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FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 4 NO. 4

## Transitioning into Adulthood: Navigating the Complex Changes Ahead

### Working with Your School District to Best Meet the Needs of Your Child

By Maria C. McGinley, Esq  
Mayerson and Associates

Parents of children diagnosed on the autism spectrum are often concerned about their child's transition from the structured environment of a school-based program to the post-secondary world and all of the hurdles that transition entails.

A student's Individualized Education Plan (IEP) is the educational "roadmap" which includes goals and objectives, related service mandates, necessary modifications, supports and other individualized components of a student's program. Under the Individuals with Disabilities Education Act (IDEA), school districts are required to implement "transition services" to facilitate movement from school to post-school activities.

This article provides an overview of the transition requirements under IDEA as well as tips on how you can effectively advocate for your child's transition needs.



#### When Must Your IEP Team Consider Post-School Transition Planning?

IEP teams must consider transition planning for the first IEP that will be

in effect when your child is 16 years old. School districts, of course, can begin the transition planning process earlier if the IEP team determines that is appropriate.

#### What are "Transition Services?"

Transition services generally include a coordinated set of activities for your child with a disability. Under IDEA these services must:

- Be designed within a results-oriented process focused on improving academic and functional achievement to facilitate movement from school to post-school activities. This can include post-secondary education, vocational education, adult services, independent living, and community participation;
- Be based on your child's individual needs including strengths, preferences and interests;
- Include instruction, related services, community experiences, the development of employment and other post-school adult living objectives and, if appropriate, acquisition of daily living skills and functional vocational evaluation.<sup>1</sup>

*see School District on page 20*

## Planning for a Successful Transition to Independent Housing

By Cynthia R. Haddad, CFP,  
John W. Nadworny, CFP  
Leo V. Sarkissian, MSW

Transition is a critical time for young adults. According to the Individuals with Disabilities Education Act (IDEA), school systems are required to begin transition services when youth reach the age of 16 years (some states do require it to start at 14 years). IDEA is the law for special education and include a section on transition. Regulations define what transition services are. Transition services are defined to be a coordinated set of activities which 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.<sup>1</sup>

As you can see from the federal regulation based on IDEA, accessing services for adult life should begin during the school years. However to access services, it's critical to understand what you (if you're the individual with ASD) or your family member needs. To do that one needs to develop a framework or plan to identify the services needed and then take steps to obtain those services.

This article suggests a framework to utilize in planning for housing for an adult with ASD. It identifies existing programs, funding and tools while providing recommendations for an adult with ASD to achieve a full life. The authors are presently working on a more comprehensive planning resource for families to develop an appropriate housing model in their next book that is scheduled for publication in January 2013.

#### The Increasing Need for Supportive Housing

One of the biggest service needs is that for housing, or residential supports. The need for housing for adults with autism or autism spectrum disorder (ASD) will grow along with the developmental disabilities population in general. "Open Doors" published in 2010 about housing needs in Arizona reported that a conservative estimate of 400,000 persons with ASD will make the transition process to adulthood in the next 15 years.<sup>2</sup>

This is only one of many reports that reference a growing need for housing for persons with autism and developmental disabilities. A television news story reported in November 2010 in Indiana confirmed that state employees considered homeless shelters as a legitimate referral point for persons with disabilities who

can no longer be supported or cared for by family members.<sup>3</sup>

"Awash in Autism," released in 2010 by Advocates for Autism in Massachusetts,<sup>4</sup> focuses on the current and impending housing crisis. The report asserts that, "For years it has been assumed that adults with autism could be served by programs and supports created for people with intellectual disabilities, without taking into account the unique communication, sensory, environmental, social and behavioral factors that distinguish autism from other intellectual disabilities."

Consequently, when considering residential services for individuals on the spectrum, it's important to discriminate between what is applicable in the disabilities field versus the specific requirements for individuals with autism or on the

*see Housing on page 30*

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“Vital Supports and Services in the Community”

**Deadline: June 5, 2012**

#### **Fall 2012 Issue:**

“The Importance of Early Intervention Following Diagnosis”

**Deadline: September 5, 2012**

#### **Winter 2013 Issue:**

“Exploring Educational Challenges and Opportunities”

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# Comprehensive Transition and Post-Secondary Programs

## *An Emerging Model for Transitioning Individuals with ASDs to Adulthood*

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

For many higher functioning individuals on the autism spectrum and their families, the road to independence and adulthood can be very puzzling. Although the student may possess the intellectual ability and be "otherwise qualified" to attend college or post-secondary vocational training, their transition to adulthood is often not a linear process. Most high school students progress directly to college or vocational training once they complete their secondary education. For high functioning individuals on the spectrum certain aspects of their disability impede success in a post-secondary environment. Comprehensive Transition and Post-secondary (CTP) programs may serve as a bridge between high school and college or vocational training.

Recent changes to the Higher Education Opportunities Act, P.L. 110-315, (2008) have resulted in greater access to college programs to students with intellectual disabilities (ID), including those on the autism spectrum. Prior to the amendments to HEOA, only students who were enrolled full time in a degree bearing program were eligible to complete the Free



**Paul K. Cavanagh, PhD, MSW**

Application for Federal Student Aid (FAFSA) under title IV of Federal Student Aid. (The FAFSA form is the gateway to all federal student aid). This precluded many students on the spectrum who could not meet the full-time student requirement. Impairment in executive functioning skills often interferes with a student's ability to maintain a full time



