

AUTISM SPECTRUM NEWS™

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

FALL 2010

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 3 NO. 2

Addressing the Growing Needs of Adults

Transition Planning for Learners with Autism Spectrum Disorders

By Peter F. Gerhardt, EdD,
Mary Jane Weiss, PhD, and
Cece 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, 1992, 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

see Fiddle Foundation on page 28

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Autism Spectrum News Theme and Deadline Calendar

<p>Winter 2011 Issue: "Understanding and Treating Conditions Associated with Autism" Deadline: December 15, 2010</p>	<p>Summer 2011 Issue: "Advancing the Science-Based Agenda for People with ASD" Deadline: June 15, 2011</p>
<p>Spring 2011 Issue: "Autism and the Law Throughout the Lifespan" Deadline: March 15, 2011</p>	<p>Fall 2011 Issue: "Understanding and Addressing the Unique Needs of Individuals with Asperger's Syndrome and High Functioning Autism" Deadline: September 15, 2011</p>

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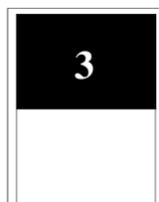
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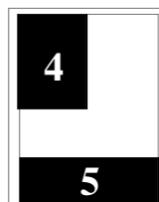
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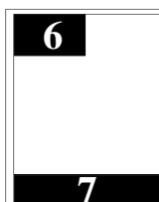
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From the Publisher

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, trained professionals and direct care workers, community recreational 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 energy needs to be directed towards adults on the spectrum, and that is why this issue of *Autism Spectrum News* is entirely 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 the 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 services as a young child, and received support in school through their IEP (Individualized Education Plan). However, with age come 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 hardship for 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 Education for All Handicapped 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 stunned to learn that when their child leaves school, the mandate for services ceases" (Ruth C. Sullivan, PhD, www.narpaa.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 trouble 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 and effective 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*, themed "Helping Families and Individuals Cope with Stress," we interviewed Dr. Robert H. Ring, PhD, Senior Director of the New Pfizer Autism Re-



Ira H. Minot, LMSW

search 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 lifetime diagnosis. 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 entitlements, 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 (such 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 adults 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 Global 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 before companies are willing to accommodate productive employees with neurological disorders like Asperger Syndrome, Nonverbal Learning Disability or Attention Deficit Disorder. 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." 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 improving 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.afa-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 engaged citizens of the US is not so much limited by their disability itself but, rather, by the failures of the system charged with supporting them. According to a statewide study conducted in Florida in 2008 by The Center for Autism and Related Disabilities (CARD), approximately 67% of the 200 families of 18-22 year olds

with autism surveyed did not have knowledge of transition services; 73% indicated they needed help with their job; 63% need help with daily living; 78% do not know of agencies or professionals who can help them find work; and while 74% want to work, only 19% were currently working. The economic cost of this system's failure is far reaching. These costs can be expected to grow exponentially without a better and more comprehensive understanding of the needs of adults with autism and plans for productive, effective, efficient and respectful solutions."

It is clear that there is a growing crisis in services and supports for adults with autism. It doesn't have to be this way for the next generation of adult children, and we owe it to them to do what is necessary so that they can enjoy dignified and worthwhile lives as contributing members of society.

With each issue of *Autism Spectrum News*, we are helping to fill an educational void with articles from leaders in the autism community who address vital areas of interest including the latest advances in autism science, legal issues, transitioning into adulthood, helpful information for parents of a newly diagnosed child etc., by experts in the field of autism that we hope will inform and inspire you.

Let me conclude by telling you about our exciting roundup of themes in the upcoming quarterly calendar of *Autism Spectrum News*. Our winter issue's theme will be "Understanding and Treating the Associated Conditions of Autism." The deadline for articles and advertising for this important issue is December 15th.

Our calendar continues with our spring issue which will focus on "Autism and the Law Throughout the Lifespan." Next summer we will take an in-depth look at "Advancing the Science-Based Agenda for People with ASD" and next fall our theme will be "Understanding and Addressing the Unique Needs of Individuals with Asperger's Syndrome and High Functioning Autism."

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community.

As a nonprofit organization, we ship thousands of free copies of each issue of *Autism Spectrum News* to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website at www.mhnews-autism.org. On our website you can subscribe to receive your own personal hardcopy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients and staff.

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

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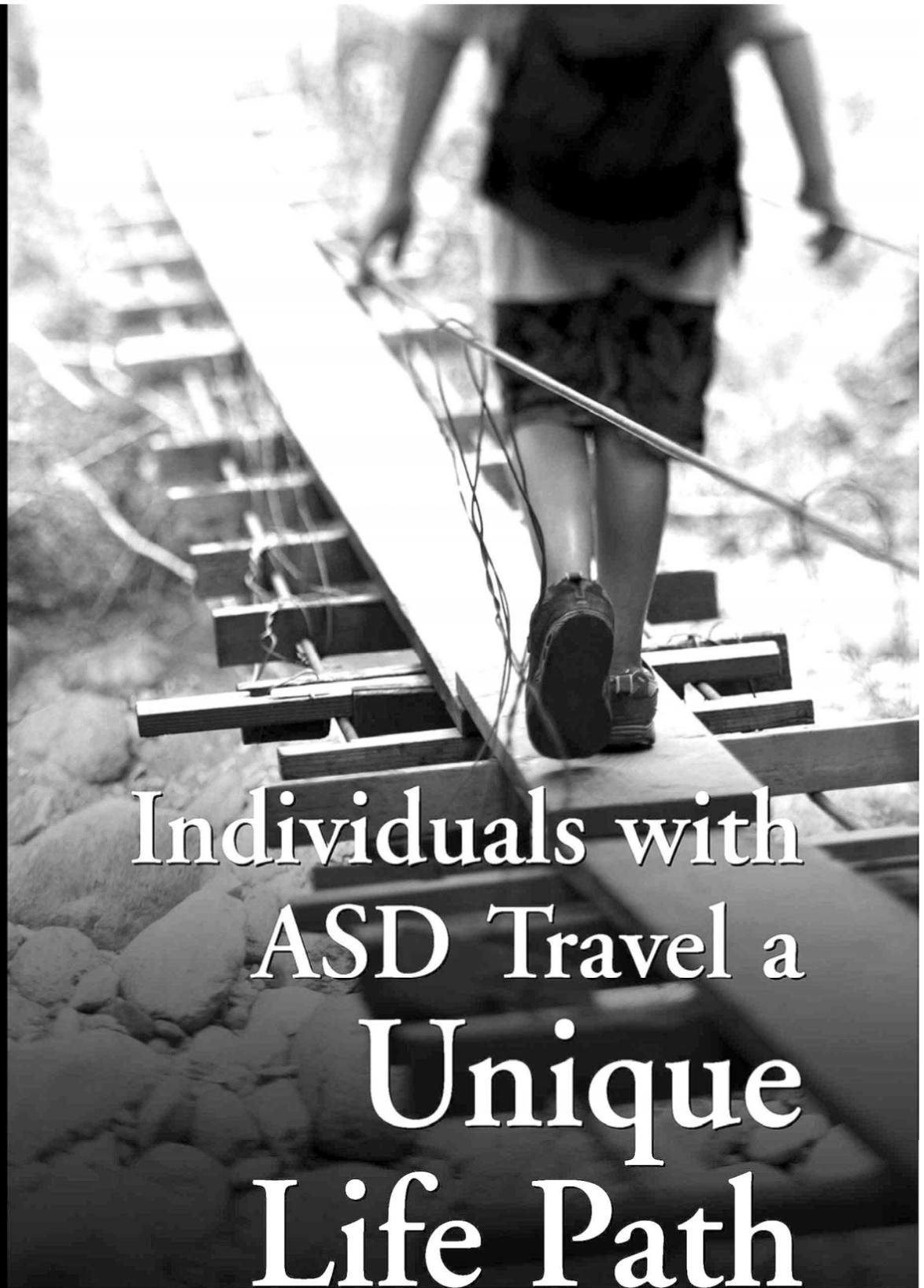
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AUTISM SPECTRUM NEWS DESK

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 **Rebecca 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 gazing 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 when 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



Rebecca Landa, PhD, CCC-SLP

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 gazing when their caregivers actively engaged them, such as pointing at the toy and expressing excitement. However, high-risk sibs 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 some-

thing novel and would give babies an opportunity to pay attention to either an object or their caregiver," said Dr. Rebecca 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

see Gaze on page 37

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.



Linda Meyer, EdD, MPA

"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 Af-



fairs 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's 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.affaa-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,

see AFAA on page 44

Transition to Adulthood: It's Not Just About a Daytime Activity

By Jennifer Shaoul
YAI Network

When people with autism and other developmental disabilities, their families and professionals discuss "transition planning," the focus is generally on day programs, supported employment, 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
Through the Office of People
with Developmental Disabilities

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 support. These services may help you achieve goals through individual support and training for your family member and through 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 indi-



Jennifer Shaoul

vidual 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.omr.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 your 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 leads to much more 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.

If your family member will require public benefits such as Medicaid to support necessary services for the foreseeable future, it's important to ensure that any inherited money or current assets be secured in a Special Needs Trust. You will need specialized legal services to create this trust. We recommend downloading the Developmental Disabilities Planning Council's Planning for your Future Guide (www.ddpc.state.ny.us/publications/childcare_education/planning_for_the_future_2006.pdf) to understand and prepare for all aspects of your child's future.

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

see *Transition* in page 36

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 profes-

sionals 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 member and a special hotel conference rate, visit yai.org/conference. The conference brochure will be available on the website and online registration will be available in the winter. You may also 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 devel-

opmental 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, New Jersey and Westchester, Rockland, 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/NIPD Network or to obtain services, call 1-866-2-YAI-LINK or visit www.yai.org.

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Serving People with Disabilities and their Families

The Impact of Autism on Adult Residential and Day Services

Alfred W. Norwood, BS, MBA
Behavior Specialist
CDS Unistel



Alfred W. Norwood, BS, MBA

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 re-diagnosed 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 "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, by definition, behavioral 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 comorbid illnesses) are driven by stress resulting from chronic anxiety.

Living in a perpetually anxious state means continuously living on the borderline of fight or flight generated behaviors. Chronic anxiety also means living in a

see Residential on page 47

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New Source of Funding for Post-Secondary Education

Higher Education and Opportunities Act Allows New Opportunities for Individuals with ASD

By Paul K. Cavanagh, PhD, MSW and Ernst O. VanBergeijk, PhD, MSW
New York Institute of Technology
Vocational Independence Program



Paul K. Cavanagh, PhD, MSW

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 intellec-



Ernst O. VanBergeijk, PhD, MSW

tual 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 func-

tioning 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

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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



Shaun M. Eack, PhD

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



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Transition on the Spectrum

The Challenges of the Law for Young Adults with Autism Spectrum Disorders

By Sheryl Dicker, JD, Professor and Kristina Majewski, Law Student Fellow Albert Einstein College of Medicine

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 de-



fine “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 re-

quires 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.

see Law on page 35



Complete Guide to Autism/ Asperger Syndrome

From relationships and making friends to emotional management and social skills



Dr. Tony Attwood

A clinical psychologist from Brisbane, Australia, Dr. Tony Attwood has over thirty years of experience with individuals with autism, Asperger’s Syndrome, and Pervasive Developmental Disorder (PDD). He has worked with several thousand individuals, from infants to octogenarians, from profoundly disabled persons to university professors. Dr. Attwood works in private practice in Brisbane, but is also adjunct professor at Griffith University, Queensland. He presents workshops and training courses for parents, professionals, and individuals with autism all over the world. In addition, he is a prolific author of scientific papers and books. His books and videos on Asperger’s Syndrome and high-functioning Autism are recognized as the best offerings in the field. Over 300,000 copies of his book “Asperger’s Syndrome: A Guide for Parents and Professionals” have been sold, and it has been translated into twenty languages.

