Addressing the Growing Needs of Adults

Transition Planning for Learners with Autism Spectrum Disorders

By Peter F. Gerhardt, EdD, Mary Jane Weiss, PhD, and Ceece McCarton, MD
The McCarton Foundation

Individuals with autism spectrum disorders receive tremendous amounts of specialized intervention during their educational years. During that time, the focus is generally on skill acquisition and behavior reduction, with a general goal of increasing competence. These interventions are often not guided by a vision of the future - by a sense of where those individuals are going, of the environments they will integrate into, of the individuals’ preferences, and of the skills that will be essential to be successful in those environments.

Logistical challenges create real obstacles as well, in terms of coordinating transition planning into adulthood. Although most states and school districts recognize the importance of coordinating transition planning with the adult services system, challenges relating to the availability of funding, the length and type of services available, extensive waiting lists, and access to reliable transportation remain significant obstacles. In short, the best planning cannot overcome the absence of programming on the other side of transition. Despite these challenges, a primary focus of transition “must be on assisting agencies to work more efficiently in coordination with one another” (Bates, Bronkema, Ames & Hess, 1997, p. 128).

How do we prepare learners with ASD for adult life? What are the critical competencies? What should guide educational programming in later years?

Definition of Adulthood

In the United States, adulthood tends to be defined along a number of dimensions. These would include what one does for a living, where and how one lives (e.g., urban v. suburban v. rural), one’s membership in religious/community organizations, who one considers to be...

see Growing Needs on page 24

An Autism Spectrum News Interview with Linda Walder Fiddle, Esq.
Founder and Executive Director of The Daniel Jordan Fiddle Foundation

By David H. Minot, BA
Associate Director
Autism Spectrum News

With the prevalence of autism on the rise, the number of adults living with autism is also increasing. The pace of the development of programs and services has not kept up with the growing needs of adults with autism spectrum disorders to enable them to participate in and contribute to community life. More energy must be devoted towards the adult population to address their unmet needs, and nobody is more aware of that than Linda Walder Fiddle, Esq, Founder and Executive Director of The Daniel Jordan Fiddle Foundation. Inspired by her son Danny who passed away a decade ago, and her concerns during his lifetime for his future as an adult, Linda is a devoted advocate for adults with autism and, through her Foundation’s vital work, has helped develop and support many of the programs that exist now for adults across the country.

Linda is changing the landscape of services for adults living with autism with The Daniel Jordan Fiddle Foundation’s new Signature Grant Programs that ultimately will lead to the creation of blueprints for organizations across the country to utilize for their own development of adult autism programs. The model adult programs developed and funded by The Daniel Jordan Fiddle Foundation can be found throughout the United States and include residential, vocational, educational and recreational opportunities that are suitable and sustainable. The Daniel Jordan Fiddle Foundation is at the forefront of the “adult autism movement,” not only as advocates but also as an organization that is addressing this challenge in tangible ways that affect lives.

Q: Tell us about the history and mission of The Daniel Jordan Fiddle Foundation and why you decided to focus on adults with autism.

A: The Daniel Jordan Fiddle Foundation’s first collaborative programs began in 2002 and initiated our focus on addressing the need for increased advocacy and services for adults with autism spectrum disorders. At that time our organization was the only one in the country even talking about the adult population.

My son Danny passed away at age 9. During his lifetime, he attended wonderful schools and I knew that he was going to get a good education and the supports and services that he needed. But even when he was that young, I was concerned about what would happen to him when he became an adult. Once I began researching to learn what was available, it became clear that there were very few programs and services for adults living with autism. There were some services for adults with various challenges, but few focused solely on adults living with autism.

After Danny passed away, friends and family urged me to continue as an advocate for people living with autism because of how deeply I care about the incredible individuals and families in the autism community. Eventually, I decided that this was indeed something I was committed to, so with the support of family and friends, The Daniel Jordan Fiddle Foundation was established as a public foundation. From the very beginning, the Foundation’s Board of Trustees determined that our exclusive focus would be on adults and young adults as they transition to adult life. No other national organization was focusing exclusively on adults and our Board had the foresight to embrace the vision I had to create opportunities for full and productive lives for the diverse population of adults on the spectrum.

The Daniel Jordan Fiddle Foundation is what I would call a “hybrid organization” in the sense that we are not a typical grant-awarding organization. We have become a co-developer of programs with exemplary partners who have expertise in various areas of serving adults. Betsey Parlato, President of Chapel Haven in...
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Autism Spectrum News - Table of Contents

Addressing the Growing Needs of Adults

1 Transition Planning for Learners with ASD
1 Autism Spectrum News Interviews Linda Walder Fiddle, Esq.
10 Transition to Adulthood: Not Just a Daytime Activity
12 The Impact of Autism on Adult Residential and Day Services
13 New Source of Funding for Post-Secondary Education
14 New Treatments on the Horizon for Adults with ASD
15 The Challenges of the Law for Young Adults
16 Couplehood and AS: Improving Important Relationships
16 When Childhood Doesn’t End
18 Modifying Evidence Based Approaches Fits the Needs of Adults
19 Program Helps Young Adults Succeed in Life, Work & College
20 The Challenge of Vocational Rehabilitation Programs
23 Beyond High School: Building a Meaningful L.I.F.E.
26 10 Areas of Support for Young Adults Transitioning to College
26 The Struggle to Transition to Adulthood and Mainstream Society
30 LifeMAP Coaching for Adults with Asperger Syndrome
30 From Modeling to Mentoring for Adults with Autism
32 Adulthood: It’s Closer Than You Think
32 Special Needs Trusts Can Be Very Helpful to Families
33 Supporting Students in Higher Education - The AHEADD Model
37 An Adult with Autism’s Positive Experience in the Workplace

From the Publisher

6 Advocating for Change: Addressing the Unmet Needs of Adults

The Autism Spectrum News Desk

8 Infant’s Gaze May Be Early Marker for Autism
8 Innovative Report Outlines Ways to Improve Quality of Life
9 Genetic Finding Identifies Male-Linked Mutation
9 AFAA Introduces National Public Policy Agenda

Other Articles of Interest

10 YAI Network’s International Conference Announcement
22 Family Creates Book Series: A Model of Inclusion for All Children
27 YAI Network Autism Workshop Featuring Dr. Ami Klin
29 The Funny End of the Spectrum - A Mom’s View
34 A Review of the Effectiveness of Hippotherapy
35 The Benefits and Dangers Behind Social Networking

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Winter 2011 Issue:
“Understanding and Treating Conditions Associated with Autism”
Deadline: December 15, 2010

Spring 2011 Issue:
“Autism and the Law Throughout the Lifespan”
Deadline: March 15, 2011

Summer 2011 Issue:
“Advancing the Science-Based Agenda for People with ASD”
Deadline: June 15, 2011

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Deadline: September 15, 2011
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Advocating for Change: Rising to the Challenge of Addressing the Unmet Needs of Adults

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

Adults with autism spectrum disorders are a fast growing population that demands attention. Currently in this country, there exists a void of supports and effective services, training and professional development for community recreation opportunities, residential services, supported post-secondary education, employment opportunities, and a general lack of awareness about the needs of adolescents and adults on the spectrum. The majority of the funding and effort towards developing best practices and evidence-based interventions, scientific research, professional training and development, fundraising, and even advocacy has been directed towards children on the spectrum. This same need energy should be directed towards adults on the spectrum, and that is why this issue of Autism Spectrum News is devoted to “Addressing the Growing Needs of Adults.”

Why is it necessary for an increase in supports and services for this growing population? Individuals with autism receive their intervention they need when they are young so that they can succeed in college and in the workplace and live independently immersed in their community. Hopefully they did receive early intervention service as a young child, and received support in school through their IEP (Individualized Education Plan). However, with age comes new personal challenges and the realization that all of the assistance that was once readily available and accessible is much harder to come by, if not impossible. “The critical shortage of services for adults with autism is a daily event that affects tens of thousands of families in the U.S. who struggle to provide a meaningful and productive life for their loved one who has aged-out of school. Since 1975 when the Rehabilitation Act (now Individuals with Disabilities Education Act, I.D.E.A.) mandated a free and appropriate education for children with disabilities, parents took for granted that their child had a firm and Congressionally mandated right to services. Many are starved to learn that when their child leaves school, the mandate for services ceases” (Ruth C. Sullivan, PhD, www.narpa.org/position.pdf). Some individuals may be more successful than others in adulthood, but the truth is that these individuals have a developmental disability that does not magically vanish once they turn 18 years old. They still have the ability to function with executive functioning skills, processing information, interpreting social cues, sensory sensitivities, etc. While these neurologically-based hidden differences were hopefully addressed and worked on in childhood, life as an adolescent transitioning into adulthood and beyond presents new challenges and difficulties; the availability of financial aid, therapeutic support becomes scarce, and eventually their parents are not going to be around to care for them anymore.

In the Summer 2010 issue of Autism Spectrum News, we featured a study conducted in Florida called “Helping Families and Individuals Cope with Stress,” we interviewed Dr. Robert H. Ring, PhD, Senior Director of the New Pfizer Autism Research and Training Unit. In our interview, Dr. Ring explained, “The public’s awareness of autism has often focused on autism as a pediatric disorder, when in reality it is a lifelong condition. In fact, patients with autism have life spans similar to those of typically developing individuals. Comparatively less is understood about adults with the disorder, and research on adults is lagging behind.” So what is the answer? How does the community rise to the challenge of addressing the unmet needs of adults with autism spectrum disorders? The answer is increased education, scientific research, advocacy and awareness, federally mandated clinical treatment best practice standards and entitle-ments, and more energy and focus specifically devoted to adults with autism.

The Need for Increased Professional Education and Awareness

In speaking with the heads of autism organizations and program directors that have participated in this issue of Autism Spectrum News, a seemingly obvious, but perhaps overlooked problem exists for service providers. While they may be interested in beginning a new program for adults, they are having trouble finding qualified and experienced staff to effectively meet the needs of adults. Most experienced employees have worked with children, and perhaps college-aged young adults. In many cases, techniques that have been applied to children are being modified for use with adults, and staff are being trained after they are hired to work with this unfamiliar population. The adult autism community needs professionals who have been trained to address their unique and specific needs. It is important to promote best practices and quality standards through training and education so that the staff working with this unique population understands and can effectively support the specific needs of adults. Colleges and Universities across the country need to address this by devoting more class time to the aging autism population, separate from children, and there needs to be more educational opportunities (e.g., as reading this issue of Autism Spectrum News) made available for organizations to train their staff.

In addition, there is a strong stigma attached to autism, in that is preventing employers from opening up to hiring these valuable members of the work force. As Yvona Fast, MLS, Director of Communications at The Autism and Regional Asperger Syndrome Partnership (GRASP) states on page 20 in her article, “The Challenge of Vocational Rehabilitation Programs for Individuals on the Spectrum,” “We’ve got a long way to go in helping people find work.” Employers need to be educated about the benefits of hiring this untapped resource of motivated individuals. A little bit of education, accommodation, knowledge and understanding can go a long way in helping the lives of adults on the spectrum. Businesses will also benefit greatly from the unique perspective, skills, and devotion that this all too often disregarded group of individuals has to offer.

Legislative Action and Federal Funding

As a result of the advocacy efforts for individuals with physical disabilities, President George H.W. Bush signed the Americans with Disabilities Act into law on July 26th, 1990. At the signing ceremony, President Bush stated, “This Act …will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard. Independence, freedom of choice, control of their own lives, and the opportunity to blend fully and equally into the rich mosaic of the American mainstream.” The struggle adults on the spectrum face are not as immediately apparent as with those who are physically handicapped. However, their struggles are just as real and their need for support and acceptance into mainstream society is equally as important.

On page 9, Autism Speaks describes a recent Advancing Futures for Adults with Autism (AFAA) Congressional meeting in Washington, DC where a consortium of leading autism advocacy organizations and service providers unveiled a National Public Policy Agenda, with the goal of inspiring legislative action to meet the increasing and unmet demand for effective services for adolescents and adults with the disorder. The hope for legislative action is bright with the persistence of this consortium and their desire for change. The AFAA website (www.aafa-us.org) highlights the clear need for a plan to address the unmet needs of adults on the spectrum. “The potential of young adults and adults (14 years of age and older) with autism to become employed and effectively contribute to our country need to address this by devoting more class time to the aging autism population, separate from children, and there needs to be more educational opportunities (e.g., as reading this issue of Autism Spectrum News) made available for organizations to train their staff. Additionally, there is a strong stigma attached to autism, in that it is preventing employers from opening up to hiring these valuable members of the work force. As Yvona Fast, MLS, Director of Communications at The Autism and Regional Asperger Syndrome Partnership (GRASP) states on page 20 in her article, “The Challenge of Vocational Rehabilitation Programs for Individuals on the Spectrum,” “We’ve got a long way to go in helping people find work.” Employers need to be educated about the benefits of hiring this untapped resource of motivated individuals. A little bit of education, accommodation, knowledge and understanding can go a long way in helping the lives of adults on the spectrum. Businesses will also benefit greatly from the unique perspective, skills, and devotion that this all too often disregarded group of individuals has to offer.

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On page 9, Autism Speaks describes a recent Advancing Futures for Adults with Autism (AFAA) Congressional meeting in Washington, DC where a consortium of leading autism advocacy organizations and service providers unveiled a National Public Policy Agenda, with the goal of inspiring legislative action to meet the increasing and unmet demand for effective services for adolescents and adults with the disorder. The hope for legislative action is bright with the persistence of this consortium and their desire for change. The AFAA website (www.aafa-us.org) highlights the clear need for a plan to address the unmet needs of adults on the spectrum. “The potential of young adults and adults (14 years of age and older) with autism to become employed and effectively contribute to our country need to address this by devoting more class time to the aging autism population, separate from children, and there needs to be more educational opportunities (e.g., as reading this issue of Autism Spectrum News) made available for organizations to train their staff. Additionally, there is a strong stigma attached to autism, in that it is preventing employers from opening up to hiring these valuable members of the work force. As Yvona Fast, MLS, Director of Communications at The Autism and Regional Asperger Syndrome Partnership (GRASP) states on page 20 in her article, “The Challenge of Vocational Rehabilitation Programs for Individuals on the Spectrum,” “We’ve got a long way to go in helping people find work.” Employers need to be educated about the benefits of hiring this untapped resource of motivated individuals. A little bit of education, accommodation, knowledge and understanding can go a long way in helping the lives of adults on the spectrum. Businesses will also benefit greatly from the unique perspective, skills, and devotion that this all too often disregarded group of individuals has to offer.

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F·E·G·S has provided person-centered, specialized supports to individuals with Autism Spectrum Disorder (ASD) for almost 30 years. Our services foster growth and success in school, at work, at home, and in the community — in an environment that embraces caring, dignity and respect in meeting the current and evolving needs of individuals with ASD and their families.

A partnership with the Seaver Autism Center at Mount Sinai School of Medicine keeps F·E·G·S at the cutting edge of assessment and treatment interventions.

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 Infant’s Gaze May Be an Early, But Subtle, Marker for Autism Risk
Research Findings Show Subtle Differences that Parents and Professionals May Easily Overlook

By Rebeca Landa, PhD, CCC-SLP, Director Center for Autism and Related Disorders Kennedy Krieger Institute

Kennedy Krieger Institute announced today new study results showing an early marker for later communication and social delays in infants at a higher-risk for autism may be infrequent gaz ing at other people when unprompted. Published in the September issue of the Journal of Child Psychology and Psychiatry, the study also found that six-month-old high-risk infants demonstrated the same level of cause and effect learning skills compared to low-risk infants of the same age.

The study observed 25 infant siblings of children with autism (high-risk group) and 25 infants with no family history of autism (low-risk group) at six months of age in order to assess cause and effect learning as well as social engagement. Infant siblings of children with autism are considered at high-risk for the disorder, as they are 25 times more likely to develop autism. Researchers at Kennedy Krieger, in collaboration with colleagues at the University of Delaware, created a novel, multi-stimuli social learning task, where infants were seated in a custom chair with an attached joystick within easy reach, a musical toy located to the right and their caregiver on the left. Researchers evaluated how quickly the infant learned that the joystick activated the toy and the infant’s level of social engagement with their caregiver.

Researchers found that, like the low risk group, the high-risk siblings exhibited typical levels of social gaze when their caregivers actively engaged them, such as pointing at the toy and expressing excitement. However, high-risk siblings spent less time looking to their caregivers and more time fixated on the non-social stimuli (toy or joystick) when the caregiver was not engaging them, which could indicate a disruption in development related to joint attention. Joint attention is often a core deficit for children with autism.

“My colleagues and I wanted to create a task that would involve learning something novel and would give babies an opportunity to pay attention to either an object or their caregiver,” said Dr. Rebeca Landa, corresponding study author and director of Kennedy Krieger’s Center for Autism and Related Disorders. “This study shows that there is a particular vulnerability in high-risk siblings at six months of age. They are not as socially interactive and engaged on their own as their peers, but still respond typically when engaged by their caregivers, making for a subtle difference that could be easily overlooked by both parents and some professionals.”

The study also showed no evidence of impaired associative learning in the high-risk siblings. Both groups demonstrated cause and effect learning abilities; once the infants learned that pulling the joystick activated the toy, they increased how often they pulled on the joystick to activate the toy’s music. This finding supports past research demonstrating that associative learning is a relative strength.

Innovative Report Outlines Ways to Improve Quality of Life for Individuals with Autism
Study Included More Than 500 Interviews of Individuals, Families and Professionals

By Linda Meyer, EdD, MPA
Executive Director
Autism New Jersey

Autism New Jersey, the state’s oldest and largest advocacy organization for individuals with autism, recently released the results of a landmark review of more than 500 interviews to determine the best ways that the needs of individuals with autism, their families and professionals who support them would be better served in New Jersey.

“This is a seminal document because it identifies the critical goals and activities that will improve the quality of life for one of New Jersey’s most vulnerable and underserved populations,” said Autism New Jersey Executive Director Linda Meyer, EdD, MPA, BCBA-D, CPT.