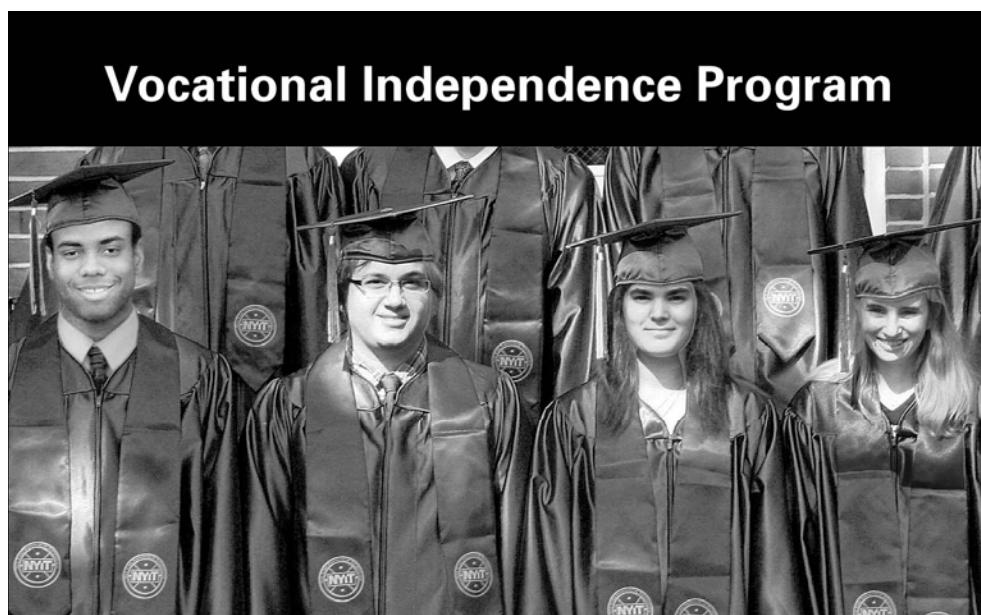
**Ernst O. VanBergeijk, PhD, MSW**

course load of credit bearing classes. Under the new guidelines established by the changes in the HEOA, students with an Intellectual Disability can be eligible for certain specific types of federal financial aid if they are enrolled full time in a Comprehensive Transition and Post-secondary program that is approved by the U.S Department of Education.

Students with ASDs, who are otherwise qualified for college admissions, often do not struggle with the academic demands. The structure of the coursework is very familiar to them. Rather, it is the level of independence and lack of structural supports that interferes with a student's success. In a college environment they do not find the supports and safe guards of the special education system. The student must provide his or her own structure in an educational environment that is highly variable (e.g. a student may have a different class schedule every day of the week). Social skills are another major area where students with ASDs struggle in the college environment. A student with an ASD may be used to interrupting and asking questions of a teacher in a small high school class setting. However, at college it may not be appropriate to ask questions during a lecture in an auditorium filled with dozens, or even hundreds of other students.

Living in a residence hall can be particularly stressful for students on the spectrum who have to negotiate sharing living space, eating in a cafeteria with foods that are not home-made, and the noise levels associated with communal living. A lack of independent living skills can interfere with a student's success at

*see Post-Secondary on page 29*



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## Early Intervention is Key

### *Focus Should Be on Transition from the Start*

Justin DiScalfani, MA  
Clinical Director  
The ELIJA School

Thanks to extremely motivated parents and professionals, a greater focus has been placed on the proper education and treatment of those with autism. There are now a number of comprehensive multi-disciplinary treatment clinics and university training programs throughout the country. Additionally, specialized schools have become available with properly trained staff to provide parents and public education systems with quality options to educate their children. More recently, professional publications and research programs have started to shift their focus to the complex process of transitioning those with autism into adulthood and the issues surrounding their continued education.

There are a number of skill domains, often not prioritized earlier in a child's life, where teaching is absolutely necessary for a smooth transition into adulthood. Examples of these include; toileting, appropriate behavior and functional daily living skills. Emphasis is often not placed on acquisition of skills within these domains in many public educational programs until they become so problematic that they are unmanageable by current staffing levels and expertise.

Educators and professionals frequently overlook educating within these domains for many reasons. Some parents and professionals hold the opinion that "he/she will grow out of problem behavior" as the child matures or will "naturally learn" functional daily living skills. For many of us that work closely with children with autism, we know this is generally not the case. The longer these domains go unaddressed, the harder they are to remediate. Educating within these domains should be at the top of the priority list for educators and professionals. This is because deficits in these domains are often the "red flags" restricting young adults from quality vocational and residential programs as well as community integration.

Proper assessment and treatment of problem behavior is the most important area to address early on in a child's development. In doing so, opportunities will arise for participation in specific programs later in life. Quality placements, which help integrate young adults with autism into the community, are less available for those who engage in aggression, self-injury, elopement or property destruction - even at low rates.

There are now very effective evidence-based strategies for in-depth assessment and treatment of problematic behaviors. Unfortunately, when a child engages in such behavior at a young age it is often unaddressed. This is when you will hear someone say, "he/she will just grow out of it" or give justifications for the behavior such as, "he/she was frustrated and didn't mean it" or "all three year olds do that." However, children with autism engage in these behaviors because it works for them (e.g., screaming results in attention from caregivers). If not addressed, they will most likely continue to engage in this type of conduct and their behavior will most likely not go away on its own. For example, parents or profes-

sionals may just redirect a four year old who hits and kicks a few times per week to get out of doing work since he/she does not have the strength to do much physical harm. However, when the child is older, bigger and stronger treating aggression will have to become a higher priority as it can lead to severe injuries to people at school or at home as well as restriction from certain placements. By this time it is often too late to eliminate such behaviors completely. Assessment and treatment are most successful when implemented immediately after the behavior is first observed.

Independent toileting skills are another important area that needs to be addressed as early as possible in order to keep all options open when transitioning into adulthood. A lack of toileting skills will restrict people with autism from many vocational and residential placements. Most vocational programs will not send someone into a community setting to work if they cannot independently request the bathroom and use it appropriately.

Toileting skills could take up to several years to acquire depending on the learner's level of impairment. There are many intricate steps of the toileting process (e.g., undressing, eliminating, wiping, and washing hands), each of which requires a thorough and systematic approach to teach in order to gain and achieve independence. Many times programs will stop once a child is trip trained (i.e., stays continent and urinates on the toilet when brought on a schedule), but the skills of requesting and using the bathroom independently are neglected until it becomes a major problem restricting the child and their family's life (e.g., traveling). Similar to treatment of problem behavior there are very successful and evidence-based treatments available for toileting and self-initiation skills.

Other functional daily living skills are also essential for placement in the least restrictive living and vocational settings. Skills such as teeth brushing, dressing, exchanging currency and safety behavior (e.g., staying with an adult and asking for help) are important to teach early in a child's development. Again, some of these skills may take years of teaching before independence is achieved.