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Couplehood and Asperger Syndrome: Improving Important Relationships

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

As 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 friendlessness 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 treatment 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



Lynda Geller, PhD

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 more challenging as time goes by. The helpful, organizing attitude of one member, or the loyal and intelligent manner of the other, may have drawn them together, but what brings them to 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 interesting special interests that have led to a successful career; others have more eccentric 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

see *Couplehood* on page 40

When Childhood Doesn't End

By Liane Kupferberg Carter
Parent and Autism Activist

The 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 guardianship of all legal, medical and financial decisions on Mickey's behalf. 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.



Liane Kupferberg 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? Which medications best treat his seizures? 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, 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 parenting choice I make. It doesn't feel good.

When Aretha Franklin called, I was my most friendly and chipper. We made an appointment. Then I stewed in an icy 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 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?

Would she ask him if he liked living with us? If we were kind to him? What if

see *Childhood* on page 38

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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

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Thinking Outside of the Box: Modifying Evidence Based Approaches to Fit the Needs of Adults on the Autism Spectrum

By Susan M. Cortilet-Jones, MS, LMHC
Life Skills and College Coaching Specialist
Discovering Your World



Susan M. Cortilet-Jones, MS, LMHC

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 spectrum. There is nothing more gratifying than helping these individuals and their families to overcome challenges and de-

velop 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).

see *Modifying on page 38*

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Chapel Haven West Prepares Graduates for the Real World

Two-Year Program Helps Young Adults with Developmental Disabilities and Autism Succeed in Life, Work & College

By Catherine Sullivan-DeCarlo
Vice President of Admissions
Chapel Haven

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 life skills, social confidence and college/work supports are helping young adults live productive, meaningful lives

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

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The Challenge of Vocational Rehabilitation Programs for Individuals on the Spectrum

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



Yvona Fast, MLS

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.

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.

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).

see *Vocational Rehab* on page 42

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Family Creates the Starabella Series: A Model of Inclusion for All Children

By Sharon Fialco
 Author/Producer
 Fialco Productions, Inc.

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, chal-



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

lenges 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 chil-

dren 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 consequential 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

see *Starabella* on page 44

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.

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Beyond High School: Building a Meaningful L.I.F.E.

By Susan G. Izeman, PhD, BCBA
Director
Abilis Autism Program

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 au-



Susan G. Izeman, PhD, BCBA

tism, 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

see *LIFE* on page 41

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Growing Needs from page 1

friends or acquaintances, and one's marital status and/or nuclear family membership. Unfortunately, the primary emphasis of most transition planning is the "school to work" transition process which, while critically important, should be considered a necessary yet not sufficient component for an adult life of dignity and quality. It is a limiting view, a truncated definition of adulthood. Effective, comprehensive transition planning should include goals across a variety of life domains that span society's widely accepted definition of competent adulthood.

**Other Elements of Effective Planning:
Focus on Family Involvement and Support**

Direct family involvement is essential for effective planning, implementation, and service coordination for the adolescent with autism. In addition to their person-specific expertise regarding their son or daughter, parents are often well-versed in state of the art autism treatment and the current state of autism services in their area through their networking with other parents, attendance at conferences, reading of relevant texts and access to the internet. Steps need to be taken to encourage a family's active participation in the transition process.

Many parents are well versed in the current state of autism services in their area through their networking with other parents, attendance at conferences, reading of relevant texts and access to the internet.

Perhaps the most important role that family members can play in the transition process is that of advocate. Stressors multiply



Peter F. Gerhardt, EDD

during the transition years for parents of children with autism (e.g., an unfamiliarity with the adult system of services and supports, the potential inability of this system to meet the needs of their nearly adult child, the stress associated with life-cycle transitions in general, and uncertainty regarding the future). However, the need for parents to forcefully advocate on behalf of their son or daughter does not diminish with age. In fact, given the challenges that they and their child with autism will most likely face in the transition process, the need for parental advocacy may be even more critical.



Mary Jane Weiss, PhD

**Other Elements of Effective Planning:
Curricular Emphases**

In addition to parental involvement, the program itself must shift in emphasis. While skills should always be selected with functionality in mind, this becomes imperative as students age. Individuals should be instructed in skills that matter, in contexts that matter, and with materials that matter.

As students reach adolescence, a critical evaluation of their skills in adaptive living must guide programming. Skills selected should be skills that help them navigate their



Cece McCarton, MD

environments independently and effectively. What are functional skills? Brown et al, (1976) identified some questions to help determine whether a skill is indeed functional. These questions revolve around the themes of independence and relevance:

- If the learner can't do it, will someone else have to?
- Is the skill age-appropriate for the learner?

see Growing Needs on page 27



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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.



Michael P. McManmon, EdD

Students also need to prioritize tasks and communicate more effectively. Each student should work to develop organizational and follow-through strategies for his/her academic schedule. By working in small groups and using visual prompts, these young adults can learn how to carry these skills into their college classes, the workplace, and daily life.

Individual Tutorials and Study Groups - Individual and group tutoring sessions that meet throughout the week keep students on track. These sessions should be designed to help students in specific areas where they have difficulties as well as improving basic academic skills. Students need assistance selecting college courses and professors that will best meet their needs. They may also need assistance in signing up for accommodations provided by the disabilities support center on campus.

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 conversation skills 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 olfactory). 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.

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

By Elizabeth Suhonen
 Mother of an Adult Child with Autism

Why 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 also had a direction. 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. Through SSI 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.



Elizabeth Suhonen

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 recall 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 ping 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

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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 midtown 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

- A practical guide to assist professionals who are working with people with ASD

Dr. Klin is the Harris Professor of Child Psychology and Psychiatry at the Yale Child Study Center. He obtained his Ph.D. from the University of London, and completed clinical and research post-doctoral fellowships at the Yale Child Study Center. He directs the Autism Program at Yale, which is one of the National Institutes of Health Autism Centers of Excellence.

Fees for the workshop are \$175 for regular registration; \$95 for a family member. For more information or to register visit yai.org/autismconference or contact Abbe Wittenberg at 212-273-6472 or abbe.wittenberg@yai.org. Registration is required as space is limited.

The YAI Network gratefully acknowledges the New York City Council Autism Awareness Initiative for helping to make this autism workshop possible.

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- 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.

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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.



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Fiddle Foundation from page 1

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.



Linda Walder Fiddle, Esq

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

see Fiddle Foundation on page 39

This is what success looks like...



This is what an adult living with autism looks like!

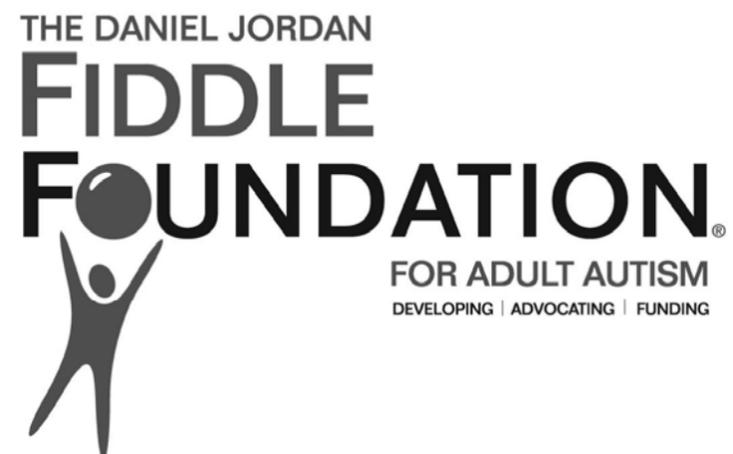
Building successful futures for adults living with autism takes innovative program development, advocacy, funding – and a belief in their strengths, talents and promise.

The Daniel Jordan Fiddle Foundation Signature Programs provide the blueprints that create opportunities for the diverse population of adults living with autism to build rewarding futures.

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the *lighter* side of the spectrum

a mom's view
by Carrie Cariello



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 full-fledged 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 call our car *Shadow!* Because it's *black!*"

Since social cues are difficult for Jack to decipher, he doesn't notice how his unblinking stare and pointed finger make his unsuspecting victim anxious. He wants answers and will go to great lengths to hear the car data.



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 about their drivers.

However, the person most revealed with the car obsession is Jack himself. He's finally cracking the venetian blinds into his fascinating brain and letting us take a peek. That can be the beauty of autism - it gives all of us a rare glimpse inside a mind as intricate and matchless as a snowflake.

I was getting frustrated when he would ask family and friends the same question about their car every time he saw them, even though he knew it. Honestly, I thought to myself, couldn't he at least demonstrate one of his fascinating skills and blow people away with his car knowledge, the way he can spit people's birthdays back to them? As a parent, is it so wrong to want to revel in the disbelief and awe for one teeny-tiny nanosecond? Why, maybe he is a genius! Maybe memorizing every Volvo, Nissan, and Cadillac will have a big payoff for Jack one day, maybe he'll be the Temple Grandin of the auto industry and his movie will win an Emmy and

he'll stand up and ask the cameras to point to me and I'll be wearing a couture gown that was designed just for me and hides the fact that I've birthed five children....

Whoops, got off track there. Believe it or not, something even better than that scenario unfolded.

About halfway through the summer we realized Jack's obsession is more than simply collecting information to categorize and store in his complicated brain. It provides him with the chance to interact with people - often strangers - about a subject he likes. "What kind of car do you drive" is the "Hello how are you, my name is Jack" of his world. It bridges a social gap that might otherwise seem as wide to him as the English Channel.

Watching our socially limited son create ways to make himself comfortable talking to people is a beautiful thing. Even more beautiful is watching as he gradually learns to turn their answers into a conversation; "Oh! A Toyota! I like Toyotas too! What color is yours?" On more than one occasion I've had to look away while my eyes filled with tears and my heart leaped with joy. Behavior we thought of as sometimes annoying, occasionally funny, and at best peculiar is something else entirely.

It's progress.

As is so often the case with Jack and autism, it's a learning curve for us as much as for him. We can't always take his quirkiness at face value - we have to look inside, around, and beyond his mysterious behavior to see what drives it.

(No car pun intended.)

Carrie Cariello lives in New Hampshire with her husband and five children.

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

For further information contact the facilitators: Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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For further information contact the facilitators:

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Adulthood: It's Closer Than You Think

By Theresa Pirraglia
Co-Founder and Board Member
The Foundation for Educating
Children with Autism (FECA)

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



Theresa Pirraglia

of the school year in which your child turns 21; but 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.

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.

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, prevocational, 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

Special Needs Trusts Can Be Very Helpful to Families

By Stanley D. Klein, PhD
Director
DisABILITIESBOOKS, Inc.

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 own 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).

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.

Managing a Special Needs Trust: A Guide for Trustees (DisABILITIESBOOKS, 2010) is an excellent reference guide for anyone who is managing a special needs trust for a person with a disability and/or who is working with families on future planning for a family member with a disability. In clear, understandable language, the book explains how special needs trusts relate to the complicated public benefit programs.

The authors (attorneys led by Barbara D. Jackins, who is also a parent) explain how a trustee can use the trust

funds for the medical, recreational, and transportation needs of a beneficiary with a disability without risking the benefits of government programs such as SSI, SSDI, Medicaid, and Section 8 housing and provide many examples.

Managing a Special Needs Trust: A Guide for Trustees is a completely revised, updated, and expanded edition of *Special Needs Trust Administration Manual: A Guide for Trustees* (2004, 2005). Although earlier editions focused on Massachusetts laws and pro-

cedures, over 10,000 copies were sold across the USA. The 2010 edition applies to all 50 states. *Managing a Special Needs Trust* is a welcome addition to any disabilities library.