Connecting with Autism: A Blueprint for Lifetime Support was developed over a yearlong period and involved more than 2,000 hours traveling across the state conducting face-to-face interviews of 537 individuals with autism, their families, and the professionals who support them. The study was designed and facilitated by James Davy, former Commissioner of the New Jersey Department of Human Services.

“I am excited about how this is moving forward. I am confident that this Blueprint for Lifetime Support will spark conversations, guide collaborative actions and produce positive and meaningful transformations for the entire autism community,” Davy said.

“What the Blueprint does, more than anything, is present a vision of a future where individuals on the autism spectrum can lead full and productive lives from their infant years through adulthood,” said Autism New Jersey Board President James Paone, II, Esq.

“Fundamentally, the Blueprint designs a lifelong system with access to services and supports when they are needed and as they are needed,” he added.

“The Blueprint is a first-of-its-kind document. It relied on face-to-face interviews to fully understand the needs and desires of the entire autism community. The Blueprint provides guidance and direction for the autism community itself as well as policymakers and leaders at the local, state and federal levels,” Meyer said.

Copies of the Blueprint are being distributed to the Governor, his staff, legislators, local officials, community leaders and others across the state.

“We didn’t want to focus on shortcomings in the current system. Our purpose was to define a future system that would support professionals and make the lives of individuals with autism and their families better,” Meyer said.

The interviews and other research activities revealed five principle goals within its central theme, “A Continuum of Seamless Services and Support throughout the Lifespan.” These goals include:

• Lifetime access to individualized services;
• Collaboration and partnerships for lifetime planning;
• Skilled and compassionate people;
• Credible and reliable information; and
• Community-based inclusion.

Within each goal, the Blueprint provides an image of the future, initiatives that would help achieve the image and success indicators for each initiative. The 28-page Blueprint includes 16 different initiatives to create a lifetime support system. Among those initiatives are:

• Screening and referral
• Services across the lifespan
• Expanded adult services and supports
• Crisis intervention services
• Respite services
• Lifetime planning models
• A navigation system to guide anyone affected by autism

see Report on page 37
**Autism Spectrum News Desk**

**Genetic Finding Identifies Male-Linked Mutation Associated With ASDs**

*Results Announced by Autism Speaks and the World’s Leading Autism Experts*

By Autism Speaks

Autism Speaks, the world's largest autism science and advocacy organization, and an international consortium of researchers, along with participating families, joined together to announce additional new autism genetic discoveries. The results were published on September 15th in *Science Translational Medicine*.

Based on analysis of genomes collected from almost 2,250 individuals, including almost 2,000 with ASD and 246 with intellectual disabilities, and more than 10,000 controls, the researchers found PTCHD1 mutations or copy number variant (CNV) associated with about one percent of the individuals with ASD or intellectual disabilities – almost all of them male – but in none of the control subjects.

"This finding begins to explain the sex bias we see in autism," remarked Autism Speaks Vice President for Scientific Affairs Andy Shih, Ph.D. "PTCHD1 is located on the X chromosome. Since males have one copy of the X chromosome while females have two, they have no ‘back up copy’ if there is a deleterious variant on the X chromosome."

"We believe that the PTCHD1 gene has a role in a neurobiological pathway that delivers information to cells during brain development – this specific mutation may disrupt crucial developmental processes, contributing to the onset of autism," said Dr. John B. Vincent, Senior Scientist and head of the Centre for Addiction and Mental Health (CAMH) Molecular Neuropsychiatry and Development Laboratory who led the study. “Our discovery will facilitate early detection, which will, in turn, increase the likelihood of successful interventions.”

PTCHD1 is part of a neurobiological pathway that determines the development of human embryos. It is one of several genes recently implicated in both ASD and intellectual disabilities. Earlier this year, Autism Genome Project report in *Nature* identified PTCHD1 as a genetic risk factor for autism. The current study, running parallel to the AGP.

See Mutation on page 36

**AFAA Introduces National Public Policy Agenda to Improve the Quality and Availability of Services for Adults with Autism**

By Autism Speaks

Advancing Futures for Adults with Autism (AFAA), a consortium of leading autism advocacy organizations and service providers, unveiled on July 15th a National Public Policy Agenda with the goal of inspiring legislative action to meet the increasing and unmet demand for effective services for adolescents and adults with the disorder. The National Policy Agenda was announced at a Congressional briefing in Washington, D.C. that brought together federal legislators, national policymakers and advocates for adults with autism – including individuals who have autism – to discuss priorities for action in the public and private sectors.

The AFAA National Public Policy Agenda focuses on three areas of priority: providing access to services and supports to develop important life skills; providing access to skilled direct care personnel; and providing access to – and choice within – the funding of services. Among other actions, the AFAA is calling for the expansion of appropriate housing opportunities, greater vocational supports, more training for service providers and portable, individualized funding streams for services.

“We are advocating for meaningful change that will empower adults with autism to lead independent and productive lives,” said Peter Bell, AFAA co-chair and executive vice president of Autism Speaks. “It is going to require persistence by the autism community and real leadership from our elected officials and influencers in the private sector to turn these policy priorities into meaningful action. We are not asking for a hand-out, but rather for the creation or expansion of programs that will maximize the potential of the growing number of people with autism and minimize, in the long run, the cost to society.”

The AFAA Congressional briefing – which featured remarks by honorary co-chairs Senator Robert Menendez (NJ) and Congressman Mike Doyle (PA) – was the latest step in an ongoing effort to identify key policy priorities to advocate for the needs of adults with autism to address critical challenges. An initial AFAA Think Tank in January 2009 was followed last November by a National Town Hall Meeting, which included almost 1,200 participants in sixteen locations across the country.

For more information about the AFAA and to view the full National Public Policy Agenda, visit www.afaa-us.org.

**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 110 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 AFAA**

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. This unique national consortium has united to set national priorities for adults on the autism spectrum and to transform public policy and programming for teens and adults with autism spectrum disorders. Throughout 2009,
Transition to Adulthood: It’s Not Just About a Daytime Activity

By Jennifer Shaoul

When people with autism and other developmental disabilities, their families and professionals discuss “transition planning,” the focus is generally on day treatment programs, advanced education or competitive employment. The transition from Department of Education services upon graduation to adult services, however, goes beyond the need for appropriate day time activities. There are some equally important steps, which unfortunately are frequently delayed or completely overlooked, to ensure a successful transition to adulthood.

Looking at this limited list may seem daunting to a parent embarking on this journey, but rest assured, there are resources available to assist you. Together, you and your family member can determine priorities that need to be addressed in a timely fashion.

Explore Eligibility for Services

Families of individuals with Autism Spectrum Disorders (ASDs) often bypass this step prior to transition because they think their child wouldn’t be eligible or appropriate to receive services. They may prefer to focus on their child’s strengths or fear that eligibility may hold them back from other opportunities. Establishing eligibility with the New York State Office of People with Developmental Disabilities (OPWDD), or your state’s Office of Developmental Disabilities, even though you may never need or use these services, could be considered insurance for your family member’s future, while you pursue other avenues of Ventures. Establishing eligibility may allow you to achieve goals through individual support and training for your family member and support for you as a parent.

The earlier that one establishes eligibility within the OPWDD system, the earlier one can access services and supports that can help an individual be even more successful as they age. Some families don’t realize that an individual can have Asperger’s Syndrome or high functioning autism and still be eligible for services if the person has difficulty functioning in his or her environment. If the individual with the disability has not been identified to OPWDD prior to age 22, it’s more difficult to prove that the individual is eligible for services, though it can be done. It’s helpful to have a knowledgeable and experienced professional in the field of developmental disabilities (DD) to help you prepare your packet for eligibility.

You can get a taste of the array of services available for people with DD in by obtaining a Family Support Directory for your county from your local New York State Developmental Disabilities Service Office (DDSO). Visit www.onr.state.ny.us/document/hp_contacts.jsp to find your local office. DDSoS may also have other directories or lists available, e.g., day service, clinic, residential.

Don’t be disappointed if you’re family member with autism doesn’t obtain eligibility. He or she may still need supports but generally will have less severe needs than others with DD. There are sometimes other funding streams or private pay options for certain necessary services.

Health Care: Transition from Pediatrics to Adult Medicine and More

Unfortunately, many families wait a bit too long to make this transition. It’s hard to leave a trusted pediatrician who has been very patient with your family member, but unless that practitioner has expertise in adult medicine, you are doing your family member a disservice. Pediatricians do not regularly manage or treat adult health care issues and their offices are generally not equipped to treat people of all ages. There are many doctors available in the New York metropolitan area that have an expertise in treating adults with ASDs.

Young women with disabilities should see a gynecologist for recommended check-ups. Whether or not these women are sexually active, they will need breast and pelvic exams and pap smears for preventive care.

Some individuals, especially those with ASDs are particularly sensitive to dentistry, gynecology and blood work. Do not avoid treatment! Lack of care often leaves them with intensive challenges later on. Work with clinicians and health care practices that are familiar with and utilize desensitization techniques to overcome sensitivity to treatment and fear.

Benefits, Guardianship and Future Care Planning

As individuals with autism reach adulthood, they can be eligible for Supplemental Security Income (SSI) and Medicaid, even if they still live at home with their families. Medicaid funds many supports and services that may be very beneficial to you and your family member.

While many parents don’t realize this, when their son or daughter turns 18, parents no longer have legal guardianship. For many individuals, especially those who are more independent, this won’t make a difference. But for individuals who require more support and who cannot manage themselves or their finances, families should obtain legal guardianship. There are supports available to assist with this process and a lawyer is not required.

Socialization

Having friendships is an important part of leading a full and satisfying life. People with ASDs often have trouble with making and keeping friends. While some daytime programs can help facilitate this, those in work settings often find navigating relationships especially difficult. There are opportunities for social skills training available and also programs both within and outside the OPWDD service system that provide opportunities for individuals to meet and form friendships.

Many people with disabilities have an interest in dating and sexuality. It is important for families and professionals to gauge an individual’s interest and activity level and make sure they have the skills and knowledge to make appropriate and safe decisions. Unfortunately, some individuals engage in what’s deemed inappropriate behavior simply because they don’t have access to socially appropriate outlets.

Behavior

Behaviors that were tolerated or even thought to be cute when your family member was younger may prove detrimental and even dangerous as he or she grows older. These behaviors may limit the programs available to them and/or limit potential friendships and relationships. Identifying the most debilitating behaviors and working with an expert on developing a behavior plan to eliminate maladaptive behaviors is an important step.

Announcing YAI Network’s 32nd Annual International Conference

May 2-5, 2011 at New York Hilton to Focus on Autism

By The YAI Network

Autism spectrum disorders will be a major focus throughout the YAI Network’s 32nd Annual International Conference on developmental and learning disabilities on May 2-5, 2011, at the Hilton New York Hotel, 1335 Avenue of the Americas in mid-town Manhattan.

Known for its comprehensive and hands-on trainings, this annual conference features some of the most prominent experts from throughout the world. The conference is designed for professionals at all levels, family members and individuals with developmental and learning disabilities. Extended sessions provide attendees with even more in-depth training.

The conference attracts more than 3,000 people and serves as a major forum for the exchange of ideas and the introduction of new models and strategies that have a positive impact in the field of autism and other developmental and learning disabilities.

In 2011, in conjunction with the International Conference, the YAI Network will host the International Society on Early Intervention’s conference on early intervention and early childhood. Many of the sessions in this conference will address autism spectrum disorders.

For more information, including early-bird registration packages, discounts for organizations sending six or more staff members, visit yai.org/conference. The conference brochure will be available online on the website and online registration will be available through mid-May. To make a registration deposit, contact, Tina Sobel, conference co-director, at tina.sobel@yai.org, or 212-273-6457.

For more than 50 years, the YAI Network has provided a place of hope and opportunity for people with developmental and learning disabilities. Comprised of seven not-for-profit, independent health and human service agencies, the YAI Network serves people of all ages throughout the New York metropolitan area, including Long Island, Orange, Dutchess, Ulster and Sullivan counties, New Jersey, Puerto Rico and the U.S. Virgin Islands. The YAI Network is recognized nationally for its conferences, training seminars and publications. For more information about the YAI Network or to obtain services, call 1-866-2-YAI-LINK or visit www.yai.org.
Fall Autism Workshop
Monday, Nov. 8, 2010

The YAI Network is proud to sponsor a full-day workshop featuring
Dr. Ami Klin
Director, Autism Program
Yale University

“How Contemporary Issues in Autism and Asperger’s”
McGraw Hill Auditorium
New York City

Regular Registration: $175
Family Member Rate: $95

Limited Seating
For more information
or to register online
visit yai.org/autismconference
or contact
Abbe Wittenberg at 212-273-6472
or abbe.wittenberg@yai.org

Hope for People with Autism and Their Families

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

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

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

YAI Network
Serving People with Disabilities and their Families
As a provider of services to adults with special needs, we are serving an increasing number of clients on the Spectrum. This is due to three factors: (1) a higher rate of spectrum diagnosis in young adults; (2) a lower rate of traditional Mental Retardation and Developmental Disabilities (MR/DD) diagnosis; and (3) a growing recognition that older adults, previously diagnosed with MR/DD, should be rediagnosed with spectrum disorders.

We anticipate this trend to continue and be seen nationally. A study conducted in Minnesota of diagnostic data for 2001-2002 as compared with 1981-1982 concluded that “a federal and state administrative changes in policy and law favoring better identification and reporting of autism are likely contributing factors to the prevalence increases and may imply that autism spectrum disorder has been under diagnosed in the past” (Gurney JG; 2003). A similar conclusion may be drawn from data collected by the State of California showing the number of people diagnosed with autism decreases dramatically after 18 years of age.

Behavioral data and observations, concurrent with the increasing psychiatrist familiarity with spectrum diagnosis indicates we will have an increasing proportion of clients diagnosed with spectrum disorders.

This increased percentage of clients with spectrum disorders will impact the role of behavioral services in adult residential and day care. Like other neurodevelopmental disabilities, spectrum disorders are generally not “curable,” and chronic management is required. Like their younger, diagnosed counterparts, many of our adult clients share the three defining characteristics of autism: impaired communication ability, impaired social interaction, and restricted and/or repetitive interests and activities.

They also share in exhibiting unwanted behaviors. In adult services, it is the job of behavior services to identify and resolve unwanted behaviors. This job evolved over decades of serving the MR/DD population. In that population, and before the current era of brain imaging, a myriad of behaviors seemed to stem from an almost innumerable number of mental and physical insults to the brain. Consequently, the same behaviors could result from a wide variety of triggers, and people with the same broad diagnosis might exhibit wholly different behaviors. As a result the role of the behavior specialists has evolved to “treat the behavior not the diagnosis.”

As the proportion of adult clients shifts from MR/DD to spectrum disorders, a great opportunity exists to reassess the role of behavior services. In a traditional MD/DD adult environment, behavior services is reactive; behavior specialists have to wait for a behavior to be reported, conduct a functional analysis and determine how to decrease that behavior or replace it with another behavior. They then write a behavior plan which is used to train and guide care staff.

With the realization that an increasing number of clients are on the spectrum, sharing a common diagnosis and common needs, adult services has an opportunity to shift from being reactive to becoming proactive. The opportunity exists for care staff to reduce behaviors, before they start, by constructing and maintaining a more prophylactic environment.

To do this we have to identify common client needs and means by which we can build a more prophylactic environment. For example, the majority of spectrum adults lead a very insular and dependent life (Howlin, 2004). They appear to lead this life to avoid anxiety and fear. Dr. Leo Kanner’s original report on autism recognized a high degree of anxious behavior exhibited in his initial sample of children. In 1998, Dr. Peter Muris restudied anxiety symptoms in 44 adolescents with autism spectrum disorders and found 84.1% met the criteria for having at least one anxiety disorder.

The importance of these observations, which can be witnessed in most adult day and residential services, cannot be overstated. Any new approach to proactive behavior management of adults on the spectrum must recognize that most unwanted behavior problems (and many co-morbid illnesses) are driven by stress resulting from chronic anxiety.

Living in a perpetually anxious state means continuously living on the border-line of flight or fight generated behaviors. Chronic anxiety also means living in a...
For the neurotypical population preparing for post-secondary education, a significant rite of passage is filling out the Free Application for Federal Student Aid (FAFSA) and indicating the colleges of their choice. The FAFSA form is required for a student to be eligible for any type of federal aid and virtually all colleges require that students apply for federal aid before being considered for any state or private financial aid. All federal aid, and just about all other types of aid, requires that the student be enrolled full time in a degree-bearing program at an accredited college or university.

The path to post-secondary education funding is less clear for students on the autism spectrum. Many students on the spectrum are not yet ready to enroll full time in a degree-bearing program. This in the past has precluded them from participating in the FAFSA process and from receiving the grants associated with it. The 2009 reauthorization of the Higher Education and Opportunities Act (PL 110-315) opens new possibilities for students with an intellectual disability to receive support for a variety of higher education opportunities. Under the new provisions of the Act, it is possible for a student with an intellectual disability to be eligible for Pell Grants, Supplemental Education Opportunities Grants and the Federal Work Study program if they are enrolled in a “comprehensive transition and postsecondary program for students with intellectual disabilities.” The Act requires the institute of higher education offering a post-secondary transition program to already be authorized to participate in the federal financial aid programs and that the United States Department of Education approves the transition program. This means a student with intellectual disabilities like Asperger Syndrome, “high functioning autism,” or significant ADHD/ADD can now enroll in an approved college-based transition program and apply for financial assistance. They no longer need to be enrolled full-time in credit-bearing classes, nor do they need to be in a degree-bearing program.

Until now if a student in a post-secondary education program was not registered full-time in a degree-bearing or certificate program, they had few options for financial assistance. Students with ASDs and their families have had to rely upon the local school districts through the Individuals with Disabilities Education Act (I.D.E.A.) to fund a transition plan that would prepare the student for the world of work or higher education. However, many school districts feel that if a student has met the basic requirements of graduation in terms of the student’s ability to read, write and do arithmetic, then their legal obligation has been met. They fail to understand that students on the autism spectrum need assistance in learning independent living skills and need remediation in their deficits in executive functioning. Families often must hire an educational advocate or attorney to compel the school district to provide funding for a transition program.