Transitioning into adulthood is a major and often difficult life change for everyone - especially those with autism. It is our responsibility as parents and professionals to properly equip our individuals with autism with the skills and behavior necessary to function at their fullest potential in adulthood. Problem behavior, toileting and other functional daily living skills are just a few examples of skill domains that need to be targeted early in order to make this transition as seamless as possible. Unfortunately, such domains are often neglected to focus on traditional academic skills (e.g., labeling colors) or due to a lack of expertise and training in current educational systems. Careful thought needs to be given early on about how to prioritize educational programming for each individual. In doing this, the greatest quality of life in adulthood can and will be achieved.

*see Early Intervention on page 34*

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## The Road to Adulthood

**By Carolann Garafola, MA**  
**Executive Director**  
**Mt. Bethel Village**

**T**ransition from school to the adult world is exhilarating for some, terrifying for others. Some families have described it "like falling off a cliff and never knowing when we will hit the bottom or climb back to the precipice." This time is well-described by the hundreds of families who worry about their 19, 20 and 21 year old adult child who will leave the cocoon of schooling to become part of the rest of the world of "work," either living at home or in a supported apartment. Transition is a coordinated set of activities in the form of a plan to move from school to the post-secondary world of work, vocational training, college, employment, and adult education, access to adult services, independent living, supported apartment living and community integration. The road to get there is fraught with quicksand, ruts and boulders for families who have children on the autism spectrum. The issue is to clear the road of obstructions to allow these individuals the opportunity to live happily with meaningful lives in a safe and supported environment.

The planning for transition for those with ASD should start at 14 years of age. The process takes into account a teenager's strengths, challenges, interests, preferences, support from agencies and inter-



**Carolann Garafola, MA**

agency linkages with parents/guardians as the primary advocates. By 16 years of age, those measurable planning goals should engage the teenager in transition activities of job coaching, self-care with activities of daily living (ADL) such as washing, eating, dressing, shopping, cooking, and generally taking care of oneself and planning ahead by acquiring skills to live, work, and engage in social activities. Most importantly, parents need to ask their adult child,

"What do you want? Where do you want to live?" Each young adult with ASD must be involved in the decision-making process. There is a need to look at assessment data from the teenager's Individualized Education Plan (IEP), observations in job settings, ADL activities, skills needed for adult life and behavioral supports into adulthood. These activities, shared by the school staff, transition staff, and family become the focus of life planning to access resources and services that will enable an adult with ASD to become, if not totally independent, perhaps semi-independent with supervision at a day program or in a housing environment. During this transition process, having an advocate is essential. This means that there needs to be someone to intervene and/or speak for the adult with ASD. This advocate can be a family member, sibling, agency, counselor, and/or the young or adult individual's own advocacy skills that have been developed.

The planning process must take into account whether or not guardianship has been established at 18 years of age, what financial resources are currently in place to support the young adult as he or she grows older, and what financial supports will be in place once the parents/guardians die. Of additional importance is estate planning (especially establishing a Special Needs Trust), an annual review with all family members, and the existence of a letter of intent for when the parent is no longer there to guide and advocate. It is important

see if the individual qualifies for the many federal financial supports available, including Supplemental Social Security Income (SSI) or Supplemental Social Security Disability (SSDI), Medicare, Medicaid, Medicaid Waiver, State Children's Health Insurance (CHIP) or Children with Special Health Care Needs (CSHCN). One of the most important questions that parents must ask themselves is, "Where will my son or daughter live when I am gone?" All of these components, as a checklist, are important not only for the parents/guardians, but for other family members to know what safeguards and supports are in place, especially for when the parents are no longer around.

As the adult individual may either be low or high functioning, the way in which he or she is presented by the parents or guardian is important; whether to a potential employer, job coaching setting, agency staff or when seeking living accommodations in a group home, supported apartment or independent apartment. In addition to their own view, parents should consider the opinions of school staff, immediate family members, supervisors at the job coaching sites, extended family members and neighbors. We must clearly remember that the adult with ASD will be out in the "real world," and those who are meeting him or her for the first time will not have the luxury of reports, introductions

*see Road on page 33*

## Spectrum Services

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**Asperger Syndrome Training & Employment Partnership (ASTEP)** has the mission of creating and supporting programs that promote employment for adults with AS in the corporate sector and training employers about their special talents and needs. Marcia Scheiner, CEO, Michael John Carley, Executive Director, and Susan Lesco, Director of Program Partnerships, will be working to raise awareness about the benefits of hiring adults with Asperger Syndrome and the challenges they face in the world of employment. [www.asperger-employment.org](http://www.asperger-employment.org)

**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](http://www.ahany.org)

**Career and Employment Options, Inc., CEO** is an award winning service providing transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities. [www.ceoincworks.com](http://www.ceoincworks.com)

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## Grant for Innovative Young Adult and Adult Autism Services Inspires Other Agencies

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

The Daniel Jordan Fiddle Foundation, a national Autism organization focused on developing, advocating for and funding programs for adults living with Autism Spectrum Disorders (ASD) is known for innovating opportunities that target the needs of the individuals on the spectrum ([www.djfiddlefoundation.org](http://www.djfiddlefoundation.org)).

The UJA Federation of New York is the world's largest community-based philanthropic organization that raises funds to sustain more than 100 health, human-services and community building agencies. ([www.ujafedny.org](http://www.ujafedny.org)). The Hilibrand Autism Symposium at the UJA Federation of New York is one of Autism's cutting-edge annual events that brings together scholars, news-makers, community support systems and service providers. Combine all three of these forces and the result is certain to ignite ideas, and in this case, directed specifically towards programs for adults living with ASD.

During last Spring's 2011 Hilibrand Autism Symposium, all three organizations announced the creation of *The Daniel Jordan Fiddle Foundation Ignition Grant Award for Innovative Young Adult*



**Participants discuss dating issues in the supportive setting of the DJF program**

and Adult Autism Services (DJF Ignition Grant). At this year's upcoming symposium scheduled for April 25<sup>th</sup> in New York City, the first program to receive this award will be unveiled. The DJF Ignition Grant is designed to stimulate the development of an innovative program for adults living with ASD or young adults as they transition to adult life (age 16 or

older) by encouraging organizations to submit proposals to develop, create and sustain new ideas.