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).

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Supporting Students with High Functioning Autism and Asperger's in Higher Education - The AHEAD Model

By Carolyn Komich Hare
Executive Director
AHEAD

AHEAD (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, AHEAD 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. AHEAD'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. AHEAD currently supports students in more than 13 cities across the



Carolyn Komich Hare

country and has recently announced remote supports to reach students beyond proximity of its regional programs.

The AHEAD 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, AHEAD'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 AHEAD.

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

Professional Staff Involvement

AHEAD'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, AHEAD 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

see AHEAD on page 41

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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 that Toni never had the wherewithal to sort through – 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 impassable for over six years. A staff member took note and thought things over, 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 –



Nomi Kaim

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 are independent contractors with an extensive professional background in ASD. They are carefully screened and individually matched to each client, with

whom they meet between several times per month and several times per week, depending on the client's needs. 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, writings, and 45 years of 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 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 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 tidying 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 downspiral 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

see Coaching on page 42

From Modeling to Mentoring for Adults with Autism

By Vicki Obee-Hilty and
Karen Shulman
Bittersweet Farms

Bittersweet Farms (BSF), a private non-profit organization that provides holistic programs 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 garnered the backing 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



Working in partnership, Bittersweet Farms' participants and staff ready the Whitehouse campus for their Fall on the Farm event.

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 commu-

nity and a day/vocational program that serves over 50 individuals. Participants can choose activities including horticulture (gardening, greenhouses, vermiculture, and crafts), woodworking, animal husbandry, pottery and art, grounds keeping, janitorial, and culinary skills. The activities 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. Our 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 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.

see Mentoring on page 44

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Devereux Pennsylvania, Kanner Center

390 East Boot Road
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Devereux Center for Autism Research and Education Services

620 Boot Road
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Devereux Community Adult Autism Partnership Program

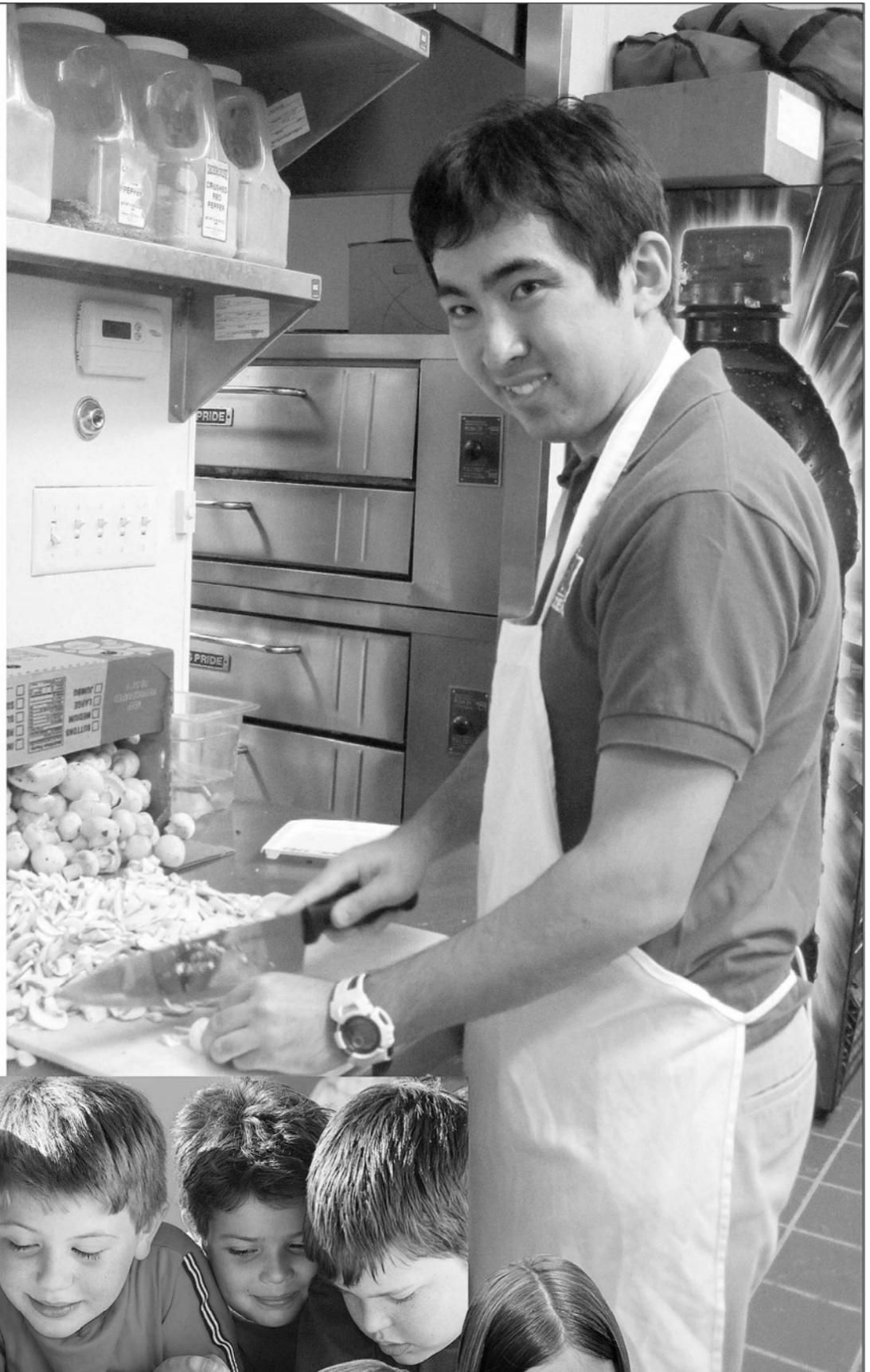
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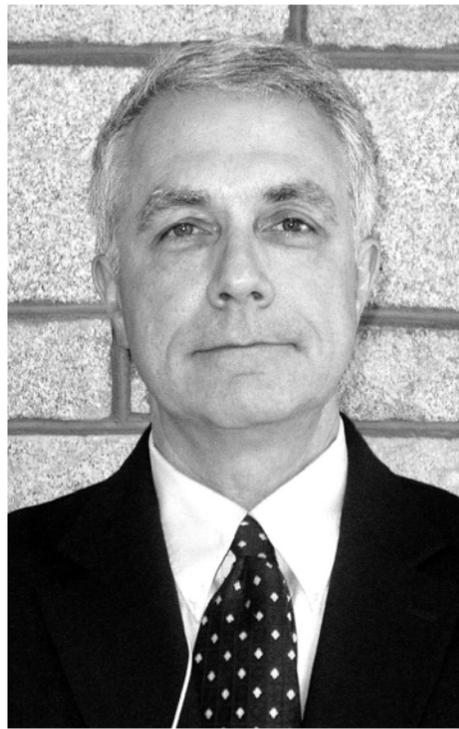


A Horse of a Different Color: A Review of the Effectiveness of Hippotherapy

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



Thomas Zane, PhD, BCBA

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, & Llabre, 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 & Cumella, 2003), depression (e.g., Folse, Minder, Aycocock, & 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 nationally. Currently, 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 Christian (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.

see *Hippotherapy* on page 46

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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 this treatment with cognitive training to improve thinking and planning using computer software programs. They also participate in a small “social-cognitive” group to learn about their condition and how to act wisely in social situations by

developing the abilities needed to understand another person’s perspective, evaluate social contexts, and be foresightful.

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, 1-866-647-3436 (toll free), or e-mail, autismrecruiter@upmc.edu.

The Benefits and Dangers Behind Social Networking

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

On 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 log-off so I can begin the 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



David J. Krainski, MS, GCDF

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 developmental disabilities, I tell my 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 an 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 post and the word gets out to every online friend 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 recruiters 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 is going to 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 if 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

see *Networking on page 40*

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 the 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, the courts also have provided oversight of the IEP transition planning process. During the first decade of the twenty-first century, parents increasingly have brought claims in federal district courts, 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 com-

plied 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 FAPE is still unknown. Courts in the future should aim to answer this question and ensure that a bare transition plan is not the goal of school districts.

On a positive note, the existence of cases that discuss transition, no matter how scarce, is proof that transition claims will become more common over time. Current and upcoming issues that the case law highlights include: (1) improper evaluation methods used in transition planning; (2) the role of the transition coordinator in the transition process; (3) the presence of insufficiently specific goals in the child's transition plan; (4) distinguishing between state law and federal law in analyzing a proper transition plan; and (5) whether a statement of transition services is sufficient, or whether a separate section in the IEP should be dedicated to the transition plan and its goals.

The above description of the law summarizes the efforts of the legislative bodies, the courts, and school districts to ensure the implementation of transition services. Transition affects every teenager and can be a very exciting experience, but it can also be a difficult experience for those with special

needs without the proper resources and support systems. Indeed, for the adolescent with ASD or other disabilities, the need for such resources and supports is critical to success after high-school. As the ASD numbers of older children grow, it is hoped that parents and advocates will seize the potential of the law's transitional provisions and work to ensure well-tailored transition services are provided to each young adult with ASD and other disabilities.

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 Permanent Judicial Commission on 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 history of advocacy 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.

Mutation from page 9

study, focused on the molecular characteristics and potential clinical implications of the CNV associated with this specific gene in individuals with ASD.

"Interestingly, the data is also starting to tell us something about the dramatic variety of symptoms observed in the clinic," further explained co-senior author Dr. Stephen Scherer, Senior Scientist and Director of The Centre for Applied Genomics at The Hospital for Sick Children (SickKids), and Director of the McLaughlin Centre at the University of Toronto. "CNV in the protein-coding region tend to travel with intellectual disabilities while CNV in the nearby regulatory regions appear more associated with Asperger's or high-functioning autism. But, as often seems the case, symptoms associated with autism can also be more complex."

While each of these variants, found in this and the earlier AGP studies may only account for a small fraction of the cases, collectively they are starting to account for a greater percentage of individuals in the autism community, as well as providing insights into possible common pathogenic mechanisms. The overlap between autism susceptibility genes and genes previously implicated in intellectual disabilities further supports the hypothesis that at least some genetic risk factors are shared by different psychiatric developmental disabilities.

Finally, identification of a male-linked

genetic mutation begins to address the previously unknown basis for often reported skewed male to female ratio in autism.

"Piece by piece, we are discovering genetic mutations that can cause autism. These findings will provide answers for families about what contributed to their autism," said Dr. Shih. "Furthermore, as we have learned from examples involving other genetic risk factors of autism (e.g., Fragile X, Rett, TSC), these genetic findings help us understand the underlying biology of autism, which can lead to the development of novel treatments."

Data was supplied to this study by the Autism Genome Project (AGP), an international autism genetics research consortium co-funded by Autism Speaks, the Medical Research Council, Canadian Institutes of Health Research, Health Research Board (Ireland), Genome Canada, the Hilibrand Foundation and Autistica which seeks to identify genetic risk factors associated with autism spectrum disorders (ASDs).

Autism Speaks provided major funding support to this study, in addition to funding from Genome Canada through the Ontario Genomics Institute, the McLaughlin Centre, the Canadian Institutes of Health Research (CIHR), the Canadian Institute for Advanced Research, the Canada Foundation for Innovation, Ontario's Ministry of Research and Innovation, the Ontario Innovation Trust, the Catherine and Maxwell Meighen Foundation, the National Alliance for Research on Schizophrenia and Depres-

sion, the Ontario's Premier's Summit Award in Medical Research, The Centre for Applied Genomics, the Chedoke Health Corporation, the Mayberry Family Fund, the Hamilton Health Sciences 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-cnvs-on-chromosome-x/>.