If the families of students on the autism spectrum fail in their attempt to secure

see Funding on page 38
New Treatments on the Horizon for Adults with Autism Spectrum Disorders

Shaun M. Eack, PhD
Assistant Professor and Director
Perspectives Program
University of Pittsburgh

Much of the treatment for autism spectrum disorders has focused exclusively on early intervention and childhood treatment programs. These programs are quite helpful for individuals and families as they move through the educational system and provide children with autism spectrum disorders specialized treatment programs to improve their lives. Unfortunately, when children reach the age of 18 (or in some cases 21), many of the services that were available and appropriate for them at a younger age come to an end. Equally unfortunate is the fact that little to no evidence-based treatments exist to help adults with autism spectrum disorders as they transition and continue into adulthood.

As anyone with an autism spectrum disorder will tell you, the difficulties that autism, Asperger's syndrome, and pervasive developmental disorder present to people with these conditions do not end at age 18. Adulthood presents its own array of unique challenges as individuals are attending college, trying to build friendships, and attempting to advance successful careers that build on their talents. For many, this time is fraught with the challenges of over-stimulation, fitting in, and shifting toward independence that come from the busy and demanding world of adult life. Many have argued that it is precisely at this time when individuals with autism spectrum disorders need help the most. Still, scientifically-validated treatments for adults with these conditions are almost completely absent.

Recent research has identified difficulties in thinking or cognition as key contributors to disability in adults with autism spectrum disorders. Studies have demonstrated that, despite frequent cognitive talents, many individuals with these conditions experience a slowing in speed of processing, difficulty with planning, and reduced mental stamina. These problems are combined with core impairments in social cognition, which are characterized by an inability to identify non-verbal cues, take the perspective of others, and understand the broader context of social situations. In addition to problems in social and non-social cognition, many adults with autism spectrum disorders experience significant difficulty in managing stress and emotions, and frequently experience what some have termed "meltdowns." Problems that may seem trivial to others are magnified to the adult with autism, shifting to new environments and situations often produce high negative emotional reactions, and many lack the skills needed to cope with the very real stress of adult life.

Not surprisingly, individuals who experience these problems in cognition and emotion (regardless of whether they have an autism spectrum disorder), find it exceedingly difficult to succeed as adults. Mental stamina and ability to quickly process information are critical to keeping up at work and school. The ability to understand social contexts and take the perspective of others provides the foundation for succeeding in interpersonal situations and making friends. Further, nearly every aspect of one's life can be disrupted by emotional meltdowns, which can also lead to a great deal of stigma. Unfortunately, interventions designed to directly treat problems in cognition and emotion management with autism spectrum disorders have yet to be developed and scientifically validated.

Recognizing the great need for the treatment of these problems in adults with autism spectrum disorders, the University of Pittsburgh Autism Center of Excellence has begun the Perspectives Program. With funding from the National Institute of Mental Health, the Pennsylvania Department of Human Services, and Autism Speaks, the Perspectives Program is aimed at pioneering new interventions to help adults with autism spectrum disorders develop the cognitive, social, and emotional abilities needed to succeed in adulthood. The focus is placed particularly on psychosocial interventions, which include non-drug therapeutic strategies to target the core symptoms of autism.

Currently, the Perspectives Program is working on testing two new and very promising interventions for adults with autism spectrum disorders known as Cognitive Enhancement Therapy and Enriched Supportive Therapy. These psychosocial research interventions provide support and are designed to improve cognition, social functioning, problem-solving, stress

see New Treatments on page 34
The number of children diagnosed with autism spectrum disorders (ASD) has increased dramatically in recent years. In the coming years, these children identified with ASD in early life will be reaching adolescence and early adulthood. Their sheer numbers – according to the CDC, an average of 1 in 110 children – will shape in unprecedented ways the transition of special education students from high school to the world of work and college. This article will review the federal law and the court cases governing transition for all special education students including those with ASD as well as raise emerging questions concerning transition.

In 1990, the Individuals with Disabilities Act (IDEA) first introduced the concept of transition services, providing a passageway for those leaving high school into higher education, jobs, and other facets of post-high school life. The IDEA, which guarantees a free and appropriate education (FAPE) for all children with disabilities, federally mandated that each Individualized Education Plan (IEP) must include a statement concerning “transition services.” The IDEA defined “transition services” as a set of coordinated activities established for each individual child. The goal was to strengthen the child’s academic and functional abilities to prepare them for post-secondary outcomes such as employment, college, vocational training, adult services, independent living, or community participation.

Despite the introduction of this promising concept, the success of transition planning and implementation of such services remains untested. The IDEA requires that a statement of transitional services be included in the child’s IEP as early as needed, but no later than the child’s 16th birthday. However, the transition plan for each student does not have to be a separate, extensive document. The case law has been clear that this requirement of the IDEA is satisfied even if there is one sentence stating that transition services are needed for the child. The result of this minimal requirement is that often the child does not receive any actual transition services.

Additionally, there are other federal laws that affect the transition process including: (1) Fair Labor Standards Act (FLSA), (2) Rehabilitation Act of 1990, (3) 1994 School to Work Transition Act, and (4) Americans with Disabilities Act of 1990 (ADA). Each law provides rights for children and adults with disabilities. These laws affect transition in a variety of ways: by ensuring that minimum labor standard guidelines apply to students with disabilities in vocational training, which helps them prepare for long-term employment after high school graduation; by creating school-to-work programs and obtaining federal grants to ensure that each district can create and maintain such programs; and by increasing awareness of the rights of all individuals with disabilities and ensuring equal opportunities. At this time, lawmakers and the courts are merely skimming the surface of this issue and not exploring the adverse consequences that inadequate transition services affect the future of children with disabilities.

The problem is exacerbated by the lack of legal scholarship on the subject. However, there have been several non-legal articles and guidebooks that address transition services and propose guidelines for educators to ensure successful transition.
Couplehood and Asperger Syndrome: Improving Important Relationships

By Lynda Geller, PhD
Spectrum Services and Asperger Center of Education and Training

A s the concept of Asperger Syndrome becomes more visible in our society, more and more undiagnosed adults and their loved ones are seeing popularized views of the condition reflected in television and movie characters and in writings about adulthood proliferating on the internet. What is the relevancy of thinking about such a diagnosis as an adult? An issue that is just beginning to gain attention is that of couplehood and marriage.

As the concept of Asperger Syndrome was developing, many thought that most of those affected lived lives of friendless-ness and certainly never married. That may have been because of “clinical bias,” that is clinicians seeing a concept through the eyes of their own experience of who seeks help. Research studies also tend to study populations of individuals who make themselves available either through volunteering or being part of evaluation or placement somewhere. From these perspectives, we miss considering those doing well enough that they do not seek help and those who have never thought of themselves as having a diagnosis of Asperger Syndrome.

Thus, the popularization of Asperger Syndrome has had the effects of making more people aware that the problems they have been experiencing may actually be part of something specific. In addition, the gradual understanding of the concept has impelled schools to give greater consideration to the development of social skills for their students identified with spectrum conditions and to extend that thinking to the general classroom as well. As children mature and their outcome is, in fact, better from a social perspective than it might have been in past times, more individuals and families expect a normalized future with full membership in all that society has to offer.

So, if we think about adults, some of who grew up in times when social skills were better addressed and others who discovered for themselves how to develop meaningful relationship and jobs, we find a population of individuals who have achieved much success, but may continue to struggle significantly with the social-emotional aspects of life. The development and sustenance of important relationships is an element of life we all aspire to enjoy. After all, humans are social creatures. How to improve that special relationship of couplehood for partners where one or both members have Asperger Syndrome is the focus of this article.

How Asperger Syndrome May Affect Relationships

For many couples, what was initially an interesting difference in the flush of love becomes a challenge as time goes by. The helpful, organizing attitude of one member, or the loyal and intelli-gent manner of the other, may have drawn them together, but what begins as having conflict or unhappiness is an inherent difference in communication skills and style that many couples find confusing and hurtful. Neither is aware of what is causing their problems, and without that understanding change and adjustment are almost impossible. Let’s consider some of the important aspects of a relationship where one of the members has diagnosed or undiagnosed Asperger Syndrome.

For those with Asperger Syndrome, there are real differences in various aspects of function depending on the individual. Some have extreme sensory sensitivities; others do not. Some have extreme rigidity that drives the household; others just a little difficulty with changes. Some have interests and special interests that have led to a successful career; others have more eccentic interests that disrupt family life. Some have slow language processing; others are quite facile. Some have anger management issues or trauma histories or coexisting anxiety or depression. Clearly understanding what differences there may be and how they impact the individual and the relationship should be a first step.

Empathy, or the ability to understand and experience the thoughts and feelings of others, is thought to be a significant problem for individuals with Asperger Syndrome. The literature on marriage and relationships is replete with articles about empathy and its importance in relationships. When one or both partners lack skill in detecting the subtle messages in

When Childhood Doesn’t End

By Liane Kuperberg Carter
Parent and Autism Activist

T he woman on the phone said her name was Aretha Franklin. “Really,” she added. She was calling, she said, because the Surrogate’s Court had just appointed her agency as guardian ad litem, temporary guardian for our 17 year old son Mickey. We had just filed papers two days earlier, asking the court to allow us to assume the personal business of how we are raising our son. This is something that must be done before his 18th birthday, the age of majority, when in the eyes of the law he becomes an adult.

While other parents have been shepherding their children through SATs and college essays, our time has been filled with lawyers and estate planners, as we struggled through setting up several supplemental special needs trusts on behalf of our developmentally disabled son. The guardianship piece is the last step in this painstaking process; we have had to examine and project every possible scenario of our deaths and what this would mean for our son. It has brought up feelings I didn’t fully anticipate. Not just the obvious ones, the fear of one’s own mortality. As the parent of an autistic child you think you’ve done your grieving. Then it smacks you in the face again. No one wants to be observed during intimate family moments. I’m tired of the well-meaning questions that often feel like veiled criticisms: Why do you let him wear sweat pants to school when the other kids are wearing jeans? Why does he use such tepid water when he showers? Why can’t you make him eat vegetables? Last year, his teacher sat in our kitchen sipping green tea one afternoon, and suggested we put kale in the blender to make a vegetable smoothie.

“What’s the point of this drink anyway?” I asked. I laughed, but thought, obviously you don’t have any children of your own yet. The underlying message often feels like, You need to discipline him better. You’re not setting the right limits. I’m weary of being watched all the time, feeling I have to defend every parent- ing choice I make. It doesn’t feel good.

When Aretha Franklin called, I was my most friendly and chipper. We made brownies together. I stewed in a very hot bath of nerves all weekend. Should I bake brownies with Mickey before she arrived, so that she would see what a great mother I am? Isn’t that what you do when you are showing off your house to prospective buyers, bake something with the subliminal scents of cinnamon and vanilla to make the house smell warm and inviting and cozy? Or would that look too obvious? I should ask him if he liked living with us? If we were kind to him? What if

Liane Kuperberg Carter

Last week we had to take Mickey to the lawyer’s office so that Diana, the paralegal, could officially serve him with papers notifying him that we were petitioning the court on his behalf. Mickey, knowing that something was up, refused to stand. He refused to shake her hand or make eye contact. Standard m.o. for him in a new situation when he is anxious. Standard embarrassment for us. “As part of the procedure, the Court has appointed Mental Hygiene Legal Services for Mickey,” she said. “Basically, their role is to complete some interviews with both of you as proposed guardians for him, and with anyone else they feel would be a useful source of information.” The Court will rely on their report to determine if this guardianship is a safe and appropriate one for Michael.”

Appropriate? We are his parents. I know that having the state appoint a temporary legal guardian while they process our appeal is pro forma. They do it for every case. It’s meant to protect my child’s best interests. It’s meant to protect all the children in the system. So why am I feeling as if someone has called Protective Services on us and now a social worker is coming to make a home visit and poke into the personal business of how we have raised our child? What if we don’t pass the Test? Does that mean the State gets to decide what school he attends? Where will he get his medical care? Where, how and with whom he lives?

For the past 17 years, we have had therapists, teachers and administrators in our home -- in our lives, evaluating him, and by extension, it often feels to us. Most of them have been lovely. (A few, not. One, it turned out, abusive. That is another story.) But there is such a lack of privacy. With ten hours a week of ongoing after-school therapy in our home, we haven’t been able to sit down and eat a normal family dinner in years. It’s bad enough we get stared at in public; you learn to expect it. But no one wants to be observed during intimate family moments. I’m tired of the well-meaning questions that often feel like veiled criticisms: Why do you let him wear sweat pants to school when the other kids are wearing jeans? Why does he use such tepid water when he showers? Why can’t you make him eat vegetables? Last year, his teacher sat in our kitchen sipping green tea one afternoon, and suggested we put kale in the blender to make a vegetable smoothie.

“And who’s going to get him to drink that?” I asked. I laughed, but thought, obviously you don’t have any children of your own yet. The underlying message often feels like, You need to discipline him better. You’re not setting the right limits. I’m weary of being watched all the time, feeling I have to defend every parent- ing choice I make. It doesn’t feel good.

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see Couplehood on page 40

see Childhood on page 38
Announcing the Opening of Spectrum Services
303 Fifth Avenue, Suite 1003
New York, NY 10016
212-686-3535  212-686-3536 fax
info@aspergercenter.com

- Spectrum Services is a cooperative of independent practices and organizations.
- All of our participants specialize in evaluation and treatment of children, teens, or adults with Asperger Syndrome and related conditions.
- Our services include specialized psychotherapy, social skills and pragmatic language groups, psychiatric services, speech and language, college coaching, executive function services, couples counseling, vocational assessment and support, social skills seminar, neuropsychological evaluation, individual and family support, certification course on college coaching, and a seminar series on autism spectrum issues.

Lynda Geller, Ph.D. Founder of Spectrum Services and Psychologist
Mary Riggs Cohen, Ph.D. Psychologist
David A. Cooperman, M.D. Psychiatrist
Enid Gort, Ph.D. College Coaching
Rhea L. Hooper, M.A., CCC-SLP. Speech and Language
Mitchell Nagler, MA, LMHC Mental Health Counselor
Shuli Sandler, Psy.D. Psychologist
Ilene Solomon, Ph.D. Neuropsychologist
Renee Soufer, M.A., Ed.M., Psychologist in training

Asperger Center for Education and Training is a virtual center that disseminates information about AS and has nonclinical services available such as coaching, coaching supervision, educational consultation, and series of workshops and courses at www.aspergercenter.com

Asperger Foundation International is being reenergized under the leadership of Marcia Scheiner who plans to take it in the direction of the development of jobs in the corporate sector and training for employers about the special talents and needs of adults with AS.

Asperger Syndrome and High Functioning Autism Association, AHA, provides support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. www.ahany.org

Career and Employment Options, Inc., CEO is an award winning service providing transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities. www.ceoincworks.com
There is a lot we know about Autism Spectrum Disorders from evidence based research. But I think with all of the confusion of services, treatments and therapies, there remains much that we are still learning when working with adults on the spectrum.

I believe there is a genuine army of professionals and parents who are desperately trying to find ways to improve the quality of life, education, housing and work for those on the spectrum. I often find myself at a loss when parents ask me if this doesn’t work, what is the plan B. This is a tough question to answer since disability benefits and criteria to qualify are complicated and confusing, and fee-based residential programs are out of reach for many families, even those with resources. The sad fact is that many families are sacrificing their financial futures to purchase services for their adult children with autism.

I can’t remember the exact day that I decided I wanted to dedicate the rest of my career to working with adults on the autistic spectrum. There is nothing more gratifying than helping these individuals and their families to overcome challenges and develop the skills necessary to lead the most productive and fulfilling life possible.

From all of my professional experiences working with adults on the autistic spectrum, I began to notice that the adults on the spectrum were an underserved population. Most of the services and research focused on children and I was anxious and determined to try a different approach that I felt could only help an individual, not hurt them. As a Life Skills and College Coach Specialist, I am not a researcher, per se. Twenty-five years ago, when I was in graduate school, I never considered pursuing the idea of the scientific aspect to psychology, counseling or social work. I understand and receive many psychometric tools and I can interpret and understand the outcomes and the effects on individuals on the spectrum and develop plans in those deficit areas. It is one thing to understand research based therapies; but what happens when a client needs a different approach?

I always try conventional, evidence-based approaches with my clients, primarily cognitive behavioral strategies, and if they don’t work then “thinking outside the box” is a great strategy. If we could only quantify the challenges, the individual’s brain wiring, and the family dynamic that greatly interfaces with these folks. For example, during a recent visit to a client whose friend stays with him periodically and is a positive influence, our goal was to continue working on motivational, organizational, planning and problem-solving strategies related to a school project. The client’s guest happened to be in the other room also working on a project. So, I seized on the opportunity to “pull in” the friend as a motivational strategy, not knowing what to expect. What happened next was unexpected and resulted in what I would classify as a productive outcome.

The guest bemoaned his home life and expressed envy to his friend of all that he had (nice home, supportive family, etc.). The guest couldn’t understand why his friend was suffering. The host responded in an assertive and slightly reprimanding way by disclosing his internal and invisible challenges that he openly shared for the first time with his friend. He expressed that the “niceties” his guest observed were “meaningless” and “unimportant.” I was silently taken aback. This to me was a breakthrough that takes place when flexibility on my part and the risk of changing directions can occur.