The DJF Ignition Grant award that is matched by UJA Federation of New York, provides seed money to pilot a new idea in the field of adult Autism to enable people in this age group to have access to opportunities that will allow them to

achieve additive levels of independence. The program idea can address any area relating to adult life including social skills, employment, education, social/sexual development and housing/residential initiatives. No matter what the program, it must push the boundaries of what is already available at UJA-Federation agencies on New York and capitalize on unrealized potential.

The first DJF Ignition Grant recipient fulfills the goal these organizations imagined and that adults living with Autism have been asking for: a program to help them form, maintain and navigate healthy interpersonal relationships. The JCC in Manhattan is the recipient of this \$10,000 grant that expands its six year old Adaptations program geared towards adults in their 20s and 30s to create four different social support groups for adults on the spectrum. Groups are co-facilitated by experienced professionals, consist of 8 to 12 individuals and meet every other week for one/two hours.

The focus of this new program, which interestingly addresses issues raised in Amy Harmon's *New York Times* cover story, "Navigating Love and Autism," is on sexuality, dating and intimacy and offers a supportive and safe setting to explore these topics. The Social Learning

*see Innovative on page 27*

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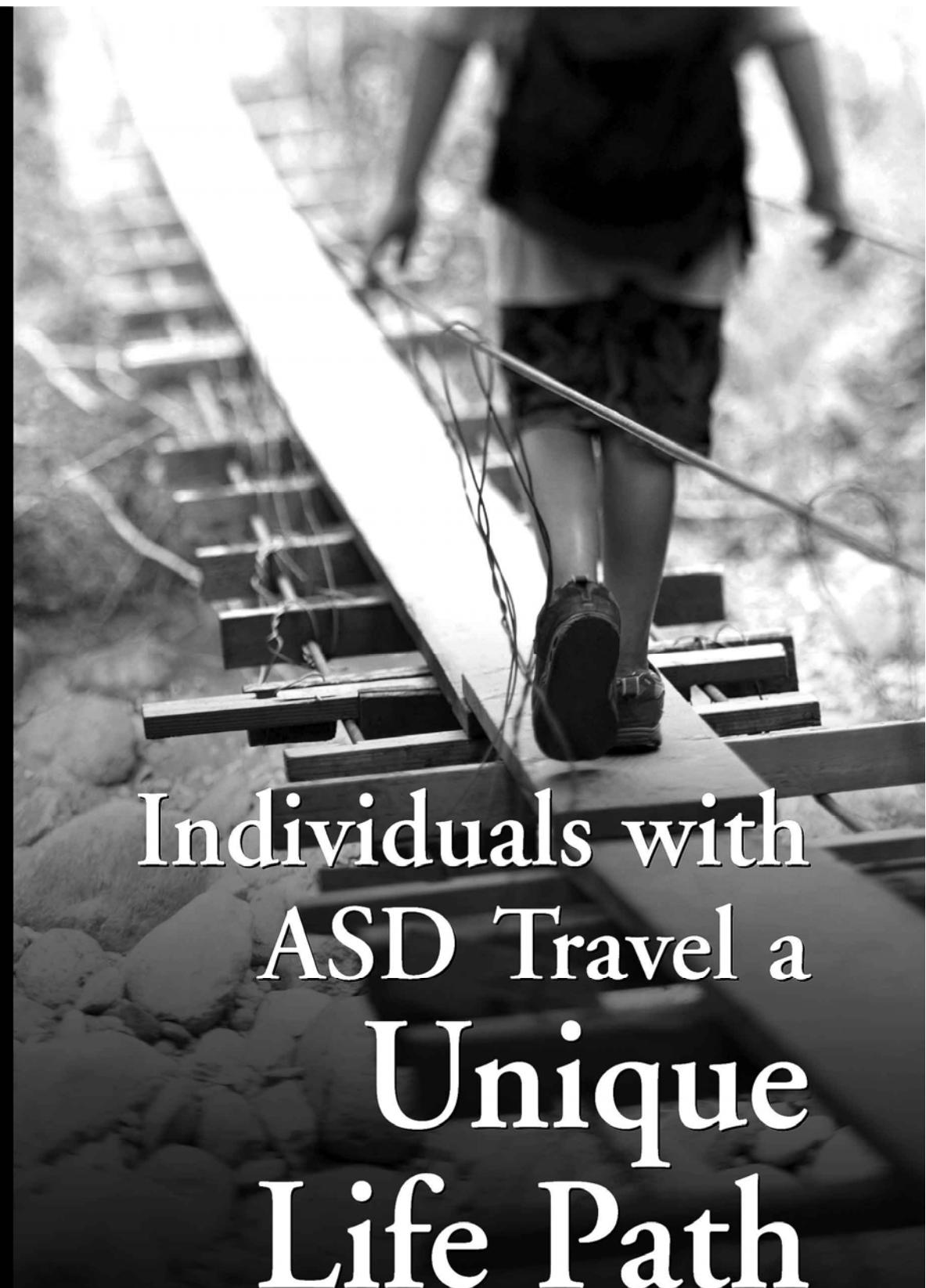


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## Making the Most of the 18-21 Period

### *Advantages of a Dedicated Transition Center*

By Jacque Murray, MA, MEd  
Director  
Vanguard Transition Center

**E**arly adulthood is a critical period for young adults with ASD and their families. Although students have been preparing for transition for many years, the process takes on new urgency as adulthood is imminent. Families know that much is at stake in shaping the course of students' futures.

The years between a student's 18<sup>th</sup> and 21<sup>st</sup> birthday are a particularly important time for taking concrete steps toward career development and post-secondary education. Those four years, during which students continue to receive funding and services, should be a time of careful planning and time allocation, with the goal of marshalling available resources to obtain valuable skills.

Unfortunately this vital period is often one in which students are the least well-served. Many students graduate from high school only to return to what is essentially a recycled high school program. During important years for growth and skill development, these students are in effect "treading water."

Programs dedicated solely to meeting the needs of transitioning students 18-21 offer so much more. They cele-



Jacque Murray, MA, MEd

brate the newfound sense of accomplishment and maturity students feel on leaving high school and they support students' social and recreational needs with appropriate activities and events. But most importantly, they prepare young adults for adulthood through a well-planned educational and vocational skill-development program individualized to each student's aspirations and abilities.