About Autism

Autism is a complex neurobiological 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 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 made enormous strides, committing 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 advocating for the needs of 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 clinical 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.

Transition from page 10

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 on the waiting list until the family 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 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

have options and your child has skills and experience. It's an important first step.

Independent Living Skills - I 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 make sure she had money for food at the end of the week. At home, if the toilet paper was running out, a new roll magically appeared. In short, she was not prepared to manage her life independently.

We all struggle with aspects of independent living but through trial and error, we learn what we need to do to manage successfully. People with developmental disabilities are no different. We can help them become successful if we prepare them. They will need skills regardless of the level of support they will ultimately require. Through individual or group training programs, services are available to support your family member learn concrete skills like budgeting, food preparation, and doing the laundry, as well as more abstract skills like sharing with and accommodating a roommate and identifying 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 oppor-

tunity. Explore 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. These programs all have distinct personalities or cultures based on the age, background and functioning level of the individuals served, their location, and the activities they engage in. Take time to visit a variety of programs. Ask questions. See how your family member seems to fit with the other attendees. Do the activities seem to be appropriate and match your family member's interests? Do people in the program look engaged and happy? Are staff appropriately interacting with the attendees and do they seem to enjoy their jobs? The same goes for employment programs or any other type of service you are considering for your family member.

Case Management: To Have or Have Not

You do not need Medicaid to have a case manager, though most are funded through Medicaid and obtained via the OPWDD system. Some families expect that a case manager or Medicaid Service Coordinator (MSC) will take care of ob-

taining all these services for them. It's important to understand that the role of the MSC is currently evolving. And while many MSCs are extremely knowledgeable and can be a great resource, the increased demand for the service and the turnover rate in recent years means that there are a large number of MSCs that may be bright and motivated but not necessarily knowledgeable and experienced. The service system is complicated and it takes some time to fully understand it and gain expertise. If you get a very experienced case manager, consider yourself very lucky. Your best approach is to ask these questions: 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](http://www.yai.org) at (212) 273-6182 and an experienced and knowledgeable Intake Specialist will provide you with information and resources to help you access the supports you need for your family member. [LINK](http://www.yai.org) 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](http://www.yai.org), 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.



David Rubin

I spent several years as a messenger. I could certainly do the job, but I felt very over-qualified, especially considering my co-workers were an ex-con, a person with intellectual limitations, and a new immigrant who could barely speak English. Good enough for a college student, but, in my mind, not good enough for a college graduate.

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 there 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 Possibili-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.

Possibili-Tees is different from a sheltered workshop in that it is not a pro-

gram. 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 Possibili-Tees ever since, two days a week, using the internet to find possible customers and philanthropic donors.

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

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Gaze from page 8

in older individuals with autism and may help to explain why children with autism respond well to teaching approaches that utilize a predictable reward system when children exhibit desired behaviors.

"Babies in both groups of the study learned the multi-stimuli task to the same degree," said Dr. Landa. "While the high-risk siblings are at a higher risk for developing autism later in life, they still have the capacity to learn cause and effect as well as their low-risk peers at this young age."

Implications from the overall study findings reveal that like older children, infants at high risk for autism may benefit from frequent exposure to simple cause and effect learning opportunities to aid in

their development. For example, Landa recommends using simple songs paired with easy, predictable gestures to promote language and social learning, rather than using electronic toys that children can enjoy and operate without engaging with their peers or caregivers.

It is expected that about 20 percent of the high-risk infants in this study will receive a diagnosis of autism. While participants in this study have not yet reached their third birthday, the age at which the research diagnoses are confirmed, the study findings help to highlight the vulnerability of developing social initiation skills in high-risk infants. This study is the first of its kind, and a follow-up will soon be published from the Center for Autism and Related Disorders at Kennedy Krieger Institute.

The research study was supported by grants from the National Institutes of Mental Health.

About Autism

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.

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.

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- Training programs specific to medical professionals
- Training programs for parents and siblings
- Evaluation of training programs
- Training programs for all professionals
- Inclusion in extracurricular, recreation and membership organizations

- Advocacy support
- Local autism awareness forums
- Local and regional business advisory councils
- Inclusion in faith-based communities

About Autism New Jersey

Autism New Jersey is the state's leading source of information, support, advocacy and public policy for parents of indi-

viduals with autism and the professionals who support them. Autism New Jersey, formerly COSAC, was founded in 1965. Autism New Jersey is dedicated to creating a society of compassion and inclusion for all. Autism New Jersey believes that actions taken to achieve this mission must be grounded in science.

About Autism

Autism spectrum disorders (ASDs) affect approximately 1 percent of New Jersey's population and has no racial, eth-

nic or societal boundaries. ASDs are developmental disorders that severely impact an individual's social interaction and communication. While individuals on the autism spectrum possess varying abilities, the majority require intensive treatment and support.

For more information about autism and how it affects individuals, families and professionals, please visit www.autismnj.org or call, toll-free 800.4.AUTISM.

A copy of the Blueprint is available at www.autismnj.org/Doc/Blueprint.pdf.

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. Departments of disability services may be reluctant to provide funding for transi-

Childhood from page 16

Mickey said the wrong thing? Once, when he was in fifth grade, a new therapist sat down at the table with him and introduced herself, and he got a glint in his eye.

"I like to play with matches," he told her.

He doesn't. But he does like to say provocative things, just to get a reaction.

Okay, I decided, bakery bought cookies would do. She probably wouldn't eat anything anyway. We vacuumed up cat hair, washed a bowl of grapes, brewed a perk pot of coffee.

"Make sure we hide the bong and the beer bottles," my husband said wryly.

Aretha Franklin was lovely, professional and pretty. And young. So young. She arrived ten minutes early with a large Coach tote bag and drew out a thick manila file folder. "Tell me about Mickey," she said.

Do you have a few hours? I thought. *Remember to smile.* "What would you like to know?" I said.

"Where is he in school?" she said. *Wasn't that already in all the documentation we provided?*

"He's in a wonderful life skills pro-

gram at the local high school," I said. *A program we had to force our school district to create.*

"What activities do you do with him?" *What haven't we tried? His repertoire is rigid and limited. That's the hallmark of autism.*

"He loves the beach," I said.

"Museums," Marc said. *Uh oh, did that make us sound like we're trying too hard to impress?*

"Sports! He loves sports, he's in a recreation program here in town," Marc added.

I thought for a nano-second of adding, *it's a sports program we started for special needs kids, because there weren't any programs that would take kids like him.* I stopped myself; it sounded self-serving.

"Visiting his cousins, that's his favorite thing. Books. T.V. Video games. But we try to limit them," I hastened to add.

What if she thought we park him in front of the television?

"Would you like to meet him?" Marc said.

"Of course." She smiled. She was really very pretty. We coaxed him into the room, set out a large black and white cookie – his favorite – and a glass of skim

milk. *See, we give him skim, not full fat, because we are conscientious parents who watch his fat and cholesterol intake.*

Mickey acted silly. He wouldn't answer her questions. "Chicken!" he said. That's what he calls people when he's anxious. "I don't want to talk," he said. He gobbled his cookie and left.

"I know this may sound strange, but why do you want to be his guardians?" she said.

Wasn't it obvious?

Marc said, "Who else? No one loves him as much as we do."

"We signed on for life," I added.

She asked for names and numbers. Mickey's teacher. Mickey's standby guardians, in case anything happens to us: my brother Marty; our older son Jonathan, away at college.

Smiles and handshakes all around; she leaves. I email my brother at work, tell him to expect a call from Aretha Franklin.

He emails back: "I will be sure to give her R-E-S-P-E-C-T."

It breaks the tension. Marc and I laugh.

"What's Mommy's job?" I used to say to Mickey when he was little.

"To keep me safe," he would say.

status with the Department of Education.

Advocates should be aware of some important 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 it is required that currently or in the past the student was deemed eligible for special education or related services by a local education agency. The federal regulations 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 Opportunities Act is welcome relief for families of higher functioning individuals on the au-

tism spectrum. The financial aid that may become available is still minimal at this point, 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 education and secure meaningful employment.

Paul Cavanagh, PhD, MSW is the Director of Academics and Evaluation at New York Institute of Technology Vocational Independence Program. Ernst VanBergeijk, PhD, MSW is the Associate Dean and Executive Director at New York Institute of Technology Vocational Independence Program.

I'm angry we have to go through this process. And afraid. Could the court possibly 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 special diet out there to try, that *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. What did I do wrong during my pregnancy? Was it that Advil I took the week before I realized I was pregnant? Did I not play with him enough as an infant? Not go to enough conferences, seminars and workshops? Or go to too many that took me away from him? Should we have taken him to see other experts? I should have done *more*.

But I don't know what *more* could have been. Sometimes, in dark moments, I think, *I have not been a good enough mother.*

Because if I had, he wouldn't be autistic anymore.

cause her ability to consider another's perspective is greatly impaired. She has difficulty accepting her diagnosis and the difficulties that come with it. These issues made college and finding employment after college very difficult. It is hard for perspective employers to deal with the issues of Aspergers; but think how different their perspectives might be if autism in high functioning adults were simply considered another type of "diversity."

Things are changing for adults on the autistic spectrum with lightning speed. Yet, there remains a slowly growing tsunami of high school students on the spectrum who don't have adequate transitional supports that have worked for them. I don't disagree with evidence-based approaches, but, if actual artists only created based on past research we would be facing a generation of art that basically is uninspiring and far from the cutting edge. We have to try new things and not scare people into thinking that the only approaches that are effective are Evidence based. Don't get me wrong, there is plenty of evidence in social scientific research that demonstrates the damage that can be done when people plow forward with wacky and destructive ideas that do more harm than good.

Susan M. Cortilet-Jones, MS, LMHC, is a Life Skills and College Coaching Specialist. To learn more, please visit DiscoveringYourWorld.com or contact Susan at (845) 406-8730.

spectrum. In the rehabilitation and counseling setting, in an office, it did not seem like enough to translate social competencies just by learning, role play and then leaving the office to put the learned skills into practice on their own. It just made sense to me that these folks in many cases needed someone to tear down the skills into manageable parts and then go into the community, college setting, or agency and apply these skills. It also made sense to take the person into the community and teach with the assistance of those people willing to help, even if it was a momentary "teachable moment" (i.e. the hostess in the restaurant, the teacher in the classroom, the secretary, the cleaning crew etc...).

I always say to people there is the "bell curve" where the majority fall into the "normal distribution" but like any measure there are exceptions. I am not pretending to be a scientist, but experience was my research and my experiences showed me that the variance in those on the high functioning end of the spectrum is as broad as the spectrum itself. Some individuals on the spectrum have social and communication issues, others do not. Some are rigid and inflexible, others are flexible. And, some have global executive functioning issues and others have aspects of executive functioning issues.

One client that I worked with at first appeared extremely anti-social and limited in his communication issues when I first met him. As I spent more time with him I also

found that he had anxiety issues that hampered his communication abilities as well as psychotic symptoms, upon which his therapist and I collaborated, to provide the best possible treatment outcomes. By thinking outside the box with both him and his family and considering their individual desired outcomes, we were able to improve his quality of life and prospects for the future. Today, he no longer demonstrates psychotic behavior, has lower anxiety, and is much more integrated into both his family and community. Another client was rejected from state developmental disability programs multiple times because testing deemed him too high functioning. Fortunately, he had a dedicated and persistent mother who pushed until he received the needed services. Though he now attends college and lives in the dorms (he was told it would never be possible) he still needs services. What professionals and the public sometimes miss are the hidden challenges and continued need for life long support. It does not mean that people with autism spectrum disorders can't blend in with the professional and social world; they just need support at times to participate fully.