Another example relates to a client who is applying for jobs for the first time. While he is an honor student in Math and Science, he did not understand the job seeking process from start to finish. We were working on online applications, interview skills, building a resume, etc. He thought that one applied for a job online and then sat back and waited for a phone call. At one place of business, there were no open positions so he couldn’t apply online. Another did have an opening so he was able to apply online. I assisted him with job skills and convinced him to visit to both job locations. On the one site, I spotted a woman who appeared to be a manager and approached her (modeling).
In June of 2010, 10 young adults marked a major milestone as they became the first graduating class of Chapel Haven West. Chapel Haven West opened in 2008 in Tucson, Arizona and provides residential transition and lifelong supports for adults 18+ with mild developmental disabilities and those on the autism spectrum. The program is a satellite of Chapel Haven, Inc., founded in 1972 by parents and dedicated to providing lifelong supports for adults with cognitive and social disabilities. Chapel Haven’s other two programs are based in New Haven, CT.

The graduation ceremony took place June 19, 2010. Some of the graduates shared their experience, as noted in their comments throughout this press release.

Ian Gordon, 20, remembers feeling uncomfortable and antisocial when he first started at Chapel Haven West. “I had no interest in hanging out with a bunch of strangers,” he said. “I did not have a social life when I moved here. I did not interact with any of my high school classmates outside of school. At the time, I preferred it. I thought I was living the life.”

Chapel Haven West’s curricular focus on planned social activities helped him make friends. Playing video games in his apartment with other students helped break the ice and has led to a richer social life for Ian. Ian is taking classes at Pima Community College and volunteering in a work study at the Star Pass Marriott golf course. He also had the chance to indulge his love of sports, working in a golf shop and shadowing reporter Ryan Recker at television station KVOA. He went from a lonely life in his parent’s house to hosting weekly pizza parties with friends at Chapel Haven West and becoming a leader in the program.

“More than anything, Chapel Haven has meant freedom, friendship and happiness to me,” Ian said. “I have more friends at Chapel Haven West than I have almost anywhere else. I have learned to essentially become an independent, socially acceptable man. I am very thankful for this.”

Chapel Haven West is a nationally accredited, 24-month transition program that focuses in four key areas: independent living, self-determination, college/vocation and social communication skills. Students live in an apartment complex within walking distance a few blocks from the University of Arizona. They learn apartment management skills along with cooking, budgeting, grocery shopping and doing laundry. The program’s close proximity to the University of Arizona provides a rich array of benefits for Chapel Haven West students, including classes, involvement in the university’s state-of-the-art SALT Center and job shadowing opportunities.

Chapel Haven West has Social Communicative Competence (SCC) as its core component. With two speech-language pathologists on staff, both trained in the social thinking model pioneered by Michelle Garcia Winner, students learn the

see Graduates on page 42
By Yvona Fast, MLS
Director of Communications
GRASP

As individuals on the spectrum, we’re different. We try to conform to the mold. Yet no matter how hard we work, it’s not good enough for the neurotypical (NT) world. The agencies that are supposed to serve the disabled can’t assist us because we don’t fit in with their usual population.

When President Bush signed the Americans with Disabilities Act into law on July 26th, 1990 he said, “A major goal of this legislation is to demonstrate that disabled Americans want to work to support themselves and maintain independence” (DeVroy). Since then, the ADA has helped those with physical disabilities to achieve this goal by creating user-friendly work environments. Public buildings are now all handicapped accessible.

However, those with neurologically based hidden disabilities often don’t receive the understanding or services that they need. Because these individuals are intelligent and articulate, their skills and abilities obfuscate their need for supports and services. Susan Moreno, Executive Director of Maap Services, Inc., explains the dilemma:

“The better they have done in rising to the challenges of their disability – the more able they are to communicate and act in a manner expected of non-handicapped people – the less likely they are to receive vocational rehabilitation (VR) services. Yet these rare and wonderful people have the potential to achieve the most vocationally with comparatively few hours of VR services to help them with those characteristics of their handicap which remain barriers to successful employment. These characteristics include being too honest or blunt with other people; difficulty controlling their tempers; trouble processing information; not knowing how to appropriately seek and/or accept help; difficulty socializing appropriately with coworkers; and problems dealing with the public. Without the help they need, they usually experience failure in the work place.”

They attempt to conform, but they’re not accepted. They try hard to be part of the organization only to be told, “Sorry, you just don’t fit in here.” They work hard, but are accused of being lazy. They do their best and are told it’s not good enough. They’re honest, and are accused of being rude. They work very hard to achieve, and are met with frustration due to repeated failure. VR counselors, employers, and others can’t understand how someone with a PhD seems so gauche, how someone who seems so bright has such problems with simple things, like pouring a cup of coffee, keeping their desk neat, or joining a conversation.

The Division of Vocational Rehabilitation (VR) in a particular state is designed to help all disabled people become gainfully employed. However, many VR counselors know little about conditions like autism, Asperger’s Syndrome (AS) or Nonverbal Learning Disability (NLD). Although many individuals with AS or NLD have demonstrated ability for college-level work, they may have difficulty keeping a job and have a poor work record.

Yet these individuals aren’t looking for excuses. They’re at the end of a long road of trying to learn coping skills in order to deal with their difficulties. They need help finding work environments where they can succeed.

Jobs available through vocational rehabilitation agencies are often inappropriate for college-educated employees with poor social skills. Laurie explains: “Everything these people had to offer was dependent on speed, requiring the ability to multi-task and the ability to think on one’s feet. Unfortunately, persons, or at least this person with NLD, are not too vocational-rehab compatible” (Reed, p.70).

When they approach VR for help and describe lifelong troubles working smoothly with others, they’re told everyone has those problems. Their problems are attributed to personality characteristics, a poor attitude or a lack of self confidence - not a disability. That’s because when people see intelligent, skilled individuals, it’s hard for them to fathom the problems caused by poor motor skills and motor planning, lack of executive function abilities, and inability to understand nonverbal social cues. The individual’s need for detailed written instructions, for extended training time, for organization, for tasks being broken down, is not well understood.

The Challenge of Vocational Rehabilitation Programs for Individuals on the Spectrum
The Simons Simplex Collection

Questions raised by AUTISM bring us together.

HELP US search for answers.

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

2,000 Families, One Mission
At 13 research sites across the country, eligible families with the following characteristics are answering our call for help.

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

Can you help us reach our goal? Learn more at www.sfari.org
My pen took off as if it were writing a story on its own. My thoughts could hardly keep up with it. Tara was now a young adult. What was this need to tell her story and rewind back to her earliest days? Was it the result of all the pent-up emotions I had experienced over the years, or was I channeling this from some creative source propelling me to share our experiences with younger parents and their children first starting out on their journey together - to help smooth out the terrain upon which they will travel?

I wrote the Starabella series with the dream of changing the social climate of classrooms. When Tara was little, I would sit home and cry, worrying about what was happening to her at school; and when I picked her up, it was always worse than I had imagined. It is one of the hardest things a parent has to do - to send a child who is full of enthusiasm and spirit out into the world, and know that child is bullied and see her personal progress be pushed back and have her spirit be diminished by her peers.

My daughter Tara has autism, but would not receive a diagnosis until her early twenties. In her childhood years, the combination of her abilities, talents, challenges and unusual behaviors presented a mystery. Though families today know much more about autism than when Tara was little, social insensitivity still continues towards any child who seems different for any reason. As I hear and read about the increasing bullying and violence in schools, I realize that though I couldn’t go back in time and change things for my daughter, I can try to use our experiences to help children today learn empathy and learn to celebrate differences. I want children to experience the rewards of sharing classroom environments where they feel physically and emotionally safe and are encouraged to share what makes each of them special.

One of the most poignant things Tara ever said was that other children treated her as if she did something on purpose to make them be mean to her or ignore her. Her first song, “Feelings of the Past,” expressed her wish to go back and change the past, because she thought that if she could start over and change herself, others would react to her more positively. It did not occur to her that society also owed her acceptance.

We were a lucky family in that Tara was born with an amazing gift of music. Tara started composing music at an early age. Despite the autism that kept her from communicating effectively socially, she was philosophically precocious, which came out in lyrics to her songs. Often bewildered by the insensitive reaction of other children and her consequent isolation, Tara would come home to her beloved piano (the voice of her soul) and play songs of hope that reflected her belief in the potential goodness in all people. One of these songs, “Welcome to a Bright New World,” became the inspiration for the Starabella series. I shaped the Starabella stories around Tara’s music, using her wonderful talent and ability not only to entertain children, but also to encourage them to have empathy for an unconventional superheroine and to believe in themselves.

Starabella tells the story of a courageous little girl with learning differences, not unlike Tara, who expresses her thoughts and feelings through beautiful music. When she’s happy, her eyes shine like stars. She becomes a kindergarten rock star and leads her classmates and listeners/viewers to a Bright New World, where...

The Fialco Family - Sharon, Tara, Dana, and Marvin

Starabella Audio Book Series

By Sharon, Tara, and Dana Fialco

These three children’s audio books with music and accompanying illustrations were inspired by the music of Tara Fialco. Dealing with autism, Tara composed music to create a magical, musical world of empathy, acceptance of others, and acceptance of self. The series contains 22 original melodies and songs.

Starabella, a courageous little girl with learning differences, becomes a kindergarten rock star who leads her classmates and listeners to a BRIGHT NEW WORLD. There, children play and get along and are accepted for exactly who they are.


Starabella Books are available for purchase at: www.starabella.com
Several years ago, at an Advisory Board meeting for what is now the Abilis Autism Program, a parent said, “You know, some of our kids are going to be ready to leave high school in a few years. You need to start thinking now about how our agency will be best able to meet their needs.” And so we began, looking at programs currently serving young adults with a variety of needs, identifying the unique needs of adults with Autism, and thinking about what a program designed just for those young adults would look like. The Abilis L.I.F.E. (lifeskills, independence, friendships, and employment) program grew out of these early, exciting conversations.

Many of the programs that existed in Fairfield County, CT at the time did not have specialized expertise in Autism. Others focused on “high functioning” adults; people who might be able to do college-level work. Still others had full independence as a program goal; a goal we knew would be out-of-reach for many of the young people we knew. Parents told us about programs that were too far away to be a practical “day program,” and we visited a few that were too off-the-beaten-path to be part of an active community. The more we looked around, the more we knew that we wanted a program that was focused on autism, close enough to our community to be a day program for families who wanted their adult children to live at home or nearby, and based in the wide variety of community settings that are within an hour of where our families live. Finally, as our conversations with families and community members progressed, we knew we had to have a program that was based in a setting where there were a lot of other young adults.

Abilis L.I.F.E. grew out of our experiences over the years with toddlers, children, and teens with autism. We have been focusing on building independence, teaching social skills and communication, and expanding functional generalizable skills will children of all ages. Developing an adult program that continues that work was almost a given.

So, in July of this year, we opened Abilis L.I.F.E., a transition program for 18-24 year olds with Autism. After a successful summer program, we expanded our enrollment this fall. Abilis L.I.F.E. is based in rented space on the UConn Stamford campus, using this space for part of the day and using the entire local community for the rest of the day. The program runs from 8:30-3:30, with a half-day of classroom-based instruction and a half-day of social, vocational, leisure, and community service activities that are conducted in a range of settings in our local area. Our staff include professionals who have decades of autism-specific experience, and (as part of a larger agency) we have close colleagues with extensive experience in adult services. Abilis L.I.F.E. is a true “transition” program – neither a substitute for the rich academic experience a student can get in High School nor a full-day vocational program. We are using established curricula, including Jed Baker’s extensive Social Skills writing, and we are excited to have the input of local and regional experts, including Dr. Peter Gerhardt, in fine-tuning our activities and goals. Abilis L.I.F.E. bridges the gap between High School and adult life. By addressing the skills needed for a successful and happy adult life, we bring our participants to the highest level of independence possible.

Abilis L.I.F.E. is designed around the unique social, communication, and independence needs presented by many adults with ASD. “Our” adults have many skills – they may be great readers, have fantastic math skills, excel musically, or be able to tell you everything there is to know about trains. But, those skills may not be fully used if an adult doesn’t know how or when to ask for help, needs constant prompting to follow written instructions, or has learned to wait for verbal prompts. So, a key component of L.I.F.E. is building social awareness, communication skills, and independent initiation. A trip to the store is not about the final purchase, as much as it is about being able to walk through the store safely, keeping distance from other shoppers, negotiating the checkout line, and interacting with the cashier. Sure, we could get out of the grocery store in 10 minutes, if I do the shopping for him, but our participant will learn an important lesson if I “underprompt” and wait for him to look around and figure out his next step. Sometimes, a participant has a hard time – he might not be able to see a circle in the store.

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

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

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Top 10 Areas of Support for Young Adults With Learning Differences as They Transition to College

By Michael P. McManmon, EdD
Founder
College Internship Program

As the number of people diagnosed with Autism Spectrum Disorders including Asperger’s syndrome, ADD, and other learning differences explodes to nearly one in 100, it is important to address the type of support these individuals will need as they transition to college. Most college age adults with learning differences have challenges in areas of social, organizational, and executive functioning skills. Many go off to a traditional college but aren’t successful because their school does not provide the day-to-day supports they require. Even though these bright young adults have great potential, many will return home from college, isolate themselves, and lose motivation.

The following are 10 key areas of support that can help this growing population transition successfully to college:

Executive Functioning - College students with Asperger’s and learning differences may be overwhelmed by the typical college experience. They need to learn executive functioning skills which include planning, goal setting, and scheduling, along with strategies for residential living.

Social Competency - The social cognitive learning difference is the most abstract of all learning differences. Students need to interpret what others are thinking and feeling by assuming another’s perspective. Students need to learn whole body listening, social inference, and use memory to facilitate friendships. Students need to learn to interpret facial expressions and take perspective on what others are feeling. They can participate in small group sessions to discuss perspectives and practice real-life social situations. They need to work on essential skills including reciprocal conversation, body language, eye contact, and spatial awareness.

Social Mentoring - Social Mentors are individuals who are a few years older than students and act as role models for social and problem solving skills. Research shows that role modeling by positive social mentors in real-life situations carries the highest degree of learning success. For example, practicing reciprocal conversations in a grocery store is much more powerful with a Social Mentor than in a classroom with a teacher. They can meet regularly with students and work to improve social understanding while participating with the students in their special interests. Mentors spend time helping students work on their social challenges while encouraging participation in real-world activities.

Sensory Integration - Students benefit from having a holistic understanding of their sensory issues. This helps them improve attention, decrease anxiety, and increase environmental comfort. Classes or individual sessions that focus on sensory integration and the importance it has in everyday tasks provide valuable insight and help to develop coping strategies. These types of sessions include work on gross and fine motor control and help students understand the effect of the individual senses (tactile, vestibular, auditory, visual, and oculofacial). Calming strategies are taught as part of the curriculum and a sensory diet, or daily activities that help calm and relax, can be established for each student.

see Support on page 41

A Mother’s Perspective on the Struggle to Transition into Adulthood and Mainstream Society

By Elizabeth Suhonen
Mother of an Adult Child with Autism

W hy can’t my high functioning autistic son fit in somewhere? He always managed to get into some kind of program when he was in elementary and in high school. The fit ranged from optimal to horrendous, but none-the-less he had some place to go during the week and on weekends. He had a plan to finish his high school years with an IEP (Individualized Education Plan) and a BOCES (Board of Cooperative Educational Services) diploma. As he reached the age of 18, he embarked into the much awaited transition years.

It’s been four years since his graduation and still he has no direction in life. Though SSA and Medicaid he has been able to access different programs and health benefits. Unfortunately, he bounced from one of these programs to the next with little success. Whether it was working with a job coach, attending an adult day program to learn vocational skills or just signing up for an evening of socialization, he would slowly shut down till he no longer was able to participate. In his own words, “I don’t want to be with disabled people.” I think what he was saying is that he would like to be part of the mainstream community and not feel like a “special” disabled person.

From these past four years I have discovered the paradox situation that exists with my autistic son. He wants to be mainstreamed into society, but unfortunately we have yet to find the means to do so. According to Markus, agencies are for disabled people, of which he wants no part of. His sister and I have helped him acquire regular jobs and volunteer positions. Without incorporating any special job supports, he was doomed to fail in this real world arena. So the big question now remains: What kind of integrated transitional model would work for my son?

I call back to the years when my son was mainstreamed in some of his elementary and high school classes. Granted, sometimes it was a disaster, particularly when he felt overwhelmed and became aggressive towards the other students. Then again, I never will forget his mainstreamed mechanical drawing class. It was the perfect setting, not too many students, a wonderfully engaging teacher, nice classroom and work that my son really enjoyed. My son loves perfection which is mechanically feasible when working with a ruler, dots, lines and a steady hand. His success in drawing was great for boosting self-esteem; he had the opportunity to be with neurotypical kids, which ranks high in his book – he even occasionally socialized with them in the classroom. It was overall a great experience for him.

Currently, my son is living with his father. He pings pongs back and forth from dad to mom because we have no solutions as of what to do with him. In the past four years he has gotten so depressed with his situation that he actually made several attempts to take his own life. Though his patient visits in psychiatric hospitals would temporarily relieve the stress of the suicide ordeal, ultimately he would be discharged and, in the end nothing had really been resolved. I continually juggle my time with running a business with my brother while also being his primary caregiver. All of my family suffers to see how miserable this high functioning individual is and how he completely depends on me for everything, as if he was still a baby. I feel like a complete burnout and often wonder how this will end.

Parents who are in similar shoes as I am need a solution for our high functioning autistic adult children. I know that there are some college programs out there for this population but from what I have researched, they are far and few between. If only my son could tap into some kind of program that did not have the word “disabled” attached to it and would incorporate varying amounts of support in a mainstreamed setting. Say for example a local college which would allow students with autism to attend several classes before they actually sign up for the class. What if that college had an advisor that would support and be a mentor to those students with autism who are looking for meaningful classes that they would like to see Struggle on page 43
YAI Network Autism Workshop
Features Dr. Ami Klin on Nov. 8, 2010

By The YAI Network

Dr. Ami Klin, Director of the Yale Autism Program and one of the nation’s prominent experts in the field of autism spectrum disorders, will discuss “Contemporary Issues in Autism and Asperger’s” at the YAI Network’s full-day Autism Workshop on Nov. 8, 2010. The conference will be held at McGraw Hill Auditorium, 1221 Avenue of the Americas, in mid-town Manhattan (entrance 49th Street).