Choosing a transition program can be difficult, but finding the right program can help families to utilize the 18-21 years effectively. Tenets of a strong transition program include: realistic goal setting, a deep knowledge of area resources, a network of support, an emphasis on self-advocacy, and addressing the needs of "the whole person."

#### Realistic Goal Setting

The right transition program will serve students with a range of capabilities and aspirations and meet their needs. Some students need practice developing life skills, while others need college support. While we, as educators, want to set goals that will stretch students and help them fulfill their potential, we never want them to "break." We must be conscious of their individual needs and capabilities, and, in some cases, factors such as comorbid anxiety and depression which may challenge them. We must know our students very well. By knowing their capabilities, strengths, and challenges, we establish realistic and achievable goals in partnership with them and their parents – an important part of the transition process. Some students and their families may need encouragement to consider college, while some students who would like to attend college may not have the capacity, putting us in the unpleasant

position of being a "dream changer." In these cases, we seek alternatives in line with a student's abilities and interests, which will allow him or her to find satisfaction while not continuing to pursue an avenue that will waste time, money, and energy. Students need to balance their strengths, acknowledge their needs, and find accommodations that will assist them in life. The impact of ASD on their lives is a fact but what they do to handle it can make a big difference in the quality of their adult lives. At a strong transition program, we can navigate these tensions and individualize transition planning to each student's needs.

#### Deep Knowledge of Area Resources

Planning for transition can sometimes seem like a chess game in which knowledge and tactical skill contribute to a winning strategy. Educators at a strong transition program draw on deep and varied experience with community resources, organizations, and educational entities to be creative in finding ways for students with ASD to progress toward their goals.

Consider "Henry," a student with a strong interest in becoming a veterinary technician. There is an excellent and highly competitive vet tech program in his region, but Henry is not ready to enter it.

*see Dedicated on page 34*

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## Changing the Mindset of Children and Adolescents with ASDs

By Robert Brooks, PhD and Sam Goldstein, PhD

A major focus of our collaboration has been to elaborate upon the concepts of both mindsets and resilience (Brooks and Goldstein, 2001, 2004, 2007, 2012; Goldstein and Brooks, 2005, 2007). We propose that all people possess a set of assumptions about themselves and others that influence their behavior and the skills they develop. In turn these behaviors and skills impact on their assumptions so that a dynamic process is constantly operating. We labeled the set of assumptions a mindset and sought to identify the features of the mindset possessed by hopeful, resilient people. These include feeling in control, possessing empathy and effective communication, learning how to problem solve, establishing realistic goals, learning from success and failure, and developing compassion and self-discipline. In our therapeutic work with children and adolescents with ASD, a major goal is to change the negative, self-defeating mindset that often comes to direct their lives.

Our interventions are rooted in an approach that focuses on developing strengths rather than fixing deficits. The shortcomings of a deficit model, especially when working with or raising children with ASD, reside in the multi-faceted problems these children display. If clinicians and caregivers spend most of their time in a reactive



**Robert Brooks, PhD**

mode, constantly and frantically moving from one problem to the next, it is difficult to have an opportunity to reflect upon and adopt a pro-active approach. It is well-documented that children with ASD require much more assistance than other youngsters if they are to transition successfully into adult life (Adams, 2009; Robbinson, 2011; Sicile-Kira, 2012). Symptom relief, while essential, is not the equivalent of changing long-term outcome.



**Sam Goldstein, PhD**

In our therapeutic work with children with ASD, we expanded upon our earlier writings about a "resilient mindset," especially given the specific challenges that these youngsters face. Social impairments have been found to be the strongest predictors of the risk of a child receiving a diagnosis of ASD (for review see Goldstein, Naglieri and Ozonoff, 2008). Children with ASD struggle to develop normal, satisfying, and appropriate social connections in relations with oth-

ers. They often do not understand how to initiate interactions. They have noticeable difficulty in developing appropriate play skills and modulating facial and emotional responses and responding effectively to social cues. They can be self-absorbed, shutting off interactions with peers and adults alike. Many display odd interests and routines, often demonstrating rigid, obsessive-compulsive behaviors that isolate them even further from meaningful relationships. They typically lag in social language or pragmatics so that a give and take discourse with others is difficult to achieve. They misread social cues, failing, for example, to comprehend the messages and jokes of others while being far off the mark with their own attempts to communicate.

Our expansion of the concept of "resilient mindset to social resilient mindset" with youngsters with ASD is to capture the key developmental problems they experience in the social domain. Though each child's journey in life is shaped by a variety of factors, including inborn temperament, family style and values, educational experiences and the broader society or culture in which the child is raised, we have selected eight Guideposts for parents and teachers to focus upon for children with ASD, guideposts that provide principles and strategies for nurturing a social resilient mindset. Each of the Guideposts involves reinforcing skills necessary for the

*see Mindset on page 35*

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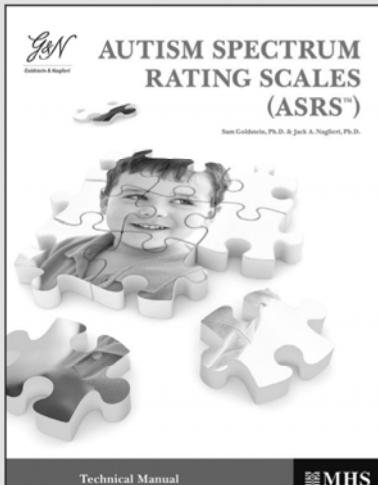
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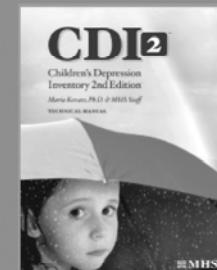
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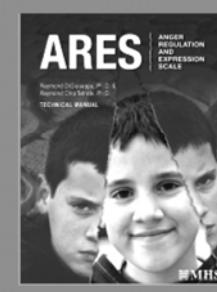


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## Guiding Families Toward Successful Outcomes

**By Suzanne Muench, MSS, LCSW**  
**Director of Admissions and Family Services**  
**Melmark**

One of the favorite things in my role as Director of Admissions and Family Services at Melmark is talking with parents about their children and helping families maneuver the complicated web of supports available to them. One of the most challenging parts, however, is helping families understand how dramatically different services and supports are in the post-21 world. Many parents just don't realize what they will face when their loved one graduates from a school program. To help alleviate some of this stress, Melmark has developed a systematic way of assisting families in addressing the various tasks necessary for a smooth transition into the adult system.

