he really wasn’t interested. However, he did want to go to college and he had professional career goals. Initial therapy sessions were aimed towards establishing “buy-in” – why is it important for me to learn social skills and interact with others? When he was able to make the connection between his career goals and the social experiences and skills he needed to meet those goals, he was able to recognize why working on social communication was going to be important. Bottom line though – being social to be social and have friends was not of interest to him. Your goals as a parent or a professional may not match your child’s or client/student’s goals. All people require an understanding of why a skill is important and how it is related to their aspirations before they will be willing to put forth effort in learning. Before specific skills are taught, programming needs to emphasize how influential adequate communication can be on the fulfillment of their life goals.

policymakers will be empowered to improve programs and policies impacting these adults.

Local and National Research Studies

Adults will also be matched with local and national research studies for which they qualify. Researchers will ask the IAN Project to help them find willing participants for their adult-focused studies; the IAN Project will let registered adults know about studies they are eligible to

What Kinds of Opportunities for Social Skill Development are Available?

There are many kinds of opportunities for continuing to work on social skills in late adolescence and adulthood:

- Formal or informal social skills groups may still be appropriate depending on interest and ability
- Community-based group participation can assist with generalizing skills and learning in natural environments (e.g., bowling league, movie club, chess club)
- Peer-mediated support groups led by facilitators who have ASDs themselves
- Incidental learning – capitalizing on naturally occurring situations to teach skills. For example, a flood in your bathroom is a situation where an individual with ASD can learn directly what to do if this were to happen to him or her.
- Self-directed learning – reading books, watching films
- Individual therapy or counselling

Choosing a Social Skills Group

What can often make or break the success of a social skills group experience is the actual group itself. Though there are many social skills groups offered in the community, not all are created in a way that facilitates a positive learning experience for group participants. Relevant issues for adolescent and adult groups include:

- Compatibility of group members: how are group members selected? Is there a screening process?
- Appropriateness of group curriculum: what skills are being targeted and are they relevant for your child?
- Efforts to facilitate generalization of skills: home activities to complete, conveying information to parents and caregivers
- Gender mix of the group: for some individuals mixed gender will make sense and for others single gender groups will be most appropriate. Importantly, the nature of the topics discussed should guide the gender makeup of the group.
- Shared decision making between group facilitators and participants that demonstrates a desire for a respectful working partnership

join. (It is up to the adult and his or her family to decide if they want to contact any specific researcher. The IAN Project does not give names, emails, or other contact information to researchers.)

We encourage everyone, and especially adults with ASD and their parents, grandparents, siblings, and friends, to spread the word about the inclusion of adults in the IAN Project. It is past time that there was more information about the situation of adults with ASD in the United States.

- Formal and informal opportunities for building skills
- Balance between focusing on strengths and identifying areas of difficulty
- Monitoring of progress towards individualized and group goals
- Core foundations for teaching including problem-solving, critical thinking and self-awareness, understanding, and monitoring. As well, the types of strategies and techniques used to teach these foundations (e.g. role-playing, visual examples).

Unfortunately there are no ideal groups that will meet everyone’s needs. Be thoughtful in your approach to deciding what social skills learning opportunities will be helpful. Will your son or daughter benefit most from attending a group or working one-on-one with a therapist? Should the group be formal or informal, community or center-based? And remember to include your child in the decision making. By listening, guiding, and coaching, you will make huge strides towards developing your child’s confidence, self-efficacy and self-determination. The journey from adolescence into adulthood may not be an easy one, but being part of a collaborative team can make the new experiences and challenges less daunting and more enjoyable!

Book Resources

- Autobiographies by adults with ASDs
- Asperger’s Guides (Social, Personal, Love) by Genevieve Edmonds, Lucky Duck Publishing
- Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger’s Syndrome, by Jed Baker, AAPC

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For more information regarding individual and group teen, young adult, and adult social skills programming offered 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.

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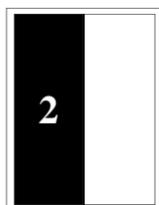
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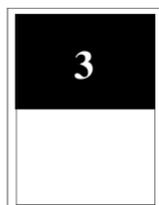
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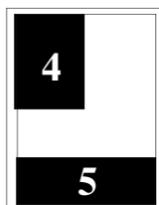
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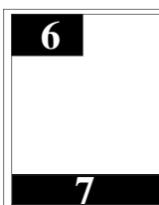
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