The workshop will focus on issues pertaining to school-age, adolescents and adults, including:

• Challenges and practical interventions/approaches
• Assessment, treatments and implications of new research

Growing Needs from page 24

• Will the skill enhance the learner’s quality of life?
• Will it continue to be needed in the future?
• Will the skill be needed in multiple environments?
• Is the skill needed immediately?
• Can it be maintained by naturally occurring events?

We need to teach learners with autism skills that they need, that they will use on a daily basis and that increase their ability to navigate their environments. Toward that end, we need to select goals that are in keeping with this vision. Is it important to continue to teach matching for 8 years, to focus on sorting shades of colors, to teach counting with manipulatives as it is taught to young elementary school students?

It makes more sense to transition to teaching in natural contexts and environments. Instruction can be done in the contexts in which skills are needed and in manners that facilitate generalization to natural contexts. Matching and sorting can be taught in the context of laundry folding, and counting can be taught as part of recipe following or snack preparation.

Creating the Appropriate Educational Environment

The right educational environment for an older learner with autism is one that emphasizes teaching in natural contexts and activities. Ideally, much instruction should be done in the community. Purchasing skills can be worked on in stores, transportation skills can be worked on in buses, and vocational skills can be worked on at job sites. To the extent possible, community-based instruction should be provided to aid generalization, increase relevance, and target skill deficits most efficiently.

This requires a shift in some other elements of programming. Data may be collected on number of minutes engaged in a task, number of feet away from an instructor, or number of prompts needed to complete a purchasing transaction. Discussions with parents may center on how independence can be fostered, how proximity of adults can be faded, and how academic skills can be emphasized within real and meaningful activities.

Benefits of a Paradigm Shift

Adolescents with autism need a shift in focus to functional, relevant, meaningful, and preferred activities. Parents and educators involved with typically developing children see adolescence as a time of self-definition and clarification of goals. We need to consider how the needs of individuals with autism are met as they mature and age. Our programming needs to be guided by our vision of their future, by a commitment to improving their quality of life, and by our values on independence and integration into the broader community.

References


Peter F. Gerhardt, EdD is the Director of Education at the Upper School for the McCarton School in New York City and Chair of the Organization for Autism Research (OAR) Scientific Council. Mary Jane Weiss, PhD, BCBA is the Director of Research and Training at the Douglass Developmental Disabilities Center and a Research Associate Professor at Rutgers University. She consults to The McCarton School. Cecelia M. McCarton, MD is the founder and CEO of The McCarton Foundation. Ivy Feldman, PhD is Educational Director at the McCarton Foundation.
Connecticut characterized us as a “social entrepreneur.” Currently, with our Signature Programs, here’s how we do it. We approach a handpicked organization and present an idea about a potential program that they might consider working with us to initiate. We then work with them to develop and implement the program. The Daniel Jordan Fiddle Foundation then funds the development of the program, sometimes for several years, until a sustainable model is created. Our primary goal is not just to develop a vital new program for adults, but also to work together with the partner organization to create a blueprint for other organizations to replicate the program in their own community.

Another aspect of our organization is that we are all volunteers. No one on our staff takes a salary, and we are all committed to volunteerism. We feel it is important to promote the idea of volunteerism in this country and that each person can make a difference. This is a core value of The Daniel Jordan Fiddle Foundation. We are equally committed to having our fundraising proceeds go directly towards our mission.

Above all else, our goal is to enhance the presence of adults on the spectrum in community life. We must respect the individuality and diversity of adults on the spectrum and society must be educated to do so.

Q: Tell us about the Daniel Jordan Fiddle Foundation “Signature Programs” that have recently been announced and what makes them unique.

A: The Daniel Jordan Fiddle Foundation doesn’t solely award grant support as I mentioned. We take it a step further by actually looking at the needs and gaps in the services and programs available for adults on the autism spectrum and then innovating an approach to addressing these needs. Our Signature Grant Programs exemplify unique endeavors that address needs or areas that have not been focused upon. Since we started the Foundation we’ve come to know and work with many programs around the country and we feel fortunate to have forged productive alliances with so many wonderful service providers. Our years of experience in fostering the development of adult programs and supervising those we have supported enables us to identify the entities that can successfully achieve programming goals. For our Signature Programs we have carefully handpicked each organization to partner with based upon their expertise and ability to achieve desired outcomes as well as their track record in implementing sustainable programming.

The Daniel Jordan Fiddle Foundation Signature Grant Programs are destined to become blueprints that address residential, vocational, educational, recreational, and health and wellness supports for adults. We hope other organizations will replicate them in their own communities, especially where such services for adults are lacking. By having our name on each Signature Program along with that of our partner, we are putting a stake in the ground for adults within the service provider organization and enhancing their repertoire. Hopefully we are also inspiring others in the autism community to forge collaborations that better the lives of adults on the spectrum. We are committed to working with each of our partner organizations for multiple years until we are satisfied that the program is ready to be shared with others. We have learned that it takes more than one year to develop quality, successful programs. This is why we have gone in what others have called a groundbreaking direction in establishing suitable and sustainable blueprints that have been cultivated over time. When a program is only funded with a single year grant that organization then has to continually look for yearly funding to keep that program going; it is often challenged to develop a sound model that can be replicated.

We feel that with the great and growing need for adult programs, we must create these blueprints. These blueprints can, of course, be adjusted within the grassroots of a given community but our goal is to provide a plan of action and implementation. Some of the areas our Signature Program blueprints will address include: How to build the program? Ideas for funding the program? How to engage participation? How to assess the challenges and success of the program? It is our view that programs should be constantly evaluated and refined by the service provider. In addition to creating replicable blueprints, the goal is to make the program a permanent entity within the service provider organization.

Using The Daniel Jordan Fiddle Foundation Peer Support Group Program at The Global and Regional Asperger Syndrome Partnership (GRASP) as an example of how we have gone about partnering to develop a signature program, I asked Michael John Carley, Executive Director and Founder of GRASP, “What are some of the gaps in services for the people that you work with?” Michael explained that there are many adults who are now becoming senior citizens and were not self-identified or diagnosed even though they suspected for many years that there was something different about them. Now they are realizing that they are on the spectrum and have many of the same qualities as individuals who live with Asperger Syndrome; a support group for individuals in their 20s and 30s wouldn’t be appropriate for them, as they need support
Obsession

Our 6-year old son, Jack, has made the leap from memorizing people’s birthdays to collecting information about the cars people drive. Now, instead of asking when someone’s birthday is, he points his finger in their face and barks “What kind of car do you drive?” His query resembles the credit card commercial where the large ogres demand “What’s in your wallet?”

What began in early spring as a cute preoccupation has exploded into a fledgling obsession. Driving Jack around all summer was like riding with a member of the census bureau. I’ve learned that Hondas and Toyotas are among the most popular vehicles in New Hampshire, with Acuras a distant third. Not to mention all of the models! This could keep Jack busy for decades. Our earnest, literal Jack, for whom memorizing the make, model, shape, size, color, and fuel source isn’t enough; he also wants to know what each car name means. Have you ever considered what a Prius is? Or how to explain the term Legacy to a 6-year old?

I’m learning a lot about people with Jack’s new interest. Responses to his question vary, but it often makes people uncomfortable to have a 6-year old glare at them and demand to know the make and model of their vehicle. Many squirm. Some snicker and look away while they pretend they didn’t hear him. Others make up cute names; “Why, my car? Oh, we pretend they didn’t hear him. Others make up cute names; “Why, my car? Oh, we

If I think it’s getting out of hand I’ll step in to redirect Jack, and mouth “Autism” while I ruffle his soft brown crew cut with my fingers. But sometimes I sit back and watch them stammer. It’s like being on the sidelines observing a bizarre social experiment unfold. Most curious to me are the people who just can’t divulge this information - it baffles me every time. It’s a car, and he’s six. If you’re reluctant to admit you drive the latest in the Mercedes series, than make something up. Pretend you drive a dented grey Toyota Sienna where the goldfish crackers outnumber the children inside so we can all get on with our lives.

It’s very revealing, this car business. How did our college-age server at Olive Garden come to drive a Lexus? (“My mother’s car” she mumbled out of the corner of her mouth with a self-conscious shrug.) Or how about the CEO of a major company in the area tooling around in a Neon? Cars seem to say a lot of a major company in the area tooling around in a Neon? Cars seem to say a lot of a major company in the area tooling around in a Neon? Cars seem to say a lot of a major company in the area tooling around in a Neon? Cars seem to say a lot of a major company in the area tooling around in a Neon? Cars seem to say a lot of...
It is difficult to think about the future; when you are just trying to make it through each day. In the early 1990’s when my son, Matthew, was first diagnosed with autism and for many years later I consistently pushed any thoughts about his future away. Inevitably, the passage of time and the new realities that accompany it have an unrelenting way of forcing their way into the present. So, eight years ago as my son turned twelve, I literally forced myself to begin thinking about his adulthood.

Where to Begin

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

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

In my son’s case I located, requested and obtained from my school district the services of an outside transition consultant from our local independent living center to help guide me and my son through the process. Over several years, the consultant, I, and a school district representative met twice a year to work on the transition component of his Individual Education Plan (IEP). During these meetings we discussed his educational, recreational, behavioral, community integration and independent living needs. (note: Remember to request that transition assessments be conducted for your child.) In addition, she helped me navigate the myriad of transition “to do’s,” such as: applying for Social Security/Medicaid benefits, registering for the draft, (No exceptions), registering to vote, getting a non-driver identification, and enrolling in our state’s adult developmental disability and vocational rehabilitation systems. She also advised me to address the issues of guardianship and estate planning and what to look for in adult agency for Matthew. Her knowledge of the adult service system was priceless. There are well over 500 Independent Living Centers in the United States. In addition, some adult service providers have begun to provide the service. One caveat, if you work with a transition consultant from an adult service provider...

see Adulthood on page 43

Many people with disabilities rely on government programs to provide them with items like cash, food, housing, day programs, employment support, transportation, and medical care. However, in order to qualify for most government benefit programs, a person can only have limited income and few resources. If a person has too much income or resources, he or she cannot qualify.

But, the government just covers the basics. They do not provide everything a person needs to have a good quality of life. For example, adults (individuals 18 or older) with a disability who qualify for Supplemental Security Income (SSI) receive a monthly check. In most states, they also receive Medicaid automatically.

To receive SSI, adults must have a disability according to the Social Security rules, have low income, and low few assets (in most cases, $2,000 or less). Currently, over three million adults with disabilities receive SSI cash benefits. In 2010, an individual can receive a maximum federal benefit of $674/month (some states supplement).

At any time during your child’s schooling but especially as he or she approaches adolescence it is a wise to step back and review your child’s educational program. Remember the “IDEA” clock is ticking. Ask yourself: How does my child learn? How long does it take him to learn a new concept or skill? How functional will the things he is learning today be to him when he graduates? Will it enable him to be employed? Will it help him enjoy life as an active member of his community? Will these skills help him lead as independent a life as possible?

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

The Process

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

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

This is where the special needs trust comes in. Since the funds in a properly drafted and managed special needs trust are not counted toward the resource limits, a person (beneficiary) can have a trust fund and still qualify for most government assistance. The trust funds can enrich the beneficiary’s quality of life by paying for some goods and services (e.g., vacations, clothes, recreation, special therapies) that government benefits do not provide.

Families with limited assets need to consider establishing a special needs trust because it is not necessary to put any money into an account when they sign the trust. When parents are gone, a portion of their estate, life insurance benefits, and other funds can pass to the special needs trust.

In addition, Special Needs Trusts can be very helpful to families

For more information on this vital resource, please visit www.disabilitiesbooks.com/managing_snt/index.html, where you will find more detailed information about this 242-page book (contents, excerpts, reviews, author bios).
AHEADD (Achieving in Higher Education with Autism/Developmental Disabilities) is a private, community organization that provides support for college students with Learning Disabilities, High-Functioning Autism (HFA), Asperger’s Syndrome (AS), Non-Verbal Learning Disorder (NVLD) and Attention Deficit Disorder (ADD). Originally developed in cooperation with Equal Opportunity Services of Carnegie Mellon University in 2002, AHEADD is specifically designed to support students with impairments in social, communication, and organizational skills by assisting them to develop individualized strategies to manage their college careers with maximum independence. AHEADD’s mission is to establish and maintain best practices of support in a manner that respects students as adults, complements the traditional college accommodations plan, and maximizes use of existing campus resources while maintaining the integrity of campus culture and academic integrity. Program fees vary depending upon program location and range from $3200-5300 per semester. AHEADD currently supports students in more than 13 cities across the country and has recently announced remote supports to reach students beyond proximity of its regional programs.

The AHEADD Model of support can be applied within any campus environment and is tailored to meet the unique needs of each student. It is the most comprehensive and effective private support structure available for students with HFA/AS, NVLD, LD, and ADD who want to attend college but may flounder in the absence of the support made available to them through high school. That said, AHEADD’s effectiveness is predicated on two factors: that its students are willing participants in the program and are able to function with relative independence on a college campus. Students who have difficulty navigating the physical campus or waking up to attend class, for example, may benefit from more comprehensive support than that provided through AHEADD.

The AHEADD Model of Support Involves Four Core Elements: AHEADD Professional Staff Involvement; Development of Campus and Community Support Network; Utilization of Campus Resources; and Peer Mentoring.

Professional Staff Involvement

AHEADD’s professional staff work alongside each student during twice-weekly, individual meetings to address personal and academic goals established at the beginning of each semester, increase academic accountability, and ensure that the student is content with his/her overall quality of life. These meetings are also aimed toward assisting students to develop individualized strategies for managing various aspects of their college careers, including:

- opportunities for social interaction and development of social skills
- self-advocacy
- faculty and classroom communication
- time management and organizational skills
- utilization of campus and community resources

These meetings may last from 30 minutes to an hour or more depending upon the needs of the student on that particular day. Each meeting begins with discussion of upcoming academic obligations, insuring that those obligations have been entered into the student’s weekly responsibilities, and a discussion to problem-solve for incomplete work or unmet obligations. During these meetings, AHEADD staff also assist students in drafting important communication with faculty, peers and peer mentors and, of equal importance, help students to identify and connect with appropriate campus resources. After the academic component of the meeting is completed, staff facilitate conversation and problem solving which is focused on larger, quality of life issues such as campus
Support that Really Works
LifeMAP Coaching for Adults with Asperger Syndrome

By Nomi Kaim
Member
Asperger's Association of New England

Toni (name changed) has lived alone for most of her 63 years, plagued with a nagging sense of hopelessness and never enough money. With no family supports to speak of, she often felt utterly alone. Her tiny government-subsidized apartment used to be crammed floor-to-ceiling with old books, papers, and nick-knacks. Toni never had the wherewithal to sort through them – but things are looking better now. For the first time in her life, Toni has found support that really works.

Toni has late-diagnosed Asperger Syndrome (AS), and she is now a member of the Asperger’s Association of New England (AANE) in Watertown, Massachusetts. One evening, while attending one of AANE’s numerous support groups for adults with AS, Toni divulged that her home walk-in closet had been impassible for over six years. A staff member took note and thought about it, and a couple of weeks later, Toni was set up with her first LifeMAP coach.

The Life Management Assistance Program, or LifeMAP, is a life coaching program designed specifically for adults of all ages with AS and related disabilities – adults who, like Toni, are self-sufficient enough to live independently or with minimal supports, but who also struggle mightily with organizational, social, interpersonal, educational, vocational, housing, or other practical difficulties common to AS. Coaches work actively with their clients one-on-one (or, in some cases, with parents) to strategically overcome specific impediments to clients’ everyday quality of life. Because LifeMAP hires a wide range of coaches from diverse professions – occupational therapists, social workers, nurses, teachers – the program is set up to tailor to just about any practical life challenge an individual with AS might encounter.

When she first met her LifeMAP coach, Toni’s primary goal was to clear out her closet. “I just couldn’t do it alone,” she says, citing her weak executive functioning and attentional deficits. “There were decades worth of ill-fitting clothes, books, papers, and letters from my parents. Physically, emotionally, I just couldn’t bring myself to get started. I didn’t have a linear way of getting through it at all. I didn’t know where to begin.”

Toni’s coach, a bright, patient woman with a keen sense of humor and a background in occupational therapy, quickly helped Toni break her gargantuan task into concrete, manageable, achievable steps. The two of them divided Toni’s supplies into designated categories: to keep, to throw out, to give away. Together, item by item, pile by pile, they cleared out Toni’s closet.

“‘I could never make those kinds of decisions by myself,’ Toni explained, ‘but with my coach helping me I was able to focus and get not get intimidated by the task.’ It felt so good to have an accessible closet that Toni decided to move on to the main room. They started with the photographs – hundreds of them – dating all the way back before Toni’s birth to her parents’ youth. As they created notebooks of her memories, Toni chatted with her coach about her unhappy relationship with her parents, who had not known about her AS. The two of them talked easily together, working all the while, and as the tidy notebooks were lined up neatly on shelves, Toni felt a tainting of her troubled mind, too. “In the process of organizing my belongings, my mind became more organized,” Toni said. Later she added with incredulity, “One year of coaching has done more for me than 40 years of therapy! Really, it has.”

Toni’s life was getting better every day, but things were not to last. Just as her home was emerging from its spatial chaos, Toni lost her coach. With the downsizing economy, the Asperger’s Association lost its partial government funding for LifeMAP – funding that had allowed Toni and a number of other low-income individuals to see their coaches at LifeMAP.