We have defined the key ages in transition related services to be 14, 16, 18, and 20. At each of these critical benchmarks, we have laid out specific tasks that families can complete, with the help of the school and county support personnel. Transition goals are reviewed at the student's annual IEP; goals such as obtaining a state ID, determining who will serve as guardian for the individual with special needs, obtaining Supplemental Security Income, and working with an attorney to set up a special needs trust. Melmark



meets with families to help guide them through these processes to ensure a successful transition.

Despite our team's guidance and all the supports focused on the post-21 transition, this particular change comes with the greatest amount of angst. While parents watch their typically developing children meet major milestones, such as getting their driver's license, graduating and moving off to college, they are reminded daily that their child with special needs may never reach these milestones. The

reality that their child may need lifelong care is becoming evident in ways many parents never could have imagined, and this coincides with the loss of major services and supports previously provided through an IEP. While services to children meeting special education eligibility standards are an entitlement through the *Individuals with Disability Act (IDEA)* via an IEP, services to adults with developmental disabilities are not guaranteed. Service levels and availability vary greatly, depending on the specific need of the indi-

vidual, the state or county the person resides in, and the family's ability to advocate. There is a significant gap in what is needed and what is accessible to families.

The services that are available to support adults with autism have not evolved at the same rate as those for children. There is no unified system of funding that has taken responsibility for these young adults. Complicating an already difficult profile, many of these individuals may have higher cognitive abilities that leave them unqualified for services.

So what is a family to do when, regardless of how well prepared a child is in school for this transition, the opportunities for support do not meet their needs? The good news is that there are many innovative programs and supports being developed to address the issues raised thus far. Melmark directly answered the call for services for individuals who continue to need a high level of support specific to challenging behaviors and intellectual disabilities. The Chris Maurer Vocational Program prepares young men and women for work environments, both on Melmark's campus and in the community, in a multitude of settings. Whether it's filing, copying or collating in the clerical room or working in the delivery and packaging areas, individuals who may require more intensive behavioral supports can still develop skills that can eventually lead

*see Guiding on page 28*

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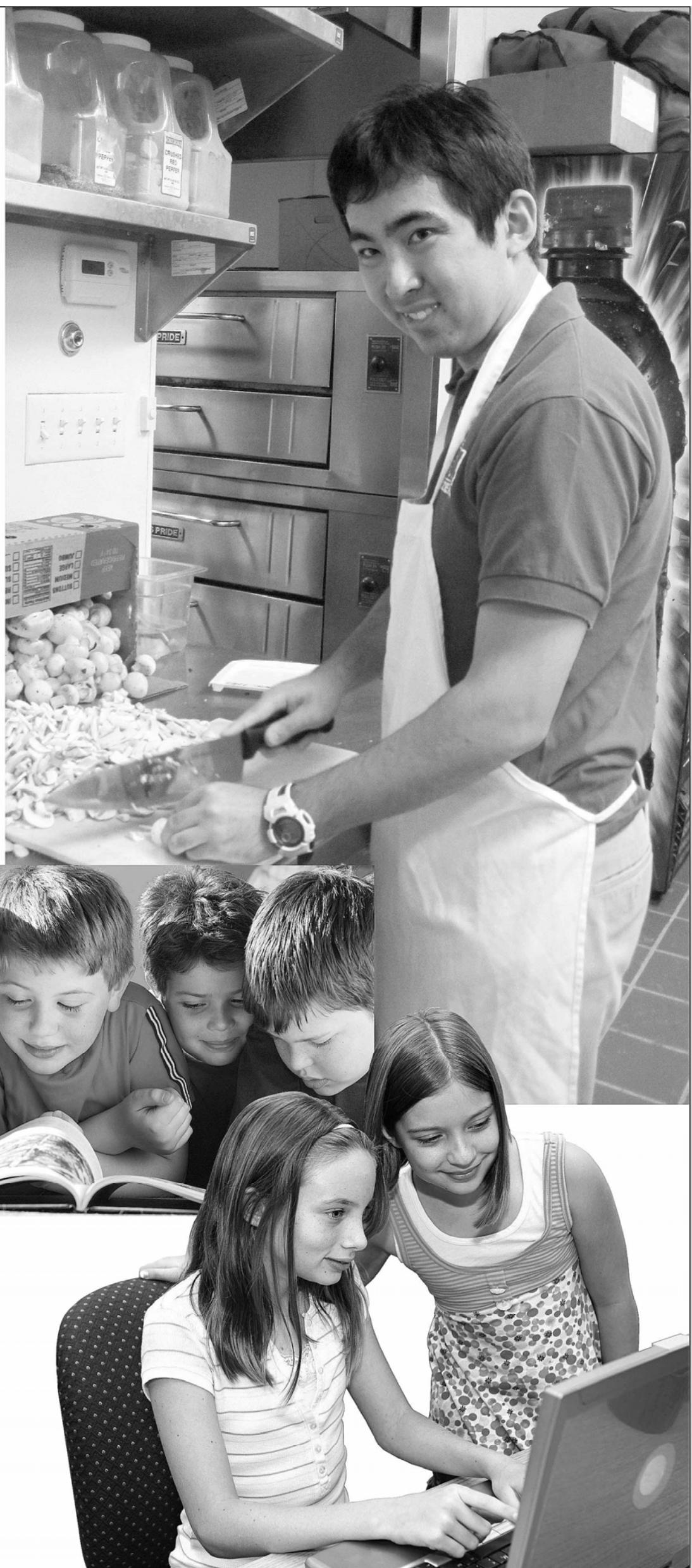
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# Devereux

## Tackling the Unemployment Crisis for Adults with Asperger's

By Michael John Carley  
Executive Director  
ASTEP

**T**ransitioning into adulthood encompasses a wide array of new experiences: The emotional changes involved if an individual is leaving home, the cognitive challenges of navigating how the world operates, the acquisition of independent living skills, and managing new relationships—both romantic and professional—all come into play. But arguably, the greatest key to independence is employment, as it so affects our status in the aforementioned areas. Some avenues for placement exist for individuals with autism, but college-educated people on the spectrum seeking entry-level positions often fall through the cracks of our existing supports, resulting in unemployment or underemployment. ASTEP, the Asperger Syndrome Training & Employment Partnership, began a little over one year ago as an employer-focused non-profit hoping to improve spectrum employment issues for this population - from the inside. ASTEP's plan is based on training larger companies and assisting them with integrating individuals with Asperger Syndrome into their diversity and inclusion strategy.