Last year at a local college forum on diversity and sensitivity training for faculty and students, "disability" was not included in the discussion of as a form of diversity. Amazingly, one young woman with a college degree is one of the more challenging clients that I work with, partly because she remains rigid and inflexible in her goals and thinking, and partly be-

cause her ability to consider another's perspective is greatly impaired. She has difficulty accepting her diagnosis and the difficulties that come with it. These issues made college and finding employment after college very difficult. It is hard for perspective employers to deal with the issues of Aspergers; but think how different their perspectives might be if autism in high functioning adults were simply considered another type of "diversity."

Things are changing for adults on the autistic spectrum with lightning speed. Yet, there remains a slowly growing tsunami of high school students on the spectrum who don't have adequate transitional supports that have worked for them. I don't disagree with evidence-based approaches, but, if actual artists only created based on past research we would be facing a generation of art that basically is uninspiring and far from the cutting edge. We have to try new things and not scare people into thinking that the only approaches that are effective are Evidence based. Don't get me wrong, there is plenty of evidence in social scientific research that demonstrates the damage that can be done when people plow forward with wacky and destructive ideas that do more harm than good.

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She was receptive and asked him some questions. Two hours later he was called for an interview. What was striking were the things "neuro-typical individuals" take for granted in this process, and he was able to articulate this as we debriefed. He asked, "How did you know she was a manager? How did you know to approach her? How did you know what to ask?" (By the way, after submitting this article to *Autism Spectrum News*, this young man was called for an interview and soon after offered a position!).

Over the past 4 years, I have worked with nearly 30 clients privately, predominantly whose diagnosis is Asperger Syndrome. After first working with a few clients and assessing their specific needs, I was motivated to develop a program that took individuals who often lacked the interest in traditional therapies and/or who also had difficulty transferring behavioral and skill sets from an office setting to real life situations. Previously, I had been working with adults in a rehabilitation setting, mostly students on the autistic spectrum. Most of these clients were college-aged students who were having a great deal of difficulty finding success in college even though they had the intellectual capacity and interest in learning. Many of these individuals dropped out within the first semester. Other clients on the spectrum had difficulty with both finding and keeping jobs.

I began slowly, by going to the home of the families with adults living on the

Fiddle Foundation from page 28

appropriate for their current stage in life. Out of this conversation, and because of GRASP's expertise in developing support groups for adults on the spectrum, we partnered with them to create **The Daniel Jordan Fiddle Foundation Peer Support Group Program at GRASP** to develop a support group that addresses the needs of these seniors on the spectrum. As far as we know, it's the only autism support group in the United States, maybe in the world, that is focusing on senior citizens.

We will periodically evaluate how this program progresses and grows and also watch the challenges of engaging a group of this age to join such a support group. We will need to learn what unique supports they want at this stage in their lives. This is a good example of how we partner with an exemplary service provider to develop a unique program that fills a gap in services and addresses an area of unmet need for adults. We currently have seven different Signature Grant Programs with partner organizations across the United States and our goal is to help nurture these programs and work closely with service providers to see that they succeed.

Q: How will these Signature Grant Programs ultimately lead to the development of blueprints that organizations across the country can utilize in the development of similar services in their local communities?

A: Using our annual magazine *DJF News to Be RED* and our website (www.djfiddlefoundation.org), we will report on the yearly progress of each of the programs. As it is still early in the development of this process, it has not been determined what the final product will look like, but we are going to share all of these different models with the community. One thing I can guarantee is that the presentation will be unique and involve a format that will be pioneering in the world of autism. It will allow for maximum dissemination within the autism community and the community at large. I hope this stimulates the public's curiosity - stay tuned!

Q: What specific areas of unmet need and gaps in adult services are you focusing on?

A: We are currently focusing on lifespan health and wellness vocational training and community life skills, the transition into adult life and facilitating the participation of adults who normally do not have access to good programs. Other Daniel Jordan Fiddle Foundation Signature Programs include a blueprint for developing a grassroots resource network and another is a respite/vacation program that is all about fun for adults and their families. In the near future we will be adding more Signature Programs that address residential support systems and self-advocacy for adults. There are really endless possibilities for program ideas, but our ultimate goal is to present viable new ways for adults on the spectrum to live, work and participate in community life. I would

like to give the readers of *Autism Spectrum News* a sampling of some of The Daniel Jordan Fiddle Foundation Signature Programs:

The Daniel Jordan Fiddle Foundation Vocational/Life Skills Fund at the Southwest Autism Research & Resource Center (SARRC) Vocational and Life Skills Academy in Arizona is designed to create a blueprint for engaging those adults in the autism community who do not normally have access to vocational and life skill training. The blueprint will include ways to enhance communication about such programs so that people in underserved communities can become informed. The fund then enables such individuals to attain the benefits of the outstanding offerings and trainings at the academy. We feel that all service providers will benefit from this blueprint we are developing as they seek to help not only those who have funding but those who are unable to afford quality vocational and life skills programming. The blueprint will also include ideas for service providers to gain funding and community support for such programs so as to enable underserved individuals to participate.

The Daniel Jordan Fiddle Foundation Workplace Development Program at the New England Center for Children (NECC) located in Massachusetts enhances their already wonderful vocational programs for adults and young adults by creating a blueprint for starting or improving such workplace training skills that are vital to attaining employment. During the next five years, the program will develop instructional modes that add to the existing workplace development program. This year they are developing a video modeling program because research has shown that modeling and showing interview skills and task analysis on video helps individuals on the spectrum learn how to improve skills. As the number of young adults and adults on the spectrum wishing to enter the workforce increases, this blueprint will help existing programs expand training and new programs develop the curriculum to prepare adults on the spectrum in their pursuit of employment.

The Daniel Jordan Fiddle Foundation Health and Wellness Program at Chapel Haven in Connecticut is a completely new endeavor for them. We were seeking a project to partner with Chapel Haven that added to their renowned programs that prepare adults to live independently in the community. Although Chapel Haven's comprehensive residential, employment and educational programming is effective, there was one piece missing: health and wellness. This exciting new program, with the research support of the University of Connecticut, will examine aspects that improve and affect the health and wellness of an individual on the spectrum. Areas to be focused on include: decreasing anxiety, increasing self-esteem, attaining a healthy weight, fostering independent healthy food choices, and independent choices of exercise and activity. The blueprint will focus on how to teach adults about

healthy lifestyles that include eating well, exercising, cooking and joyful relaxation.

One program that we fostered and have worked with since 2002 is with an organization called J-ADD (Jewish Association for Developmental Disabilities) located in New Jersey. **The Daniel Jordan Fiddle Foundation Hotline and Resource Guide at J-ADD** is a grassroots initiative that provides a free hotline and resource guide for families with nearly one hundred community resources. We have found that parents and caregivers, especially of adult children, and even the adult individuals themselves, often have questions about accessing information regarding programs and services that relate to their daily life such as, "Where do I find transportation? How do I find a program to learn about my recreational interest?" We are really committed to the idea that there should be a central repository of information where one can call free of charge to access information about local resources in the community. This blueprint will offer a way for communities around the country to create not only the resource guide but also a complimentary hotline where people can call to get personal attention regarding their questions.

These are some of The Daniel Jordan Fiddle Foundation Signature Programs for 2010 and more information can be found about our other programs on our website.

Q: In the future, what do you see as some of the next Daniel Jordan Fiddle Foundation Signature Programs?

A: As mentioned, we will be adding more Signature Programs, but in a thoughtful manner. We are deliberately only adding a few programs at a time so that we can allocate the attention and resources necessary for each current Daniel Jordan Fiddle Foundation Signature Program to develop into a blueprint. In some cases this may happen in a year, in other cases it will take several years. Future programs will likely include ones relating to fostering strengths and talents of adults on the spectrum, such as in the arts, science and technology. We will most definitely focus on lifespan learning and educational opportunities for the diverse population of adults. Another area ripe for development are different kinds of residential-related programs for rural, suburban and urban communities. The development of our Signature Program is intentionally meant to be fluid and evolve to address the existing and changing needs of adult individuals with autism.

Q: In addition to the Signature Programs, in what other ways is the Daniel Jordan Fiddle Foundation active in the autism community?

A: Besides co-developing and funding programs for adults on the spectrum, we also have been a very strong advocate on the state and national levels. I am a member of the New Jersey Adults with Autism Task Force and last year we presented a comprehensive legislative and policy agenda for improving the lives of adults on the spectrum. In addition, in our home

state of New Jersey, we have worked very closely with legislators, including the former NJ Assembly Speaker Joseph Roberts, Assemblywoman Joan Voss, and Senator Loretta Weinberg. For example, we have collaborated to create first responder training, money for autism pilot programs for adults, insurance support for ABA therapy, as examples. Much of this work on the state level has translated to the federal level where we have worked closely with Senator Robert Menendez (NJ), who is extremely committed to helping families and individuals affected by autism. This past July, as a member of the Steering Committee for Advancing Futures for Adults with Autism (AFAA), a consortium of autism organizations committed to advocating on behalf of adults, a congressional briefing in Washington, DC was hosted by Honorary Co-Chairs, Senator Robert Menendez (NJ) and Congressman Michael Doyle (PA), where we presented a policy agenda relating to adults. I was honored to moderate a panel of Stakeholders who exemplified the diversity of adults living with autism.

It is my view that we need more collaboration between the public, private, and community sectors. That is what The Daniel Jordan Fiddle Foundation has been doing since our inception and this is what the AFAA is about - engaging the government to become a partner in creating the best futures possible for adults living on the spectrum. It makes perfect sense that the more organizations, businesses, community and government can work together, the better it will be for the adults we are serving through our efforts.

Q: What hopeful message would you like to leave for families of young adult children who are transitioning into adulthood and also to adult individuals on the spectrum?

A: During the past decade it is absolutely gratifying to see how far our society has come in realizing that autism is a lifespan challenge that does not just affect children. So many years ago, when I sat alone researching how I would be able to find programs and supports for my son when he attained adulthood, I was dismayed and frightened. Today, parents of children and young adults do not have to feel so terribly alone, and indeed they are not. I am proud of The Daniel Jordan Fiddle Foundation Board of Trustees and their pioneering commitment to embrace the cause for adults and I believe we have been successful in opening many new doors for adults and hopefully opening the eyes of the community at large too. Sure, there is still much to be done, and many more doors need to be opened. I am confident that together we can do this. Each parent as an advocate for their adult child, each business that employs an adult on the spectrum, each community that says yes to a group home and each supportive neighbor makes a difference. We must not give up, we must continue to strive for the best futures possible for all adults living with autism, and in doing so, we will fulfill for all people on the spectrum, the dreams I had for my Danny.

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Networking from page 35

is that people conduct themselves in a manner that is congruent with how they would act around friends in private. The only problem is that if 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 earlier in the day might see a comment 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 steer clear of using swear words, making comments that could be perceived as nasty or hateful, and stay away from dis-

cussing 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 considered 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: "Would I post this online if I knew 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 and should possibly not be posted. Using a simple technique like this can mean the all the difference when it comes to landing that interview or not.

There are three other points I make to my students when speaking about social networks. The first, and maybe most obvious, is that they need to go into their social networks privacy settings and switch on the settings that provide them with the most privacy. The second suggestion I give is that they register on the social networking sites with a different email address than which is on their resume since many of these sites allow you to search for profiles by typing in an email address. Finally, I suggest that they only allow people that they actually know to view their full profile. By following these guidelines, they make their online profiles harder to find and therefore they will be less visible to the eyes of the hiring managers that may be searching for them. These sug-

gestions are helpful, but it is important to understand that even if every precaution is taken, resourceful individuals can find ways around these safeguards and still may be able to view a profile.

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 individuals with autism spectrum disorders 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 especially true when it comes to educating individuals on the spectrum in regards to the dangers associated with social networking and how those dangers can impact upon their lives.