By Vicki Obbe-Hilty and Karen Shulman
Bittersweet Farms

Bittersweet Farms (BSF), a private non-profit organization that provides support services for adults with autism, was opened in 1983, when the incidence of autism was reported to be 1 in 10,000 births. The founder was a Toledo Public School teacher, Bettye Ruth Kay, who became fascinated with autism while teaching a group of adolescents in the 1970’s. She used her classroom as a laboratory to discover how best to create an environment where students with autism could learn and grow. She became very concerned about what life as an adult would be like for her students and made it her mission to learn about and develop adult services. Through her studies, she grew the concept of a “farmstead” where adults with autism could live and work in a rural environment rich with a variety of occupations related to the farm. She envisioned the backdrop of a group of parents and professionals and, with community support, was able to create Bittersweet Farms, an 80 acre farm that afforded 15 individuals with autism the opportunity to live and work together to create a meaningful life. Bettye Ruth Kay’s philosophy of supporting adults with autism incorporated and stressed the importance of truly getting to know each person while matching each individual’s interests and abilities with the various occupations on the farm. The mission of Bittersweet is “to maximize opportunities for individual development of persons with autism by providing an array of premier services to individuals and support to families.”

Bittersweet receives funding through various Medicaid programs, grants and donations. Today we accomplish our mission through programs that have expanded to include serving 40 individuals who live on the farm or in the surrounding community and a day/vocational program that serves 150 additional individuals. Participants can choose activities including horticulture (growing, greenhouses, vermiculture, and crafts), woodworking, animal husbandry, pottery and art, grounds keeping, janitorial, and culinary skills. The opportunities evolve as opportunities are presented – for example, in horticulture we are now developing a Community Supported Agriculture program to offer vegetables to neighbors in the community.

Serving adults with autism was a unique concept itself in the 1980’s, creating a farmstead environment to provide those services has made Bittersweet almost iconic to those who study support services for adults with autism. From the beginning, Bittersweet served as a demonstration program for others to replicate, and virtually all other farmstead programs created for those with autism have studied Bittersweet for inspiration. While people are fascinated with the physical environment and the idea of agricultural occupations, the key to success really lies in the philosophy developed and taught by our founder. ’ur success proves that providing adults with autism with a palate of meaningful tasks can be engaging and therapeutic, but it is also essential for building self esteem and promoting emotional well-being. Meeting the sensory needs of adults through physical activity and movement is a critical part of each day at Bittersweet Farms. Building social connections through a partnership with staff and with those in our small town community has brought many rewards in creating quality of life. The environment is also rich in supports, some naturally following the progression of the seasons, some provided via schedules. We have found over the years that our participants have continued to grow, learn and develop when provided with supportive and empowering experiences.

At Devereux, we understand the unique challenges facing families caring for individuals with autism. We live by the promise that every Devereux program and service must be of such superior quality that we would enroll our own child with complete confidence.

In our service to those living with autism, several factors make us outstanding:
1. Applied behavior Analysis principles are used in all areas of programming.
2. Instruction occurs wherever necessary: in school, at home and in community settings toward the goal of less restrictive placement and a higher quality of life.
3. Goals and objectives are highly individualized and take the form of skill acquisition and positive behavior development.
4. Parents and guardians are critical team members, and we focus on parent education and support.
5. We focus on employment preparation and placement.

For more information, call one of the following autism-specific Devereux programs:

Devereux Connecticut, Glenholme School
81 Sabbaday Lane
Washington, Connecticut 06793
(860) 868.7377

Devereux New Jersey
200 Mantua Grove Road, Building #4
West Deptford, New Jersey 08066
(856) 595.6400

Devereux New York, Millwood Learning Center
14 Schuman Road
Millwood, New York 10546
(914) 941.1991

Devereux Pennsylvania, Kanner Center
390 East Boot Road
West Chester, PA 19380
(610) 431.8100

Devereux Center for Autism Research and Education Services
620 Boot Road
Downingtown, PA 19335
(610) 873.4930

Devereux Community Adult Autism Partnership Program
150 E. Pennsylvania Avenue
Suite 400
Downingtown, PA 19335
(610) 269.5318 x 224

Or contact our National Referral Office at 800.345.1292.
www.devereux.org

Devereux offers programming and services in 11 states – Arizona, California, Colorado, Connecticut, Florida, Georgia, Massachusetts, New Jersey, New York, Pennsylvania, and Texas.
A Horse of a Different Color: A Review of the Effectiveness of Hippotherapy

By Thomas Zane, PhD, BCBA, Director Center for Applied Behavior Analysis at The Sage Colleges

Hippotherapy (“hippo” means “horse” in Greek), sometimes also called “equine-assisted therapy” or “therapeutic riding”, involves the use of horses to provide various therapies to persons who display a number of challenging conditions (American Hippotherapy Association; AHA). According to its website, the horse is used because of the “multidimensional movement” of this animal, which provides “sensory input through movement which is variable, rhythmic, and repetitive.” The movement of the horse then requires reactions on the part of the rider that mimic movements of the pelvis while walking. Such movement is claimed to be beneficial to the rider, with the speculation that mobility, posture, and balance can be enhanced (e.g., Bliss, 1997).

Smith (2009) noted that only registered occupational, physical, and speech therapists incorporate horses into treatment, using the horse as a sensory “input”, much like other sensory objects and activities. For example, physical therapists see hippotherapy, in conjunction with other motor tasks planned by the physical therapist, to facilitate improved gross motor skills, such as sitting and walking. Some occupational therapists assert that using hippotherapy along with “standard intervention strategies” from the field of occupational therapy can focus improvement on fine motor control and other skills, such as daily living skills and sensory integration. Speech-language pathologists incorporate the movement of the horse to stimulate and use the “physiologic systems” that are supposedly related to speech and language. Note that in all three of these professions, there is recognition that therapies in addition to the horse are used simultaneously. Additional psychosocial benefits are suggested as well, such as improved self-esteem, self-image, and more adept interpersonal relationships (Bliss, 1997).

Hippotherapy has been used as a therapeutic tool frequently with adults with Autism Spectrum Disorders and other developmental disabilities, such as mental retardation and Down syndrome, and for a wide variety of challenges, such as hearing loss, visual impairment, cerebral palsy, spina bifida, and muscle dystrophy (e.g., Apel, 2007; Barker & Dawson, 1998; Bizub, Ann, & Davidson, 2003, as cited in Bass, Duchowny, & Llare, 2009; Bliss, 1997; Johnson, 2009; Swindell, 2010; Trotter, Chandler, Goodwin-Bond, & Casey, 2008). Women who survived domestic violence have participated in hippotherapy to overcome their low self-esteem and empower them to attain career goals (e.g., Froeschle, 2009). This therapy has also been used with persons with eating disorders (e.g., Christian, 2005; Marx & Cuabella, 2003), depression (e.g., Folse, Minder, Aycock, & Santana, 1994), language and learning disabilities (e.g., Macauley & Gutierrez, 2004), and with girls who were sexually abused (e.g., Reichert, 1994).

Therapeutic use of the horse for persons with disabilities is quite popular. Suhfras (1996) reported that there were more than 500 accredited riding centers serving more than 25,000 patients nationwide. According to the North American Riding for the Handicapped Association (NARH), there are over 3,500 certified instructors, 800 accredited riding centers worldwide, and over 42,000 participating children and adults.

There does not seem to be a standard protocol for administering hippotherapy. For example, Froeschle (2009) and Christianson (2005) failed to delineate their procedures for using the horse in therapy. In the published case studies, there is quite a variety of approaches. One example was Bliss (1997), who described a weekly therapeutic riding session. Persons with significant physical (e.g., uncontrolled epilepsy, serious scoliosis) and mental (e.g., severe mental retardation) challenges were disallowed from participating. Riding helmets and a physician’s permission were required. The activities during the sessions included becoming familiar with the horse, learning how to mount and dismount, feeding, grooming, and riding. Depending upon the particular needs displayed by a rider, the therapist might include other sorts of activities while on the horse.

New Treatments from page 14

management, and other skills needed for individuals to succeed in adulthood.

Cognitive Enhancement Therapy aims to help adults with problems they experience in thinking, planning, and socialization, which are extremely important for adult activities like completing college, finding a job or getting a promotion. Participants begin through the use of horses to learn about social contexts and how to act wisely in social situations by developing the abilities needed to understand other person’s perspective, evaluate social contexts, and be foresighted.

Enriched Supportive Therapy uses individual therapy to help adults learn about their condition, manage their emotions and stress, improve their social skills, and cope with everyday problems. Since adult life can be particularly challenging, both emotionally and socially, for individuals with autism spectrum disorders, this treatment focuses on helping individuals meet and overcome these challenges so that they can succeed in adulthood. In the treatment, the management of emotion and arousal is vital. Participants learn about the impact of stress on their lives, how to identify their own early cues of distress, and how to apply effective coping strategies. Ultimately, these activities are targeted toward improving interpersonal functioning, as well as life success and achievement.

The Perspectives Program is one of the first of its kind to develop and test new interventions specifically for adults with autism spectrum disorders. It is expected that this program will be a resource for individuals and families in the Pittsburgh community who live with an autism spectrum disorder. It is also expected that through the testing of these two novel treatments, the relative benefits of cognitive, supportive, and emotional interventions for adults with autism spectrum disorders will be firmly established. Eventually, it is hoped that by providing this evidence, such treatments will become a standard of care and routinely available to help adults with these conditions maximize their strengths and lead successful and fulfilling lives.

Individuals interested in participating in the Perspectives Program are encouraged to contact the University of Pittsburgh Autism Center of Excellence by telephone, 1-866-647-8436 (toll free), or e-mail, autismrecruiter@upmc.edu.
The Benefits and Dangers Behind Social Networking

By David J. Krainski, MS, GCD
Vocational Counselor/Instructor
New York Institute of Technology
Vocational Independence Program

In a daily basis, I walk into the classroom and find my students all glued to the computer screens waiting for class to begin. Before I ask them to begin class, I quickly glance over their shoulders to see what they are doing online. What I find is that a majority of my students are using some sort of social networking website. Websites like Facebook.com and Twitter.com give users the opportunity to create personal profiles, post photos, play games, and connect with friends both new and old. For those on the Autism Spectrum, websites like Facebook can play an especially important role in their social lives. It affords them the opportunity to directly message and chat with friends which, for someone with social difficulties, can be much easier than picking up a phone.

Along with the numerous benefits of social networking, there are an equivalent number of dangers also associated with it. Recently, the media has brought to light a number of these issues with some of the more publicized threats including online stalking, identity theft, and cyber bullying. To illustrate the dangers of social networking, I often share a personal story with my class in which a social network account I had was hacked (taken over without my knowledge or permission). The person who had hacked into my account began messaging my friends and asking for money that I needed quickly in order to get out of trouble I was in. Luckily, none of my friends had fallen for this trick and I was able to regain control and change the password to my account. It was my personal account that had been hacked, but I often think about what would have happened if my school account had been hacked into. I wonder how trusting my students (many of whom are on the autism spectrum) would be if someone they presumed to be me was messaging them. Would they hand over personal bank and credit card information to a teacher in need?

As a vocational counselor and classroom instructor for students with learning and other educational disabilities, I log-off my computer when students that while social networking sites can be a big help, they can also pose a true threat to an individual’s job search. In my classes, I discuss with my students the topic of networking as it pertains to the job search. However, I am very aware that networking skills can be difficult for an individual on the spectrum to master. That’s when online social networking site like Facebook comes into play. An individual can go online and post a note to their friends that they are looking for a job. All it takes is a simple posting and may get to other online friends they have. In fact, a few of that individual’s friends may post a similar note in hopes of helping their friend find a job. Networking for a job in this manner is simple and may not cause the anxiety that can be created by making a phone call or having a face-to-face conversation with another person.

Beyond Facebook, MySpace, and Twitter, there are social networking websites available with the specific purpose of helping people market themselves and find jobs. Websites such as LinkedIn.com provide people with a forum to post their resume, list their skills, and make connections with people in the same profession in which they are interested in working. Job seekers will often use these sites to search through profiles and find possible candidates for job openings. Just keeping a profile on a site like this could be beneficial, as you never know who it is that might see it.

As mentioned previously, with each benefit of social networking, there is an equal danger and that especially holds true when it comes to an individual’s job search. Just as human resources personnel are using social networking sites to find potential candidates for job openings, they are using these sites to screen job candidates as well. In fact, according to an article from CIO.com, the number of HR managers that used social networking sites to research potential employees nearly doubled from 22% in 2008 to 45% in 2009. These numbers are staggering and what they imply is that an individual is not careful, something they have posted online can possibly prevent them from being hired for a job.

What we need to keep in mind is that in private and with friends, most people conduct themselves differently than they would in their professional place of work. So what happens on social networking sites can play an especially important role in their social lives. It affords them the opportunity to directly message and chat with friends which, for someone with social difficulties, can be much easier than picking up a phone.

Law from page 15

Currently, organizations such as the Association of University Centers on Disabilities (AUCD) and the American Academy of Pediatrics (AAP) are working together to address the lack of transition services for teens with disabilities, particularly in health care. Individual states have also worked to ensure their educational laws conform to the requirements of IDEA (Massachusetts, New Jersey, and New York have implemented regulations concerning transition process since 1990). Some states have even required more than the federal law concerning transition services. In particular, New York has enacted a regulation stating that transitional support services must be provided to students with ASD at the recommendation of a special education teacher with background in teaching students with autism. Federal law does not require a specific provision of services based on a student’s disability.

In addition to federal and local involvement in providing transition services, courts also have provided oversight of the IEP transition planning process. During the first decade of the twenty-first century, parents increasingly have brought federal disability claims in court, under the IDEA, seeking monetary awards and compensatory education, as well as adjustments to their child’s IEP and transition plan or its goals. In most cases, the courts have applied a two-part test to analyze the appropriateness of an IEP, and its statement regarding transition services. In order to pass the test, the school district must have complied with the procedures set forth in the IDEA regarding transition services, and the IEP must have been reasonably calculated to provide the child with educational benefits.

The steady but slow increase in these claims is evidence of the court’s growing involvement in the transition process. Currently, there exist no more than 50 cases that discuss transition from school to adulthood for children with disabilities. Of these cases, a mere 15 provide insight into the guidelines and measurements a court uses to determine whether the transition plan (providing for transition to adulthood), was proper. In general, most of the cases involve claims concerning the implementation of a child’s IEP, i.e. whether there was a transition plan or whether it included a statement for transition planning. A few involve claims concerning the content of the transition plan, i.e. whether the child’s IEP was complete in light of a one-page transition plan that abruptly ended mid-sentence. Currently, there are a handful of cases that involve children with ASD. However, the majority of these ASD claims are limited to short-term transition plans, such as a young child’s transition from one district to another, or transition from public to private (or at home) settings. Overall, they fail to explore long-term transition planning, such as preparing an adolescent for employment and/or higher education. Nonetheless, the cases hint at the courts’ future involvement in ensuring each IEP includes an appropriate transition plan; one that hopefully addresses the unique needs of an adolescent with ASD.

Unfortunately, the case law that does exist highlights shortcomings in the area of transition. The cases fail to cover a wide array of disabilities (including ASD as well as other disabilities with behavior, emotional, and learning impairments), and the courts rarely comment or establish measurements for the substance of the transition plan. Further, many important questions are left unanswered, causing a delay in the development of the transition process. For instance, the amount of transition planning required in an IEP to ensure that the student is knowledgeable of the transition services offered, whether a more transition plan is required, or whether such resources and supports is critical to the adolescent’s transition to adulthood, was proper.

On a positive note, the existence of transition services is sufficient, or whether a more modern plan is required, or whether such resources and supports is critical to the adolescent’s transition to adulthood, was proper. In general, most of the cases involve claims concerning the implementation of a child’s IEP, i.e. whether there was a transition plan or whether it included a statement for transition planning. A few involve claims concerning the content of the transition plan, i.e. whether the child’s IEP was complete in light of a one-page transition plan that abruptly ended mid-sentence. Currently, there are a handful of cases that involve children with ASD. However, the majority of these ASD claims are limited to short-term transition plans, such as a young child’s transition from one district to another, or transition from public to private (or at home) settings. Overall, they fail to explore long-term transition planning, such as preparing an adolescent for employment and/or higher education. Nonetheless, the cases hint at the courts’ future involvement in ensuring each IEP includes an appropriate transition plan; one that hopefully addresses the unique needs of an adolescent with ASD.

In addition to being a proud parent of an adolescent daughter with ASD, Sheryl Dicker, JD is Assistant Clinical Professor of Pediatrics and Family and Social Medicine at Albert Einstein College of Medicine, the Children’s Hospital at Montefiore, Rose F. Kennedy University Center for Excellence in Developmental Disabilities. Sheryl has been working for over three decades as an advocate on behalf of those challenged by developmental disabilities, poverty and the child welfare system. Sheryl was appointed by President Clinton to the President’s Committee on Mental Retardation and served as then Governor Clinton’s General Counsel of the Department of Human Services. Before joining the faculty at Einstein, Sheryl was the Executive Director of the NY Parent Training and Education Center for Justice for Children (the nation’s first children’s commission based in the judiciary).

Kristina Majewski is the sibling of an adolescent with special needs and has a long interest in the capacity for individuals with disabilities. Kristina is a law student at Cardozo Law School, Class of 2010 and is a LEND Law Student Fellow at the Einstein College of Medicine.
Behavior and facilitate adaptive behavior is critical. The “one-to-one paraprofessional” that you fought for in the Department of Education is not generally available as an option in adult programming.

Independent Living and Residential Life

Some individuals with autism will require full-time support to live in the community and some will require very little support. There is a broad continuum of options that exists, but the waiting list for residential opportunities is daunting. You may be expecting me to say, “Get on the waiting list right away.” I’m not.

OPWDD and most agencies don’t want you to wait in the same way. If you have a family member and individual in question are really ready for placement. The important thing, at this early stage, is to prepare your family member for community living.

Overnight Stays - Make sure your family member spends nights away from home. It’s an important rite of passage and there are many ways to accomplish this. The first time away from home should be positive, planned, and brief. Don’t wait for an emergency. Have the individual spend the night at a relative’s or friend’s home. Use OPWDD-funded overnight respite programs. There is availability throughout New York City and people with DD can start with just a night visit or a weekend. And of course, sleep away camp is a terrific and fun option, but usually requires a longer commitment. You may have to build up to it. This separation is particularly difficult for parents. The person with autism and the disability, in most cases, adapts pretty quickly. If not, all the more reason to keep trying under controlled and positive circumstances. Then, in an emergency, you can have options and your child has skills and experience. It’s an important first step.