Historically the autism/Asperger's Syndrome (AS) world promoted our population as capable workers through messages of social good or civic responsibility, with less of an emphasis on the economic and



**Michael John Carley**

business advantages of employing this population. During our first year, ASTEP has learned that bringing the employer and their perspective to the process is key as solely training individuals with AS to "fit in" is not sufficient. Corporate culture itself needs to be a collaborator capable of adaptation as well.

In order to develop a true partnership between employers and vocational rehabilitation professionals, three things need to happen – outreach, training and demystification.

### Outreach

In order to engage employers as partners in this process, organizations representing individuals with Asperger's must meet them on their home turf. Corporate conferences focusing on Diversity & Inclusion (D&I) or Human Resources (HR) are an ideal place to reach out to employers to begin the long relationship-building process required. While speaking at these types of conferences, ASTEP has found the response to our efforts to be extremely positive. Not only are conference organizers excited to have Asperger Syndrome represented on their agendas, the sessions are well attended.

And we have learned that, though large knowledge gaps exist, the corporate world is very familiar with AS, most likely thanks to both fictional and non-fictional portrayals through the media. Whenever we cite that most large companies - due to the prevalence numbers - probably already *have* many (undisclosed or even undiagnosed) employees with AS, from our vantage point on stage, the audience is a sea of nodding heads. These presentations are wonderful door openers, often leading to follow on discussions with employers.

### Training

Yet even among corporations that are excited about increased behavioral pluralism inside their offices, most employers

are unsure that they have the managerial skill to integrate employees with a disability they only know about through the media, and to handle it over the long haul rather than the short term. This creates an opportunity for those looking to increase the employment rates of individuals on the spectrum. To take advantage of this opportunity, advocates must sell the benefits of hiring—accentuating the talents, the reduced turnover rates, and the untapped workforce for businesses that comes with the 80-85% unemployment rate for adults with AS. But perhaps the best first step is to focus on training programs that prepare companies to be successful employers of individuals with Asperger's.

All large employers are experienced users of D&I and HR training materials, making themselves better employers and managers of a diverse talent pool is a necessary goal. Large corporations often require their employees to complete a pre-defined number of training hours per year; and a course in creating a diverse work environment is often a component of this requirement. This, again, presents an opportunity to meet employers needs in a way familiar to them, while advancing the cause of employment for adults with AS. ASTEP fills this need by offering training materials targeted at managers, colleagues, recruiters and HR professionals that can be delivered to a broad audience

*see Unemployment on page 32*

## I Know the Periodic Table, But I Can't Make My Bed

By Edel McCarville, M.S.Ed.  
Psychology Intern  
Fay J. Lindner Center

**I**ncreased attention has been recently given to the needs of individuals with disabilities who are transitioning from high school, particularly those individuals with High-Functioning Autism Spectrum Disorders because of their unique and specific needs. Many individuals with High-Functioning ASDs encounter challenges post high school in areas including communication, socialization, and daily living skills. Although these individuals may participate in mainstream education and are often academically successful in high school, many are unable to perform basic everyday tasks including preparing a simple meal or folding laundry. Tremendous barriers to independence may be encountered by these individuals if they don't acquire age appropriate life skills when transitioning from high school.

Individuals with ASDs typically need, but are often not given, specific instruction to master daily living skills that are required for independent living. These skills include household cleaning, doing laundry, washing dishes, and preparing a simple meal. Due to deficits in being able to independently complete daily living tasks, many individuals with High-Functioning ASDs have limita-



**Edel McCarville, M.S.Ed.**

tions in adulthood. Increasing adaptive independence, particularly in the area of home living skills for young adults with High-Functioning ASDs, is important because learning these skills can enhance their independence at home, increase their ability to obtain paid employment, allow them to participate in leisure activities and increase the likelihood of their being able to live more independently as an adult.

It is important to recognize the need for daily living skill building for individuals early in the teen years. Findings from the National Longitudinal Transition Study (NLTS) data show that only 1 in 8 youth with a disability live independently 2 years after leaving high school. However, students have limited amount of time in school to learn and master all of the academic skills being taught, leaving little time for functional activities. Throughout secondary education, the amount of time dedicated to each student that will focus on academics, social skills and functional skills should be specific, meaningful and focus on planned outcomes that will directly improve adult functioning. Through personal experience in working within the school system, I have encountered many parents of children with ASDs who have stated that they want their children to learn skills that will allow them to live as independently as possible as an adult. In order to increase independence for students with ASDs, appropriate functional daily living educational goals should be created and addressed as needed to help promote happy, healthy, well-adjusted adults on the spectrum. Research has shown that an increased level of independence in daily living skills produces better outcomes in adulthood. For example, higher scores on the Vineland Adaptive Behavior Scales (VBAS), a measure of overall independent life skills functioning, are closely re-

lated to better social and independent living for individuals with autism who have average cognitive abilities (Farley, McMahon, Fombonne, Jenson, Miller, & Gardner 2009). Additional evidence further indicates that teaching daily living skills to teens and young adults with high-functioning ASDs has the potential to improve functioning long term, as research suggests that the discrepancy between intellectual ability and independent daily living skills functioning increases with age (Klin, Saulnier, Sparrow, Cicchetti, Volkmar, & Lord, 2007).