Couplehood from page 16

communication, misunderstanding can result. However, there are 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 misunderstanding and finding our way with each other early on, but when understanding does not progress, the partners may become concerned that they have serious "relationship" issues. The stronger the love, the more upset partners may become when mutual understanding does not develop well. Particular problems that may arise in a couple where one member has Asperger Syndrome include differences in understanding indirectness, irony, sarcasm, and figures of speech; poor use of intonation, loudness, conversational pace, and facial expression to frame the true meaning of an utterance; wide differences in what each member finds interesting; great differences in speaking directly versus indirectly; lack of understanding of the social use of small talk; and communicating everything informationally, without awareness of metacommunication (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 within the couple or through a counseling and skill development intervention.

Partners can sometimes have very different expectations of social behaviors. Some may want frequent engagement with friends and relatives and others may prefer a more private existence with occasional contact with others. What is considered proper social behavior can also be very different between parties. When one

member of a couple has Asperger Syndrome, these differences can be magnified by the need to have recovery time from the world of work or the desire to minimize interactions with groups of people.

Many couples have difficulty discussing sensuality and sexuality openly. A partner with Asperger Syndrome may have sensory differences that have an affect or may have poor appreciation for the more subtle aspects of verbal and nonverbal foreplay.

Parenting brings challenges for every couple. If one member has Asperger Syndrome, the characteristics can create additional difficulties. Children present constant needs for parents. It is important that there is flexibility within a family to adjust schedules, priorities, and roles. This kind of flexibility can be hard to achieve for those with rigid expectancies of how a day will go. Other issues can sometimes result from theory of mind deficits. A parent who has poor ability to understand other adults' perspectives may have double difficulty deciphering the thoughts, feelings, and abilities of children. Telling way too much about a subject when a simple homework question was asked or expecting more maturity in behavior than has yet developed are examples of how theory of mind can influence child management. Being rule-bound can sometimes be an asset and sometimes a liability. Children need structure to thrive and well-established family rules can be helpful in creating organization. Alternately, rigid adherence to rules in the face of a need for flexibility can be counterproductive. A parent with Asperger Syndrome may have difficulty differentiating circumstances when rules should be kept or bent.

Executive functioning deficits are extremely common for individuals with Asperger Syndrome. Areas considered under this umbrella are thought to be organizational abilities, emotional regulation, shifting mind set, getting started, inhibiting impulses when something needs to be accomplished, and keeping more than one thing in mind at a time or multi-tasking. Executive functioning problems affect many people, not just those on the spectrum. However, it is important to remember that these deficits are not character flaws or purposeful behaviors. They represent real differences in brain function that need to be specifically addressed and supported. Being the partner of someone with executive function difficulties can make one feel alone in assuming family responsibilities. Understanding the specific areas of weakness and strength in this domain can be very helpful in resolving conflicts based on perceived inequality of effort or commitment.

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 communication and/or information processing 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 are 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 sometimes developing an understanding of what underlies differences in this area can make a significant impact on both parties. In general, understanding one's partner's neurobiological make-up is also helpful in exploring how differences can derail a relationship and figuring out together how to realign the relationship and develop new resources to facilitate interaction. How should one go about making needed changes in such a relationship?

If an individual or partner suspects that Asperger Syndrome is an important contributing factor to relationship difficulties, a diagnosis and evaluation can be helpful. While having a professional give a name to a group of characteristics can be valuable, what is equally important is to assess the components contributing to the diagnosis. There is wide variety in how Asperger Syndrome manifests and examining these components should drive treatment recommendations. For example, some individuals have sensitivities, rigidities, processing difficulties, facial recognition issues, high anxiety, co-occurring depression, or are very easily upset or hurt. Obviously, these individual traits should be taken into account when planning an intervention.

Sometimes one member of 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 disagreement. In these cases, it can be comforting to meet with an expert on Asperger Syndrome to understand if that is or is not a direction worth exploring. How to think about finding someone who can be helpful in the world of Asperger Syndrome was addressed in "Making the Right Decision When Choosing a Psychologist" (Autism Spectrum News, Volume 2, No. 4, Spring 2010). Getting and understanding the diagnosis or discussing the issue of Asperger Syndrome with an expert can be a good first step in the process of relationship improvement.

When there is an understanding of just what may be happening because of Asperger Syndrome, the next stage one may wish to think about is becoming more informed about what can be helpful. Books about personal experiences such as "Alone Together, Making an Asperger Marriage Work" by Katrin Bentley, about the process of working on marital issues such as "The Asperger Couple's Workbook," by Maxine Aston, or about how communication works in couplehood in general such as "That's Not What I Meant! How Conversational Style Makes or Breaks Relationships," by Deborah Tannen can jumpstart an understanding of what may be happening.

Finally, the importance of finding a therapist who has an understanding of both couplehood and Asperger Syndrome 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 therapists who lack understanding of 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 Asperger Syndrome and couplehood may not only help the couple in question, but bring about an understanding that will allow that person to have a keener ability to assist other such couples.

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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 per-

fect 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 cues and reinforcers. 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 disabili-

ties 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.

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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 themed pro-social activity that aid 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.

Relationship Development - Students need to explore attitudes and values regarding healthy relationship development with special consideration given to issues related to learning differences. Present topics such as friendship building, communication skills, relationship dynamics, and sexuality education. Don’t assume that your student on the spectrum does not need basic instruction in common strategies such as initiating friendships and conversations, and learning how and when to be intimate.

Individual Therapy - Many students on the spectrum need support with social, anxiety, and sensory issues. Every student arrives at college with a unique set of challenges. Most attend college without being able to ask a teacher for help, work in a group, or develop typical college friendships. Individual therapy utilizing cognitive behavior therapy is very effective in assisting students to deal with their emotions and to solve problems.

As the number of students being diagnosed with Asperger’s and learning differences increases dramatically, colleges need to develop curricula and supports that provide them with individualized services. It is of paramount importance that institutions hoping to address this increase can incorporate at least some of these concepts into their special programs for this population.

Michael McManmon has 35 years of experience with students with learning differences and Asperger’s syndrome, and he himself was diagnosed with Asperger’s syndrome. He is the founder of the College Internship Program (CIP - www.collegeinternshipprogram.com), a program that eases the transition to university and independence for young adults with learning differences.

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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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Graduates from page 19

appropriate interpretation and use of non-verbal language in a variety of settings. The students describe the SCC lessons as "learning how to define sarcasm; how to tell if someone is interested or just playing along to keep you happy; how to appropriately exit and enter a conversation and how to balance things so you're not just constantly talking about yourself."

The SCC lessons aren't learned in a vacuum. The students can then take what they've learned and go out and practice them in the real world with the help of the staff: in the college classroom, in the work setting and in the apartment with roommate interactions.

In addition, students enroll for two years in a college-level, credit-earning social communicative competency (SCC) class held on the campus of the University of Arizona and co-taught by Chapel Haven West staff and clinicians in the university's Speech, Language and Hearing Sciences Department.

Graduate Sara Goralnik said the focus on social skills has really helped her. "Many people, such as friends and family members, have noticed that I am much more perceptive of other people and ask how other people are doing without thinking only about me. I am more comfortable making eye contact and talking to people that I do not know."

Karin Frodel, Director of Chapel Haven West, said the SCC instruction "is invaluable in helping our students with the concepts of social thinking and perspective-taking – how to establish and maintain relationships, problem solving, how to make social judgments and how to deal with communication breakdown." Having a link to the University of Arizona also gives students many campus benefits, including a student ID card; the CatTran shuttle; campus email; library privileges; the Campus Rec center; Zona Zoo passes and discounted tickets for events.

Half of the 10 graduates are now enrolled in college studies, thanks to the

help of the program. Staff help students acclimate to the more rigorous environment of university or community college life (versus high school) by assisting with the college application and registration process, setting up accommodations and assistive technologies as needed, classroom support, time management/organizational skills and setting up tutoring services. Students receive a primer through Chapel Haven classes such as Intro to College and Becoming a Master Student.

Sara is currently taking courses at Pima Community College and is job shadowing at Pima Animal Care Center, where she observes animal surgeries in the mornings and works with puppies in the afternoon. She is interested in becoming a vet technician. "I am doing a lot better in college than I would have done without this program because of all the support," she said.

Another key goal is helping students choose vocational paths. All of the graduates have rotated through a series of work

assignments, from serving as docents at the Reid Park Zoo to food services, hotel work and a variety of jobs at the Arizona State Museum. Students are ready now to transition into employment.

The students come from many states, including: Florida, Washington, Colorado, Illinois, California, South Dakota, New Jersey, Pennsylvania and Arizona. What they have in common is their ability to master challenges related to having a development disability in order to pursue independent lives.

"These have been the best two years of my life," Ian said.

Founded in 1972, Chapel Haven teaches adults with cognitive disabilities and social disabilities to live independent and productive lives. For more information about Chapel Haven West, the Asperger's Syndrome Adult Transition (ASAT) Program or the REACH program, call the Admissions Office at (203) 397-1714, ext. 148. Read more at www.chapelhaven.org.

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Vocational Rehab from page 20

The fault is not entirely with vocational rehabilitation. While jobs in supermarkets, the food industry, or cleaning services are plentiful, at professional levels the competition is fierce. Employers aren't willing to hire professionals with invisible handicaps who are clumsy or have poor social skills, even if these employees are capable and talented.

Social demands are part of every workplace. Each job has its own social code. Rules change. New employees must be able to figure out people's various temperaments, who's good to work with, and who isn't. You have to learn how hard to work: hard enough to get the job done, but if you're too good or too quick, your coworkers may not be happy with you. You want to be seen as sharp, but not as a know-it-all. These are fine lines that are very difficult for the AS/NLD individual to master.

We need to acknowledge that NLD and AS are disabilities which may require accommodation in the work setting, and allow the person a measure of accomplishment and success in the work world by providing those accommodations.

Supports exist for others with disabilities. The blind person gets readers. The deaf have interpreters. Public buildings

are wheelchair accessible. Even individuals with attention deficit disorder (ADD) have gained increased acceptance. But autism spectrum disorders are still poorly understood.

Education and training for VR staff about autism spectrum disorders and their effect on the employee is sorely needed. Vocational counselors, job coaches, and others working with this population need a good grasp of the person's capabilities as well as disabilities. Only then will they be able to place these valuable, skilled employees in a work setting appropriate to their level of education and ability.

The AS/NLD employee can do a fantastic job if the employer is friendly, accommodating, and understanding. In a supportive, congenial environment, the right job, and with the right supervisor and supports, the individual with NLD/AS can succeed. James Emmett of the Vocational Alliance says, "Employers must understand that they are gaining a wonderful employee, but they must also realize the importance of structure and clear feedback to help the employee succeed." Peter Gerhardt, EdD, who has many years of experience working with AS adults, recommends training for NT coworkers so that they'll better understand the social and behavioral issues, and look past them to see the individual's strengths. Other-

wise, the most well meaning people – counselors, bosses, and job coaches alike – will say, "he's not trying hard enough" or "she needs more confidence."

Developing natural supports on the job site is an important function of vocational rehabilitation. If coworkers are understanding of the individual's communication, learning, and work style, and act accordingly (communicating explicitly; giving specific and step by step instructions; etc.) problems can be greatly diminished.

Self-advocacy is another important area where vocational rehabilitation can play a role. It's helpful to be able to tell one's employer, "That's not how I work best," and to suggest ways of handling things that may be more productive and satisfying. For example, "That's not what I do best. Maybe I could work on a different piece of the project where I could make a better contribution." But this is only possible if the employer understands the disability and is willing to make accommodations. Otherwise, the person may come across as having an attitude when they make such requests.

The employee needs to be taught how to state his or her needs. When someone says, "I can't handle multi-step instructions, I'm NLD," the other person may write them off (at worst) or won't know

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.