Independent Living Skills - 1 once read an article in The New York Times about a freshman at a prestigious college. She said she fully expected that the hardest part of college life would be the schoolwork. It wasn’t. She wasn’t prepared to deal with living with others or with budgeting to support your family member learn concrete skills like budgeting, food preparation, and responding to emergencies.

Travel Training - Travel training is an integral part of independence. When a person is travel trained for a fixed route or for general travel, the door opens to an array of social and work opportunities. In fact, most employment training programs require travel training skill. Start young with basic skills like finding a room within a building, graduate to crossing a street safely, then train on navigating the local neighborhood. Some may never reach the ultimate goal of using public transportation independently, but each step allows for more freedom and opportunity, the Ontario’s Premier’s Summit Award in Medical Research, The Centre for Applied Genomics, the Chedoke Health Corporation, the Mayberry Family Fund, the Children’s Treatment Centre Foundation and the SickKids Foundation.

For more on the study, see this by post by Dr. John B. Vincent on the Autism Speaks blog at http://blog.autismspeaks.org/2010/09/16/new-cns-on-chromosome-x/. About Autism

Autism is a complex neurological 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 a 100 Day Challenge in the United States, affecting four times as many boys as girls. The prevalence of autism increased 57 percent from 2002 to 2006. The Centers for Disease Control and Prevention have called autism a national public health crisis whose cause and cure remain unknown.

About Autism Speaks

Autism Speaks is North America’s largest autism science and advocacy organization. Since its inception in 2005, Autism Speaks has invested over $142.5 million to research through 2014 and developing innovative new resources for families.

The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and locating for and ensuring the future of all individuals with autism and their families. In addition to funding research, Autism Speaks also supports the Autism Treatment Network, Autism Genetic Resource Exchange and several other scientific and educational programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2 and an award-winning “Learn the Signs” campaign with the Ad Council which has received over $235 million in donated media. Autism Speaks’ family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit and a community grant program. Autism Speaks has played a critical role in securing federal legislation to advance the government’s response to autism, and has successfully advocated for insurance reform to cover behavioral treatments. Each year Walk Now for Autism Speaks events are held in more than 80 cities across North America. To learn more about Autism Speaks, please visit www.autismspeaks.org.

This article was reprinted with permission from Autism Speaks. You may view it on their website at www.autismspeaks.org/press/male_linked_mutation_autism.php.

The New York City District 75 Travel Training Program within the Department of Education (DOE) before a child graduates. There is a strong curriculum and success will prove useful for future program placement. You do not need to be a student of District 75 to avail yourself of this program, though you do need to be a DOE student with a disability.

Day Service/ Employment Programming Is Important Too!

This is the main focus of most transition planning and a very important part of an individual’s future. Ignore labels. Just because you visited a one day habilitation program and didn’t like it doesn’t mean that this service won’t be a good fit for your family member. The most common questions are: Is he/she bright and motivated? What kind of training will the agency provide? Does the supervisor have a lot of knowledge and experience? If the answer is no to any of these questions, ask for another case manager or try another agency. If the person you get is willing to do research with and for you, he or she can be a real asset.

Help is Available!

Don’t be discouraged. Yes, there is a lot to do and a lot to think about, but there is help available. And some things are more urgent than others depending on your family member’s abilities and needs. Feel free to call YAI LINK at (212) 273-6182 and an experienced and knowledgeable Intake Specialist will provide you with information and resources to help you access the support you need for your family member. YAI LINK makes referrals both within and outside of the YAI Network and keeps a vacancy database to help people get connected to agencies that have availability.

Jennifer Shaoul is the Senior Coordinator of Intake at YAI LINK, the intake, information and referral unit at the YAI Network.
An Adult with Autism’s Positive Experience in the Workplace

By David Rubin

Adult with Autism

People see kids who are developmentally disabled and on the autism spectrum and think it’s so wonderful there are so many treatments and so many “special” schools for kids like us, but once we grow up, what do you do with us? Thank G-d, we don’t get warehoused anymore. Sheltered workshops work for some, but some of us are too bright to be adding parts and assembling the latest gadgets. You’ve seen Criminal Minds? Can you picture how bored to death Spencer Reid would be in such an occupation? Unfortunately, we can’t all work for the FBI and not all of us individuals with Asperger Syndrome are geniuses (If you’re really interested, my IQ has been measured at 126, fourteen points below genius, though twenty-six points above average). We can’t all be mainstreamed either. Many of us don’t have the interpersonal skills to be a doctor or a lawyer. I tried working as a substitute teacher. It was a horror. I had no idea how to behave as a teacher or any other kind of authority figure. My license was lifted after two years.

I spent almost thirteen years in an earlier screen printing shop, doing nothing more than cleaning squeegees and reclaiming screens after a job. It was the kind of over-simple but tedious work best suited to my intellectually limited co-worker. He once told me how he wished he was smart like me. I pointed out that, despite my intelligence and education, I was still working right next to him doing the same work. I hoped it made him feel better, because it depressed me!

Fortunately for me, Thomas Siniscalchi understood our needs, so he started Possibili-Tees, a custom screen printing nonprofit business located in Staten Island, NY, created to hire people just like me.

Tom, Executive Director of Possibi-Tees, and I met fifteen years earlier when he started the screen print shop I worked for earlier for individuals with mental disabilities. I worked there because developmental disabilities often carry with them mental disorders, such as chronic depression, which I keep under control with medications and counseling.

Two years ago, Tom became frustrated with the way I and other employees were treated, so he left to start Possibili-Tees and invited me to join him.

Possibi-Tees is different from a sheltered workshop in that it is not a program. It assumes we employees are employees and treats us like it. In other situations, there are special counselors, trained to look over the shoulders of “mental health service consumers.” In the first year of Tom’s previous screen printing shop, we were required to interrupt the day for group counseling. Tom stopped this and fired the counselor. One of our first firings in that shop was because the employee went outside to beg for cigarettes and change. Tom said that this was inappropriate behavior for an employee, regardless of his disability. As employees, we all have the responsibility to adhere to employment requirements such as grooming, attendance, quality control and attention to task; yet it still works to serve our special needs, such as allowing, even demanding, that we take the time to see psychiatrists and psychotherapists as needed.

I’ve been working here at Possibi-Tees ever since, two days a week, using the internet to find suitable customers and philanthropic donors.

David Rubin is an adult with autism who works in sales and marketing at Possibi-Tees, a screen printing business in Staten Island, NY that employs individuals with developmental disabilities.

The Calais School

Wilmington, NJ  973.884.2030

www.thecalaischool.org

About the Kennedy Krieger Institute

Internationally recognized for improving the lives of children and adolescents with disorders and injuries of the brain and spinal cord, the Kennedy Krieger Institute in Baltimore, MD serves more than 13,000 individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how disorders develop while pioneering new interventions and earlier diagnosis. For more information on Kennedy Krieger Institute, visit www.kennedykrieger.org.

Autism spectrum disorders (ASD) is the nation’s fastest growing developmental disorder, with current incidence rates estimated at 1 in 110 children. This year more children will be diagnosed with autism than AIDS, diabetes and cancer combined, yet profound gaps remain in our understanding of both the causes and cures of the disorder. Continued research and education about developmental disruptions in individuals with ASD is crucial, as early detection and intervention can lead to improved outcomes in individuals with ASD.

possibilitytees@possibilitees.org  Visit our website: www.possibilitees.com  www.mhnews-autism.org
Funding from page 13

funding from the school district or their student has already graduated from high school, then families must attempt to secure funding from state offices of vocational rehabilitative services or state office of developmental disabilities. This can be a difficult and arduous process. Vocational Rehabilitative Services may state that they provide these services already; however, their focus is not upon the aspects of the world of work most vital to students with ASDs. Most offices will not provide assistance with issues concerning independent living or social skills that many transitional programs provide. Dependent on family status may be reluctant to provide funding for transi-
tion programs for higher functioning individu-
als with average to above average intellectual abilities without clear documentation that the student’s adaptive functioning is delayed.

Since the regulations governing the im-
plementation of the legislation where only final in Fall of 2009, institutes of higher education with an existing transition pro-
gram, or those considering initiating one, are only now in the process of applying for recognition. As of this past August, no pro-
gram had yet received approval from the Department of Education. If families or self-
advocating individuals are considering a post-secondary transition program as an option, they must consider if it will be the right fit for their family. The best advice I can give is that they should ask any prospective programs about their status with the Department of Education. Students with autism should be aware of some im-
portant definitions and criteria in the new legislation. In order to be eligible for an approved program a student must meet the legislative criteria for having an intellectual disability, and be in the process of applying for special education or related services by a local education agency. The federal regula-
tions allow for a rather broad definition of intellectual disability and leave it to the discretion of the individual transition program to identify what definition they will use.

The passage of the Higher Education Op-
portunity Act and the recent legislation of higher functioning individuals on the aut-
ism spectrum. The financial aid that may become available at this time is tough, but it is an important beginning. By providing financial support for these families, to help pay for post-secondary transition programs, we are increasing the odds that students with a diagnosis of an Autism Spectrum Disorder will be able to have access to a college educa-
tion and secure meaningful employment.

Paul Cavanaugh, PhD, MSW is the Direc-
tor of Academics and Evaluation at New York Institute of Technology Vocational Inde-
pendence Program. Ernst VanDergeij, PhD, MSW is the Associate Dean and Executive Director of the Institute of Technology Vocational Independence Program.

I’m angry we have to go through this process. And afraid. Could the court pos-
sibly rule against us?

Because no matter how much I know logically all that we have done for our son, it never feels like enough. It’s the endless loop in my head: Could’ve, should’ve. After he was first diagnosed, I continually felt as if there were always one more therapy, one more intervention. One more thing we didn’t do out there to try, that would be the critical one, the magic, miraculous cure that eluded us, and that if we didn’t try it, meant we weren’t good parents. The recriminations.

So I do now. Sometimes, in dark moments, I think, I have not been a good enough mother.

Because if I had, he wouldn’t be autis-
tic anymore.
Get Noticed - Advertise in Autism Spectrum News!!
is that people conduct themselves in a manner that is congruent with how they would act around friends in private. The only difference is that an individual is not careful, their online profile could be visible for all to see and that the hiring manager of the company that individual applied to later on, could review their comments or photo that was only meant for friends.

What one hiring manager may find offensive on someone’s online profile, another may not. I instruct my students that when posting online, they should not steer clear of using swear words, making comments that could be perceived as nasty or hateful, and stay away from dis-#

Networking from page 35

communication, misunderstanding can result in a conflict that can stem from an evidence-based methods to improve empathic accuracy in which individuals can learn how to attend to and interpret the more subtle aspects of communication (Ickes, W., “Empathic Accuracy,” 1997). Poor communication can be an impediment to understanding and intimacy in any relationship. However, when one member of a couple has Asperger Syndrome, significant differences in communication style and skill can particularly strain a relationship. The partners may feel misunderstood, ignored, criticized, or insulted when that was never the intent of the other. So much can be in play contributing to communication issues that it is important to fully understand the styles and approaches of each partner, as well as the particular skill strengths and challenges each brings to the relationship.

Communication is really the glue that binds people together. Many enter relationships expecting to find perfect communication in a partner. We expect misunderstandings and finding our way with each other early on, but when understanding does not progress, the partners may become frustrated that they have serious “relationship” issues. The stronger the love, the more upset partners may become about an understanding that will allow that can arise. Sometimes one member or a couple. It is critical to understand the expectations and experiences of the social use of small talk; and communicating everything informationally, without awareness of metatext (the how and why we are saying something the way we are). Assessing communication skills and styles can be very helpful in resolving misunderstandings if a concerted effort to improve communicative interactions can be made through a counseling and skill development intervention.

Partners can sometimes have very different expectations of social behaviors. Some may want frequent engagement with the other, others may prefer a more private existence with occa-##

Couplehood from page 16

There are three other points I make to my students when speaking about social net-##

It is always important to remember the many positive things that drew a couple together. Asperger Syndrome is not a collection of negative traits, but a different way of seeing the world based on brain differences. Just as couples where one is right handed and one is left handed sort out how to sit, lie together, or arrange things, couples with Asperger Syndrome need to learn how to accommodate and support each other. In 1990, Deborah Tannen published “You Just Don’t Understand,” a popular bestseller that addressed the differences between male and female communication and how these differences develop. Some of the differences couples experience when one has Asperger Syndrome, the similar issues as those many other couples face. But Asperger Syndrome, in all its variations, can add an additional element of complexity to a relationship that needs to be addressed if a couple is struggling to relate.

What Can Help?

If you recognize yourself, your partner, or your relationship in the descriptions above you may be thinking that nothing can change. It is true that communication style is difficult to modify, but some changes can change. It is true that communication style is difficult to modify, but some changes can be invaluable. An intervention plan that incorporates communication changes for each member, specific skill development in areas causing misunderstanding, and concrete suggestions for family or couple functioning in the areas delineated earlier is critical. Sometimes working with marital or family counselors, understanding the unique contributions Asperger Syndrome makes to relationships cannot help couples develop useful plans for change. Of course, finding all that a couple needs in one professional may not be possible, in which case a cooperative effort between someone who can truly understand the aspects of Asperger Syndrome that are salient to the particular couple and someone who can address relationship and communication issues and make concrete recommendations may be the best available alternative.

Encouraging a therapist to learn about As-##

with an individual or a couple. It is critical to understand the aspects of Asperger Syndrome that are salient to the particular couple and someone who can address relationship and communication issues and make concrete recommendations may be the best available alternative. Encouraging a therapist to learn about Asperger Syndrome and find someone who can provide support is a first step. However, a couple may view their relationship as having significant trouble and the other may not. One partner may suspect Asperger Syndrome and the other may be in total dis-##

sussing topics online that some could find controversial, like politics. I also advise my students that they need to take care in the types of pictures they post online and to stay from posting pictures that may be consid-##

ered risqué or depict alcohol/substance use. To assist my students in deciding if what they are posting online is appropriate or not, I advise that they should ask themselves one question: “What if my parents or grandparents would see it?” If the answer to this question is a “no,” it is likely that what is about to be posted online may be considered inappropriate to some ulterior motives, poor forgiveness, and righteness. This kind of simple technique like this can mean the all the difference when it comes to landing that interview or not.

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Encouraging a therapist to learn about As-##

With everything that is reported in the media about social networking websites, it may be hard to see the benefits. However, it is important to consider that these sites allow for all levels of participation on the spectrum disorders. Many individuals find a place in which they can keep connected with people they meet in school and meet others who share commonalities. The old adage is “knowledge is power,” and that holds espe-##

sentially true when posting online. Differences can also learn how to accommodate and support each other. In 1990, Deborah Tannen published “You Just Don’t Understand,” a popular bestseller that addressed the differences between male and female communication and how these differences develop. Some of the differences couples experience when one has Asperger Syndrome, the similar issues as those many other couples face. But Asperger Syndrome, in all its variations, can add an additional element of complexity to a relationship that needs to be addressed if a couple is struggling to relate.

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LIFE from page 23

able to wait to pay for his purchase, he might find the store too loud, he might not be able to take “just one book” out of the library. But, as we go through the day with our participants, we welcome each “slip up.” These communication gaps, social misses, and behavior challenges tell us what we need to teach next, and help us continue to focus on social and communication fluency. Abilis L.I.F.E is based in our community. In designing this program, we felt very strongly that we wanted to be able to help our young adults use as much of our community as possible. We wanted to expand their leisure options, make sure they knew how to be safe, give them skills they need to work, live, play, and shop in their community. Our location, in the middle of Downtown Stamford is the perfect backdrop for this kind of program. All successful autism programs focus on generalization of learned skills – a skill is only useful if you can use it when you need it. And the best way to get generalization is to teach skills in the natural contexts, with natural consequences. What better way is there to teach safe walking on a sidewalk, careful crossing of driveways, and waiting for the “walk” sign than by taking a walk around the block!

Abilis L.I.F.E. is located near other young adults. This very key piece of our program came from the insistence of parents. Having watched their children grow up in Fairfield County schools surrounded by their typical peers, “our” parents wanted their teens and young adults to continue that experience after they left High School. We’ve learned from our work in integrated and inclusive public schools that just having kids with disabilities and typical kids in the same space isn’t “enough,” but it’s a great place to start. Now that we are in our classroom, we can see so many opportunities for our students to learn from their peers – sometimes informally (like when waiting in line to pay for lunch) and maybe also in a more structured way. Having our classroom in this setting has another advantage. It reminds us, the “adults,” what is typical behavior for a teenager or young adult. When our group looked a little groggy on a recent Monday morning, we laughed at how they looked like everyone else around us – having a hard time getting back to routine after a relaxing weekend. And, if we need to know what social behavior to teach, how you’re supposed to behave in public spaces, and what language to focus on, we can look around and get our answers. We have already learned so much from our participants about the unique needs presented by autism, the specific needs and interests of young adults, and the compelling need to build as much independence as possible.

Abilis L.I.F.E. currently enrolls three students, with a fourth to start this winter. We are currently accepting applications for a Spring, Summer, or Fall start in the program. Our program is the best fit for someone 18-24 years old, with a diagnosis of Autism, whose challenging behaviors are minimal, and who can work successfully in a small group setting. Interested families, agencies, and school districts can start the application process with a phone call to the Director of the Abilis Autism Program, Dr. Susan Izeman at izeman@abilis.us or (203)324-1880, x327 or the Abilis L.I.F.E. Program Coordinator, Elizabeth Reagle at reagle@abilis.us or x301.

Support from page 26

Internships and Community Service - Internship placement is a crucial part of the college transition experience, especially for students with learning disabilities. Students who can apply their academic and social knowledge directly in real-life workplace experiences will be successful. Teachers can help students by assessing their interests and abilities to find appropriate internships. Group meetings wherein students can openly discuss personal experiences, performance, advocacy, challenges, and what they have learned about themselves during the internship process are very beneficial for all who attend.