Yvona is the author of "Employment for Individuals with Asperger Syndrome or Non-Verbal Learning Disability: Stories and Strategies," published by Jessica Kingsley Publishers, 2004.

Coaching from page 30

no fee. Without this crucial financial backing, a LifeMAP coach costs \$60-\$75 per hour – markedly less than a typical psychotherapy session in the Boston area, yet still far more than clients like Toni can afford (Life coaching is not covered by most forms of health insurance).

Right at this point Toni began to feel ill and lost her appetite. She was losing weight, and doctors' advice to modify her diet wasn't working – because once again, Toni just didn't know where to start. She was in desperate need of nutritional counseling, but she could never have afforded a nutritionist.

Luckily, Toni lives near AANE and was able to obtain a new coach in exchange for volunteering at the office sev-

eral times a week. Toni's needs were different now – more urgent – but LifeMAP was set up to meet them. The second coach was exceptionally gentle but highly proactive. She lost no time in helping Toni design a daily meal plan, plan a shopping list, and stock her cupboards with nutritious, affordable foods. Faster than ever before, Toni was back on her feet.

As her health improved, Toni and her new coach gradually moved on to other areas of her life. They tackled her longstanding 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); 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 and;
- 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 vo-

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

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

educational evaluation. [34CFR 300.43 (a)] [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.

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 heard 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 of getting health insurance and encouraged us to get further diagnosis that has helped him understand him-

the weekends. If 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

- 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 transitioning 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 college experiences during his final years under IDEA if you feel that is appropriate.
- Contact your states office of developmental disabilities about enrollment requirements and supports.
- If applicable, contact your state office of Vocational Rehabilitation Services 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.

self and his world a little better. She is now training him to manage employment and social issues that arise in a society that doesn't always make sense to someone with Asperger's. She has kept in touch with us and made suggestions we had never thought of. We truly feel that our son's coach has saved his life and our sanity!! We will forever be grateful to AANE and the LifeMAP program!"

As for Toni: one year into her LifeMAP coaching, she has never felt more optimistic. She relishes her meetings with her coach and her new lease on life. "My coach is so encouraging, so positive," she says. "I have become a more positive person myself. I went from living aimlessly to a more focused approach to life. Now

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

Resources for Transition Planning**Print Resources**

Smith, M.D., Belcher, R.G. & Juhrs, P.D. (1995). A Guide to Successful Employment for Individuals with Autism. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P., (2001). Life Beyond the Classroom: Transition Strategies for Young People with Disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P. & Kregel, J. (1994). More Than A Job: Securing Satisfying Careers for People with Disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Wehman, P. & Targett, P.S. (1999), Vocational Curriculum for Individuals with Special Needs: Transition from School to Adulthood. Austin, TX: PRO-ED.

Life Journey Through Autism: A Guide For Transition to Adulthood, published by the Organization for Autism Research, 2006 www.researchautism.org. An excellent and comprehensive guide on the transition process.

Internet Resources

U.S. Department of Education - idea.ed.gov
IDEA 2004 legislation and regulations.

National Dissemination Center for Children with Disabilities (NICHY) - www.nichcy.org
A central source of information on disabilities, IDEA and effective educational practices.

Wrightslaw, - www.wrightslaw.com
A comprehensive website about special education law and advocacy.

Division on Career Development & Transition (DCPT) - www.dcdt.org
A wealth of information on how to access career/vocational and transition services for persons with disabilities.

Theresa Pirraglia is the Co-Founder and Board Member of The Foundation for Educating Children with Autism (FECA). Theresa is also a Board Member of Mental Health News Education, Inc. and on the Editorial Board of Autism Spectrum News.

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.

Nomi Kaim was diagnosed with Asperger Syndrome at age 20 and currently volunteers at the Asperger's Association of New England (AANE) in Watertown, MA, where she is a member.

For more information about LifeMAP, please contact Nataliya Poto, LifeMAP program director, at nataliya.poto@aane.org or 617-393-3824 x19 or visit www.aane.org.

can be useful contributors to our society.

Elizabeth Suhonen 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 class make friendly social choices. There is a "Magical Mirror" at the back of Book Three in which children will see that when they make friendly choices, their eyes like Starabella's shine like stars!

The *Starabella* series consists of three fully narrated audio/picture books with music. Children listen to the story on a CD while they follow along with pictures and captions. 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. Tara composed and played the piano or keyboard for 17 of the 22 songs which have been professionally 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 behind the story tells of 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. Dana narrates the *Starabella* stories, wrote additional music, sings most of the songs,

and performs the parts of 12 characters. I published the *Starabella* series with my husband, Marvin. It has enhanced our lives with special meaning and purpose.

The *Starabella* series includes three books:

Book One - "*Starabella: Mystery girl of Music*," features Starabella at home. Children meet Starabella and follow her through babyhood and her early toddler years. Her mysterious behavior and surprising talent puzzle her parents. Above all, her parents wish for "Starry's" eyes to continue to shine and for her to know she is always their little star.

Book Two - "*Starabella: New adventures and Mixed Emotions*," features Starabella in the community. She encounters demands for conformity and expectations for appropriate behaviors and following the rules.

Children who listen to and view Books One and Two celebrate Starabella's accomplishments, feel compassion for her extra challenges, root for her to reach her goals, and gain understanding of her emotions through her music. In this way, they acquire empathy for her by the time she enters kindergarten.

Book Three - "*Starabella: Welcome to a Bright New world*," features Starabella at school, as she begins her first day of kindergarten. Children listening and viewing meet Starabella's classmates, a lively group of

students of varying ethnicities, attitudes, abilities, challenges, and dreams. Though happy in their wondrous new classroom, sometimes the children face social dilemmas. Starabella becomes the catalyst for solving the various social conflict situations. Children listening/viewing the story, share in the wonder as Starabella, through her special connection to the stars and the goodness inside 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 classrooms, as shown in Book Three of *Starabella*. The children in Starabella's class work together to get to the Bright New World. Participating in diverse learning and social environments prepares children to become responsible members of democratic 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 musical message to children. I had been Tara's 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 a hand 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 Sharon Fialco, based on music composed and performed by Tara Fialco, narrated and sung by Dana Fialco and illustrated by Anton Petrov. Accompanying CD recordings are produced by Joe Vulpis, AP Music, Inc. Books are available for purchase at: www.starabella.com.

Mentoring from page 30

As a means to accomplish the "support to families" part of our mission, we have always had families and 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 experts and academics, as it was seen as going against the idea of community integration. In the past eight years, we have seen a growing interest and acceptance of this model and a movement to make sure it is an option open to families who see it as the best choice for their child. Many families share that their children with autism love the outdoors, enjoy being around animals and appreciate the chance to be creative. For many, the idea of their adult child being in a safe environment where they can be accepted and honored is important. Family members appreciate the opportunity that their adult children with autism are given to continue to learn, develop skills and abilities, and to make a contribution to their communities.

In recent years, we have moved from being a demonstration project to stepping into a role of advocating, supporting, and mentoring those who are interested in creating this kind of environment. Visitors have come from around the world, each with stories to tell, some of which are heart-breaking. A couple from Australia told an especially compelling account of their son ending up in prison; the saddest part was

that he was treated better in jail than he was in a medical institution. This couple's dream is to establish an agricultural residential program in Australia. A Chicago father of a seventeen year old son with autism has started a national network for existing and future managers of agricultural communities to share best practices, advocate for policy changes, and encourage more development. Another parent of an adult child with autism who visited Bittersweet years ago realized his passion by opening a program in Ohio this spring; Safe Haven Farms provides residential and day program services. This summer, Bittersweet was asked to participate in an international autism conference focusing on residential and vocational program development in Taipei, Taiwan. As the incidence of autism in Taiwan mirrors ours, families are quickly realizing the great need for services. Even in the highly urban country of Taiwan, they are embracing this agricultural model as a way to provide a safe, meaningful life for their children as adults.

Despite our humble beginnings, we have come to recognize that we have an interesting and successful model, mission, and philosophy. We now have a vision of serving as a global model of unity in partnership with all individuals affected by autism. This new focus has driven us to expand our training and consulting (T&C) programs. When we first began training and consultation activities several years ago, we primarily focused on visitors coming to BSF to tour our campus and learn about our philosophy. While beneficial and still an important component of our T&C services today

(Consulting Tours/The Bittersweet Academy), the numbers we reach are limited.

Training Others to Replicate Our Successful Model

Since April of 2009, our focus has shifted to attempt to develop a way to help more people and do so more economically. Many who desire to establish support services for adults with autism have neither the time nor money to travel to Whitehouse, Ohio for training courses. The lead time required to plan for, create, and open farmstead-like models for adults with autism is approximately five to seven years, a huge obstacle given the crisis-mode in which families find themselves. In addition, BSF has limited resources, including a small training and consultation staff. We determined that it would be wise to utilize a cyber classroom to accommodate our staff and shorten the lead-time to develop new entities for parents, agencies, and others who wish to start adult support services.

The pressing need for helping others develop adult services pushed us to create computer-based courses we call Bittersweet's WISDOM. The WISDOM acronym stands for "Why Invent Solutions? Duplicate Our Methods." The concept is that we can help others shorten lead times by using our methods and model.

Based on our many visits from people who want to start support services for adults with autism, we have identified which training topics are most de-

sired. As a result, the WISDOM curriculum has four series to address these areas—Business, Programming, Staffing, and Applicants and Families. Interested individuals can take reasonably-priced WISDOM classes and learn from experienced professionals in the comfort of their own surroundings at times that meet their needs. The WISDOM Curriculum is in its infancy and will continually be expanded to meet the needs of our patrons.

We continue to do our best to accomplish our mission of "providing an array of premier services to individuals and support to families." We realize that the need for adult services is so great, that, even if we grew all Bittersweet campuses to serve more individuals, we would fall woefully short of all those in need. We cannot do it alone, nor can the parents, individuals, and agencies who know little about building programs for adults with autism. Our hope is that we can positively touch the lives of more people with autism by utilizing our knowledge of supporting adults by mentoring parents and other organizations to do the same.

Please be sure to visit our website www.bittersweetfarms.org to learn more about Bittersweet Farms and review all of our offerings.

Vicki Obee-Hilty is the Executive Director and a 23-year employee at Bittersweet Farms. Karen Shulman is Bittersweet's Training and Consultation Consultant.

AFAA from page 9

AFAA will collect information, develop strategic solutions and advance the national agenda.