Community service can be a less stressful opportunity for students to learn more about themselves and what they like. Through community service, students gain a sense of accomplishment and achieve personal growth by contributing their time to help others.

Wellness - A healthy lifestyle can help a person both reduce stress and elevate their level of healthy functioning. Exercise and a good diet increases energy, promotes positive social behaviors, and strengthens the immune system. It can also improve self-esteem as well as perceptions of others. Starting with individual assessments, students can then focus on the areas of nutrition, hygiene, sensory diets, weight control, and physical fitness.

Reframing - Reframing is a concept that helps students connect the dots between behavior and emotion. Reframing is a therapeutic intervention that students’ self-understanding and provides daily structure to one’s life.

A gathering once a day, usually in the morning, provides a consistent schedule where students can evaluate their feelings and plan out their day. This may seem mundane, but students with Asperger’s and learning differences may crave consistency, so a daily practice strongly aids the alteration of behavioral patterns.

AHEADD from page 33

involvement, roommate relations, completion of activities of daily living (i.e. hygiene and diet), getting a job, etc. As the student and AHEADD staff develop a rapport, this aspect of each meeting becomes increasingly meaningful and productive.

Development of Campus and Community Support Network

Outside of the twice-weekly meetings, staff regularly liaise with Disability Resource Services regarding development and implementation of accommodations, as well as with each student’s faculty and related professionals. The objectives and benefits of these interactions include:

- developing awareness within the campus and community network of support
- ensuring that all team members are aligned in their perception of the student's needs and performance
- problem solving when there is a disconnect between the student and professor's perception of his/her performance
- providing a consistent message from all team members to the student

Utilization of Campus Resources

While AHEADD’s professional staff provide particular expertise in supporting students with Learning Disabilities, HFA/AS, NVLD and ADD, it is important to engage “natural supports” through existing campus resources which provide essential expertise in the following areas:

- Student Health and local medical professionals
- Disabilities Resources
- Counseling and Psychological Services
- Academic Development/Learning Center for content tutoring and writing assistance
- Academic Advisors and Faculty Mentors
- Extracurricular activities and Clubs
- Career Counseling
- Work-study programs
- Peer Mentoring Program

The Peer Mentoring Program is comprised of “typical” students who volunteer their time to provide (empathetic) social opportunity and outlet for students enrolled in AHEADD. The Mentors also contribute valuable insight into challenges that our students may be facing during social situations which AHEADD’s staff can then incorporate into discussions during the twice-weekly meetings.

Our Peer Mentors enter into the program through a comprehensive orientation program and are then paired with an AHEADD student. The mentors and students make arrangements to socialize independent of staff involvement and aim to get together at least once every week or two. AHEADD also hosts a monthly “large group” mentoring activity during which all of the Mentors, AHEADD students and staff are invited to join in various events around town including dinners, bowling, pot luck and board game parties, as well as picnics and athletic games.

Peer Mentors are asked to participate in two “decompression” meetings over the course of each semester during which AHEADD staff provide professional guidance in response to any challenges the Mentors are experiencing.

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“We Learned About Your Organization in Autism Spectrum News”
Graduates from page 19

appropriately exit and enter a conversation and how to respond (at best). He will need to be able to say, "I'm sorry, could you repeat that for me so I can understand it better?" or "Let me summarize our understanding thus far to see if I've gotten everything." Unfortunately, many busy supervisors loathe taking the time to repeat instructions and make sure the trainee understands.

It's important that the VR agency have connections to businesses and employers in the community who will take the extra effort to ensure success for these valuable and skilled employees. VR should have contacts with employers who would be willing to hire individuals with a range of strengths and weaknesses, abilities and liabilities, and who would be willing to work around individual challenges.

We've got a long way to go before companies are willing to accommodate productive employees with neurological disorders like AS, NLD or ADD. Yet, if employers recognized that some people who look, think, or work differently can still be productive employees, they might be more willing to accommodate different work styles or a longer learning curve.


Coaching on page 43

As her health improved, Toni and her new coach gradually moved on to other areas of her life. They tackled her long-standing spending problem (Toni said it was easier to spend wisely just by virtue of being able to locate all of her belongings!). They sorted out her finances and organized all her medical information.

Coaching on page 43
Adulthood from page 32

make sure that they are advocating for the interest of your child, and not as recruiter for their agency’s services.

IDEA and Transition

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

Transition Services - Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include:

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

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

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

• Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); and/or, continuing and adult education, adult services, independent living, or community participation;

• Is based on the individual child’s needs, taking into account the child’s strengths, preferences and interests;

• Includes instruction, related services, community experiences. The development of employment and other post-school adult living objectives, and if appropriate, acquisition of daily living skills and functional vocational evaluation. [34CFR 300.43 (g)] (20 U.S.C. 1401(34)).

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

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

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

• The student must be invited to participate in IEP meetings to discuss his/her goals after high school.

• You can request additional IEP Transition meetings during the school year.

• You can invite local provider agencies to attend your child’s IEP meetings.

• The IEP, including the transition plan, should incorporate person-centered planning, and reflect the student’s interests and skills.

• The work experiences or “community based work assessments” chosen should be based on the student interests and skills. Students should not be placed in a community based work assignment simply because it is available.

• Any placement should help the student develop skills in a setting of personal interest to him/her, and where his/her unique abilities can be utilized and improved with job coaching.

• Annual transition goals in the IEP should lead to successful post-high school outcomes.

• Student progress should be documented and measurable.

• Obtain progress reports about your child’s community based work experiences.

• Maintain a portfolio and resume of your child’s experiences, progress reports, and favorable reviews from your child’s supervisors. (Adapted from Wrightslaw: Transition Planning, Graham & Wright)

Start Today

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

• Contact adult provider agencies before your child “ages out” to see if they will provide job coaching for your child during the transition phase. This may help to ensure that there will be no break in services between school and the beginning of the adult program.

• Invite representatives from adult provider agencies to attend your child’s IEP meetings.

• You can request that the IEP team allow your child to experience community based centered experiences during his final years under IDEA if you feel that is appropriate.

• Contact your state office of developmental disabilities about enrollment requirements and supports.

• If applicable, contact your state office of Vocational Rehabilitation about job training and support. Be aware that the supports provided under this system are time limited.

Some Final Thoughts

Since you are the captain of your child’s transition team you will also have to foster a feeling of active cooperation among your child’s school district, teachers, future adult service providers, and governmental agencies for several years. Knowing your child’s rights, timely planning and acting in incremental steps will help to make the process less stressful. It will also enable you and your child to have time on your side.

Coaching from page 42

which did a lot to put Toni at ease about living alone, far from friends and family.

Although Toni’s no-fee coaching arrangement is now an anomaly (and a lucky break!), her experience with LifeMAP is hardly unique. LifeMAP has transformed the lives of AS adults in all walks of life, from seasoned professionals facing communication hurdles with their supervisors or colleagues to recent high-school graduates stuck in their bedrooms playing video games. Some of the most vocal “satisfied customers” are parents of young adults on the autism spectrum who are relieved to see their recently-grown children receiving the supports they need to gain skills and independence as they head off to college or look for or begin jobs. The parents of a newly-employed young man with AS wrote in, “Our son is so proud of himself right now and so happy to have a job. So far, we have had quite a few compliments about him, from both his boss and two co-workers. His anxiety level has plummeted since he has a job where people are encouraging him rather than putting him down. We have to believe it is the coaching that is making the difference. Thank you!” Another couple reported, “We are more than pleased with our son’s coach! She has helped him through the paperwork to get him on an active positive person on my own. I went from living aimlessly to a more focused approach to life. Now I’m thinking more specifically about what I want to do with my time, what I want from my future, what kind of legacy I want to leave behind.”

Two years old and counting, LifeMAP is eager to spread its legacy of success.

Struggle from page 26

attend? A local college could offer them the possibility of living on campus during the week and then going home on the weekends. If it if...but isn’t that how great ideas begin? Our society seems better equipped to deal with the physically handicapped and mentally challenged individuals than with the high functioning autistic population. With the ever-staggering increase in numbers of autistic adults, this mom thinks it would make sense to find ways to mainstream this population so that one day they can be useful contributors to our society.

Elizabeth Sahonen is the mother of an adult child with autism and Board Member/ Treasurer of a local NY chapter of CHADD.
Starabella from page 22

children play and get along and are accepted for exactly who they are. An interactive segment of the story encourages children listening to help the children in Starabella’s school. The combined audio and visual presentation enhances comprehension and appeals to different styles of learning. Because the pages only have captions, children can go back through the picture books and tell the stories in their own words. The original music in the stories highlights the messages. Tana composed and played the piano or keyboard for 17 of the 22 songs which have been professionally audio orchestrated. These songs, many of which she wrote as a child, are now inspiring other children. Children will dance, dream and sing along. The Starabella series itself is an example of inclusion. The story highlights the special relationship between Tara and her sister, Dana. A talented singer, Dana has always been supportive of Tara and they have come together through their music. In this way, they acquire empathy for her by the time she enters kindergarten.

Mentoring from page 30

As a means to accomplish the “support to families” part of our mission, we have always had families or professionals visit Bittersweet Farms to learn about the model. In recent years we have seen a dramatic increase in interest. For a while, the idea of a farm and keeping a group of people with autism living together was not popular with the public. Despite our humble beginnings, we have grown. In the past eight years, we have seen a dramatic increase in interest. For a while, the idea of a farm and keeping a group of people with autism living together was not popular with the public. We now have a vision of serving those who are interested in creating a role of advocating, supporting, and flattened the Starabella class and dreams. Through happy in their wondrous new classroom, sometimes the children face social dilemmas. Starabella becomes the catalyst for solving the various social conflict situations. We have performed the class series, looking at the wonder as Starabella, through her special connection to the stars and the goodness in her, magically transforms into a kindergarten rock star. She leads her classmates and listeners to the Bright New World where all their unique paths meet in harmony.

Through the combined efforts of the many parents journeying on their paths and advocating for their children, there are now better educational options for children with special needs. Parents must seek out which program best serves the needs of their individual child. For parents who feel that it compromises their children’s civil rights and optimal social and learning potential to be segregated into separate classrooms, more and more children are now members of inclusive communities where people cooperate to reach common goals.

With her innate strength and determination, Tara went on to earn a certificate in Early Childhood Education. She put her education to good use by bringing her music message to her study buddy. Based on what we learned about child development, I became inspired to write children’s interactive, educational shows incorporating Tara’s music. Tara performed these shows regularly in schools throughout Honolulu. These shows served as precursors to the Starabella stories. Some of the dialogue in Book Three came directly from the children I observed at the schools where Tara performed. I noticed that anyone can become the object of ostracism. Combining Tara’s childhood dilemmas with those of other children, Starabella covers a broad spectrum of social situations children confront at school every day.

We hope children everywhere will see how brilliantly their eyes will shine and how they become empowered when they have the courage to act on their own to reach out to another child and see that child reach out to another child and on and on and on. These are the hands that can unite the world. Together we can create the world of our dreams. Get ready to rock! Starabella is leading the way.

Starabella (Books One, Two, and Three) is written by Shara Fialco, based on music composed and performed by Tara Fialco, narrated and sung by Dana Fialco and illustrated by Anton Petrov. Accompanying CDs and of AP Music, Inc. Books are available for purchase at: www.starabella.com.

AFAA from page 9

AFAA will collect information, develop strategic solutions and advance the national agenda. Autism Speaks, the nation's largest autism science and advocacy organization, and the New York Center for Autism are the AFAA organization chairs. The AFAA partners are: Global Communities of Support; Alpine Learning Group; The Autism Program of Illinois; The Daniel Jordan Fiddle Foundation; Easter Seals; Hallmark Community Solutions; Organization for Autism Research; Southwest Autism Research & Resource Center; and the University of Miami-Nova Southeastern University Center for Autism and Related Disabilities. For more information, please visit www.afaa-us.org.

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Hippotherapy from page 34

From the perspective of evidenced-based practice, the question that naturally arises is whether there is evidence that hippotherapy is effective in causing any positive, measurable change in some aspect of functioning? Electronic databases were searched for research articles on experimental research testing the effectiveness of hippotherapy. The results showed numerous publications and testimonials describing the therapy, but no well-designed experiments on its effect. An example of a study that seemed to be experimental and showed a positive result is the one that multiple baseline – will hopefully be used to begin to generate a solid research base to empirically determine the effects, if any, of this therapeutic approach. However, with the current state of the evidence, hippotherapy should not be considered an intervention that has a solid research base showing effectiveness and thus should not be recommended for use.

Dr. Thomas Zane is an Associate Professor in the School of Education and the Founder and Director of the Center for Hippotherapy and Applied Behavior Analysis at West Virginia University. He is a licensed psychologist in New York and Massachusetts. Dr. Zane has published in various journals and books, presented at regional, national, and international conferences, and has been an invited lecturer in Ireland and the Republic of China. He is the Director of the Center for Applied Behavior Analysis at The Sage Colleges, and offers a Master's Degree in Applied Behavior Analysis and Autism, a distance-learning graduate program.

References


bath of hormones that reduce brain plasticity, neurogenesis and immunity. Chronic anxiety explains why aging individuals with autism frequently exhibit reduced variety but greater frequency of repetitive behaviors. As our brain ages, “neurons that fire together, wire together.” As a result, repetitive behaviors, which originally provided purpose (e.g. sensory stimulation), with age become an automatic, procedural memory-based behavior to any stressful situation.

Frequently observing this ingrained behavior to any stressful situation. automatic, procedural memory-based behavior originally provided a purpose (e.g. sen-

3) Reduce the dependence of psychiatrists and spectrum clients on psycho-
tropic medication coincident with steps 1 and 2.

4) Constantly review clinical journals to identify potential application of new childBooK spectrum research to adults—e.g. PANDAS (Pediatric Autoim-

This has led us to consider moving upstream in the unwanted behavior chain, from the consideration of the behavior itself to its frequent precursor: chronic stress. It has been shown that chronic stress, over time, can cause limbic neural circuitry to transition from normal vigilance to pathological anxiety (Anantha Shekhar, 2005). As people on the spectrum age, the neuroanatomical differences seen in young individuals with autism persist (Armin Raznahan 2010). However, chronic anxiety appears to decrease the threshold level of behaviors and reduces the range of responses available, thus automatically locking the client into ever more frequent & automated responses. And as Dr. Ole Ivar Lovas suggested in 1977 and Dr. Frank Cicero confirmed (F.R. Cicero, 2007), these “locked in” behaviors may become difficult to extinguish and, in time, they become their own reinforcement.

This has led our behavior services department to formulate a strategy to first focus on reducing chronic stress, by building a more prophetic environment. Over time this will eliminate many unwanted behaviors. Remaining behaviors will be treated traditionally using functional analysis and Applied Behavior Analysis. This strategy requires 4 major changes:

1) Care staff has to be educated in envi-

inual memory to reduce brain stress due to less frequent environmental e-

Reducing Off-the-Shelf Technology

In the 1970’s Gordon Moore developed a set of curves that said, as electrical circuits became smaller, they would become more complex and useful, be in greater demand and therefore progressively cheaper. His predictions have held up until today: we can purchase a personal, portable computer for under $100 and have several clients who use PDA’s (Personal Digital Assistants or talking watches) to keep on schedule. The combination of higher performance and lower costs creates a real opportunity for people on the spectrum generally and for adult services specifically. Adult services are a sector of the economy that has a growing number of clients but suffers from annual budget cuts. Using off-the-shelf technology offers the opportunity to replace uneconomic ongoing labor expenses with one time capital investments.

For example, we would not think of employing one full time staff today to monitor the door of a group home resident when the door can be monitored electronically. Electronic or electromechanical devices are enabled patient and vigilant. When programmed appropriately they can provide clients on the spectrum with stress reducing information and individually tailored learning opportunities. We anticipate increasing use of small, portable electronic devices to reinforce schedules and provide stepped instruction to reduce client stress due to uncertainty. We anticipate increasing use of audio and video messages blended in with our client’s regular media diet to assist in developing improved decision making, prompting and stepped learning of functional activities.

Reduce the Use of Medications

A 2003 study found over half of autism spectrum patients were prescribed psychotropic (antidepressants, neuroleptics, anxiolytics, and mood stabilizers) drugs (Michael G. Aman, 2003). A second study tracked autistic spectrum drug use over time. It found that drug use increased with age and elapsed time (Anna J. Ebenson, 2009). Because of this perva-

Identifying New Treatments and Interventions for Adults

The combination of concurrent advances in neuropsychiatric research and genetic research has provided an increasing menu of potential autism treatments and interventions. My 5 year old nephew, who was diagnosed with autism at 18 months, has never really displayed a consistent or comprehensive set of autism symptoms. Since diagnosis he has worked weekly with occupational therapists, physical therapist and speech therapists. Up until recently we attributed his progress to their expertise. We did not know what to attribute his almost cyclical retrogression and recurring periods of unwanted behaviors. It was by accident we were referred to PANDAS research and discovered that his behavior might be attributed largely to recurring infections. After talking to other PANDAS parents, my nephew’s parents are moving ahead with treatment.

Until my experience with PANDAS I thought I had the ability to both keep up with developments in autism and help translate those developments to my clients. Now I am less sure. Previously I viewed PANDAS as a childhood treatment for a childhood disease. But now I realize that I have several middle age clients who exhibit behavioral reactions to infections and reduced behaviors when on antibiotics. While the NIH still states that PANDAS can only be a childhood disease, a small but growing body of research indicates otherwise (Germana Moretti, 2008, G Maina). Unfortunately, since the vast majority of research on the autism spectrum is conducted on individuals under 18, we adults have to build better resources and relationships to explore and advocate for adult applications or adaptations to promising research on youth.
Helping families understand and cope with a child on the spectrum can only be achieved by providing them with information that is based upon the best scientific research and medical evidence.

Autism Spectrum News provides vital news, information, education, advocacy, and resources in the community that adhere to our strict evidence-based standards.

Contact us today at (508) 877-0970 and visit our website www.mhnews-autism.org to learn how Autism Spectrum News can help provide your organization or community group with an affordable and trusted source of autism education.