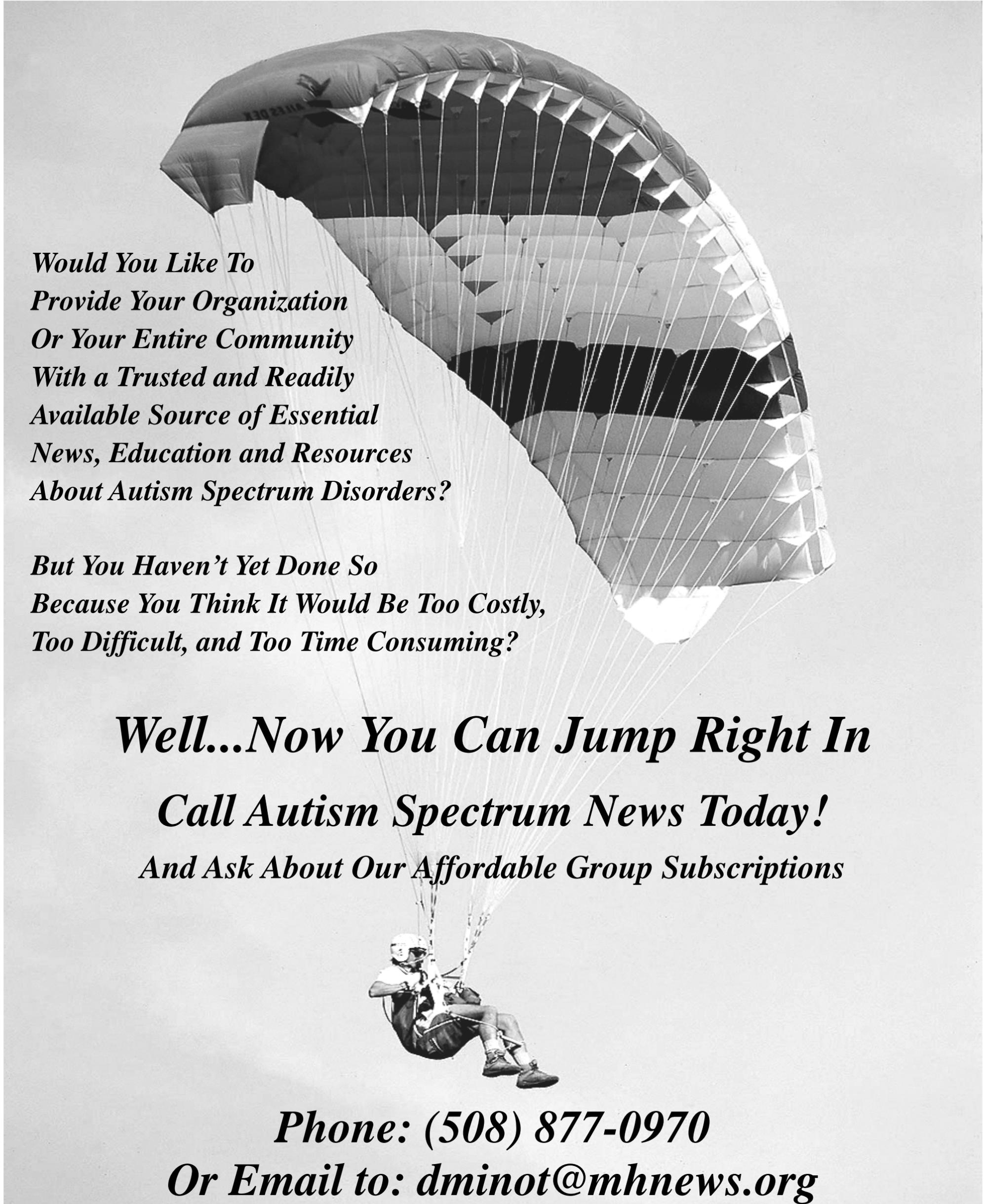
Autism Speaks, the nation's largest

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 Re-

lated Disabilities. For more information, please visit www.aaaa-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 showing positive results for this therapeutic approach was Trotter, et al. (2008). They compared the effectiveness of horse therapy with participants placed in an experimental group and those in a control group of no hippotherapy. Although the authors claimed that post-tests showed a significant improvement in the participants in the experimental group, the design involved a nonrandom convenience sample (i.e., a weak experimental design), poor reliability and validity of one of the measuring instruments, no objective assessment of the accurate implementation of the equine therapy protocol (i.e., no procedural fidelity data), and a focus on statistical significance, rather than clinical significance of actual behavioral change in the participants. When reviewing the many published papers on hippotherapy, many authors actually admitted the lack of experimental assessments of its benefit (e.g., Bliss, 1997; Marx & Cumella, 2003; Smith, 2009).

At the AHA website, there were ten abstracts of published "research" articles testing some aspect of hippotherapy. One (Benda, McGibbon, & Grant, 2003) involved a random assignment design to test the difference between hippotherapy and sitting on a stationary barrel on muscle activity in fifteen participants diagnosed with spastic cerebral palsy. The results showed statistically significant changes in the subjects in the hippotherapy group. Seven of the remaining nine articles used single-group convenient samples (not allowing a causal relationship to be determined), another article was a survey, and the tenth article was simply a description of hippotherapy.

At another link at the AHA website (www.americanhippotherapyassociation.org), six "research" articles were listed, from the journal *Hippotherapy*. Casady (2003) did not present the results of an actual experimental study; instead, she called for more research into the effectiveness of hippotherapy using a variety of research designs with adequate internal and external validity. The article by Casady (2004a) was not a research study testing hippotherapy in a controlled way; instead, she described the use of case studies when testing the effectiveness of hippotherapy. She accurately described the process of case studies, but later admitted "...because there is no experimental control, conclusions about the effectiveness of an intervention unfortunately may be viewed as mere presumptions."

Later, she discussed the process to be used in deciding upon a problem to research, defining it clearly, and generating hypotheses to test (2004b). Casady (2005) described the threats to internal validity that must be minimized to increase confidence of a causal relationship between independent and dependent variables. Casady (2006) summarized the

findings presented at the Twelfth International Congress of Therapeutic Riding in Brazil in August. Case studies were the most often used design, and she did not present any definitive research findings in support or in contrast to the effectiveness of therapeutic riding. Lastly, Casady (2007) briefly described single subject research, explaining the basic procedure, terminology, and how to use something called "single subject group designs." She did not mention the traditional within-subjects designs of reversal, multiple baseline, or alternating treatments, nor did she present any quantifiable data from any single-subject design testing the effectiveness of hippotherapy. However, she did mention that the journal *AHA Hippotherapy* has published studies using single subject designs over the past two years. In sum, at the AHA website, only one of the 16 papers purportedly showing research results actually could be considered an actual experimental test – with some control over internal and external validity – of the effectiveness of hippotherapy, and the focus of that study was on motor ability.

Marx & Cumella (2003) discussed the effectiveness of hippotherapy in improving eating disorders. They concluded that there was no research to support a causal relationship between hippotherapy and diminished eating difficulties. The authors, however, asserted that research evidence exists for the efficacy of animal-assisted therapy in treating persons with dissociative and other disorders (Arnold, 1995). However, a review of Arnold's article found that he did not include a research design or controls for internal and external validity threats. Furthermore, variables such as more intervention than just the presence of the animal (specifically, a support group), and the long duration of the therapy for one year or more, add additional skepticism to the belief that the single patient in the Arnold study improved due solely to animal therapy.

Bass, et al. (2009) studied the effect of therapeutic horseback riding on the improvement of social skills in children with autism spectrum disorder (ASD). Children were randomly assigned to either a 12-week session of horseback riding or a control group receiving no horse therapy. The dependent measures focused on social skills, sensory seeking, and social motivation. The authors concluded at the end of the study that these children did in fact show improved social skills, better sensory seeking and sensitivity, and more social motivation. However, the authors used survey instruments as the means for collecting data on the dependent measurements, and thus there is no confidence in the reliability of these measures (e.g., Fraenkel & Wallen, 2009). Thus, this study's results and conclusions must be viewed with skepticism.

In sum, it seems that the level of quality research that would allow us to conclude that hippotherapy is an effective strategy for persons with developmental disabilities does not exist at this time. Much of the published papers are either simply descriptive in nature or case studies that do not allow any confidence in a causal relationship between hippotherapy and improvement in the participants. Many proponents of hippotherapy seem sensitive to the need for conducting valid, well designed experiments that hopefully will show that hippotherapeutic techniques can effect change in consumers. As Casady rightly points

out, single subject research – using well established within-subjects designs, such as 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 Applied Behavior Analysis at The Sage Colleges. Dr. Zane earned his Bachelor's and Master's degree in psychology at Western Michigan University and his doctorate in 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 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 of Science Degree in Applied Behavior Analysis and Autism, a distance-learning graduate program.

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bath of hormones that reduce brain plasticity, neurogenesis and immunity. Chronic anxiety explains why aging individuals with autism frequently exhibit a 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 a purpose (e.g. sensory stimulation), with age become an automatic, procedural memory-based behavior to any stressful situation.

Frequently observing this ingrained behavior pattern leads to staff often discounting that behavior saying things like, "Oh that's just Randy being Randy." Their belief that the behavior is inevitable blunts efforts to address or attempt to alter the behavior. Research on repetitive behaviors offers little help. Conflicting theories suggest these behaviors occur because they may:

- Be built & retained, unconsciously, through procedural memory to reduce anxiety (Legendre, 1992)
- Be chosen consciously because, over time, they are seen as the sole alternative to any other behavior (Charlop, M, 1990)
- Result from mental impairment; individuals with autism are often unable to contemplate or communicate about their own mental states (Baron-Cohen, S. 1989)
- Result from mental impairment; they can't be inhibited due to executive dysfunction and disinhibition (Turner, MA, 1997)

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 responses 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 Lovaas suggested in 1977 and Dr. Frank Cicero confirmed (F.R. Cicero, 2007), these "locked in" behaviors may become difficult to extinguish as, 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 prophylactic 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 environment management for clients on the spectrum and the continuous use of positive reinforcement.
- 2) Off-the-shelf technology has to be enlisted to offset the cost of direct supervision, reduce client dependence, and improve client communication.
- 3) Reduce the dependence of psychiatrists and spectrum clients on psychotropic medication coincident with steps 1 and 2.
- 4) Constantly review clinical journals to identify potential application of new childhood spectrum research to adults – e.g. PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections), PKU (Phenylketonuria) disease, gastrointestinal disorders, etc.

Educating Care Staff

Of the four changes above it is anticipated that training staff on how to better manage their environment will yield the biggest short-term payoff. Both in day care and group homes, most people on the spectrum have fixed schedules. Some picture or sign communication and "escape activities" are often used when stress warning signs first appear. In day programs the current emphasis is on improving socialization which requires all clients to participate in changing peer groups and work areas. We anticipate, after more intense training on spectrum disorders and positive reinforcement techniques, that we might shift primary emphasis from improving socialization to improving communication skills for those clients on the spectrum. Communication problems have been long viewed as a source of chronic stress (Schopler & Mesibov, 1985), a means of nonverbal means of communication (E. G. Carr and V. M. Durand, 1985), and a point of leverage for development of joint attention and functional skill development. Shifting emphasis would ultimately decrease spectrum client stress due to less frequent environmental change and improved communication. These changes would be facilitated by use of off-the-shelf technology. We envision employing a similar strategy in group homes. We hope to use new tools like video messaging for schedule reminders and notices of change. We also hope to exploit room video and software to increase opportunities for learning – e.g. expanding attention span and improving functional ability and social and communications skills.

Exploiting 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 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 unnecessary 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 reliable, 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 pervasive drug use, John W. Harrington postulated in 2008, "We have relegated intensive persistent behavioral strategies to the background for parents who may not have the time or the skills to manage these difficult children." In adult services where psychiatric appointments are often only 15 minutes long, and the prospect of getting all prescribing clinicians (e.g. neurologist, general practitioner, psychiatrist, etc.) to agree on a comprehensive patient drug regimen impossible, drugs trump behavioral interventions. Unfortunately most psychotropic drugs are prescribed for their side effects (many drugs were originally developed

for another purpose) and thereby carry adverse reaction and side effect baggage. Recent research has shown that many psychotropics can;

- Be less effective than placebos (Mihir S. Parikh et al; 2008, BH King, et al 2009, Lukas Propper, MD)
- Cause side effects particularly as patients age (Abhilash K. Desai, MD, 2010)
- Cause heart disease with prolonged use (Kovacs, Daniela MD, 2008, K Jolly 2009)
- Contribute to death with prolonged use (Christine Montout, 2001)

As a result of decreasing stress through training and technology, we believe we will decrease unwanted behaviors and the use of psychotropic medications.

Identifying New Treatments and Interventions for Adults

The combination of concurrent advances in neurology, biological 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 to 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 and for juveniles and not adults, we will have to build better resources and relationships to explore and advocate for adult applications or adaptations to promising research on youth.

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