There are a variety teaching approaches that have been successful in teaching daily living skills to individuals on the Autism Spectrum, but behavioral teaching methodologies including the use of assistive technology, reinforcement contingencies, and corrective feedback have shown to be the most effective in improving independent daily living skills in High-Functioning young adults with ASDs (Palmen, Didden, & Lang, 2012). Many studies however fail to support the generalization and maintenance of these taught skills, as the skills are usually taught in only one environment. This means that if students learn a skill only at school, it is likely that they will be unable to perform that skill at home; practice at home is necessary for it to be generalized to that environment as well. Therefore,

*see Make My Bed on page 28*

## Healthy Relationships and Sexuality for All

**By Patricia L. Grossman, LCSW and  
Kari Y. Phillips, LCSW**  
**Outpatient Services for People with  
Developmental Disabilities**  
**Westchester Jewish Community Services**

**I**t has become commonplace to read about or hear stories about issues related to people with autism spectrum disorders (ASD). Healthcare, education, mental health and social services offer options for children that did not exist years ago. As these children grow up, their needs change. Older teenagers and their families are facing challenges in the arena of employment, daily living and social relationships. While some families are reticent to recognize it, transitioning into adulthood also includes readiness to form and maintain relationships, engage in dating and sexual activity.

Misconceptions about their interest in and need for social and sexual relationships have often served to further isolate young adults and adults with ASD from their typically developing peers; put them at risk for sexual victimization; and deprive them of the opportunity to experience rich, intimate, emotional relationships. Parents and caregivers are often reluctant to discuss sexuality and relationships with their children for a variety of reasons. They themselves may be uncomfortable talk-



**Patricia L. Grossman, LCSW and Kari Y. Phillips, LCSW**

ing about body parts and reproductive organs. Some have the misconception that and fear that talking about sexuality and reproduction will encourage their children to experiment with sex. Whether or not parents and caregivers teach their children about healthy relationships, it is inevitable that they will receive information from one source or another and that they are likely to misinterpret the information they receive.

Recognizing the need to educate teens, young adults, adults and their parents, Westchester Jewish Community Services (WJCS), through a grant from Autism Speaks received training from Shana Nichols, PhD, and Samara Pulver-Tetenbaum, PhD, of ASPIRE Center for Learning and Development in Melville, NY to develop curricula on healthy relationships and sexuality. At the 2010 Hilibrand Autism Symposium at UJA-Federation of New

York, Dr. Nichols stressed that "...sexual development, learning, and education are essential for young adults with ASD. Social skills are the building blocks of sexuality." Additionally, she stressed, "It's critical kids learn skills to make them less vulnerable, and what to do if something happens so they don't stay quiet." It was this speech of Dr. Nichols that inspired WJCS to start our Healthy Relationship and Sexuality Initiative.

The WJCS initiative is based on an understanding that whether or not the individual has autism, they will move through the same developmental stages as their typically-developing peers to become sexually mature adults. Our goal was to obtain the training needed to develop specialized programs to work with teens and young adults with autism to help them learn about healthy relationships, appropriate expressions of sexuality and about social boundaries including those related to sexuality and dating.

Training for staff focused first on acknowledging each person's level of comfort with the subject matter. We recognized the similarity between the interventions for teaching healthy sexuality and the interventions used for teaching other social and life skills. Through our training we broadened our knowledge base to understand the various components of healthy sexuality, even for those who are not interested in being sexually involved

*see Sexuality on page 28*

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## Transition From Middle School to High School

### *Valuable Advice from a High School Senior with Asperger Syndrome*

By Grace Barrett-Snyder  
Student Intern  
AHA Association

**T**he hallways are crowded. Lockers are lined with chatty students and the cafeteria is serving what may or may not be food. Where will you fit in? The homework is demanding. Your teachers have high expectations and you may be unsure about how to meet them. Would they understand? As you've heard, high school's tough.

But I'll let you in on a little secret: you will survive. As a soon-to-be graduate, I'll tell you what you need to know. I've come a long way since freshman year and the road wasn't easy, but I've become a stronger person. You can have the same success. So, where do I start?

#### Teachers

Right off the bat, establish a good relationship with them. Understand how they run the classroom and what they expect of you. If you want help, they'll give it! (Trust me, if they didn't want to help you do well, they wouldn't be teachers.) But you'll have to ask for it. They can't read your mind, so if you're having trouble with homework and classwork, let them know. Sometimes it's intimidating to have to approach them,



**Grace Barrett-Snyder**

but if you're nervous about it, try emailing them first. Express any difficulties you're having and ask questions. Remind them of your IEP (all your teachers should have a copy, but they may not have had time to read through it yet). Attend extra help and participate in class – if it's too daunting, just give it a whirl! It gets easier the more you try. What's the worst that can happen?

#### Homework, Tests, and Studying

Always, always, always write down homework assignments, test dates, and deadlines. Keep an agenda and be organized. Before you leave for dismissal make sure you have the handouts and books you'll need to do your homework. Plan ahead. Make a to-do list and prioritize. Consider what needs to be done and how long it will take. Break down assignments into steps. As for studying, the possibilities are endless! Try making flashcards, playing review games, re-reading your notes, and doing practice problems – whatever works best for you and helps you do well. Start studying ahead of time so if any questions come up, you can ask your teacher in extra help.

#### Friends

Sometimes they're hard to come by, but other times it's as easy as turning to the person next to you and asking about their weekend. Maybe compliment them and ask what they think of the lesson. Even if the subject material is really tough, they might feel the same way and you will share something in common. Having a conversation about something school-related is always a good starting point. Exchange phone numbers. Try to

establish a mutual friendship; take turns initiating conversation, let them talk about themselves (it's their best subject!), and maybe arrange a get-together after school. Remember: Not all friendships work out, but if you can find someone that enjoys company and makes you happy, they're worth sticking with.

#### Scheduling Courses

When it comes to choosing your courses, there's a lot to consider. Do you want take NY Regents-level courses or accelerated courses? Are you considering an AP course? Will you have resource room and/or speech services? Do you have a lunch period? Answer these questions for yourself and discuss possibilities with a parent or your guidance counselor. Ask about the pros and cons. Put effort into researching the courses available. Sometimes the best feedback comes from someone who's already taken the class. What did they like/dislike about it? What challenges did they face? Is the teacher any good? And remember if they had a tough time and didn't really like the class, it doesn't mean your experience will be the same way. You might enjoy it! You know yourself best.

*see Advice on page 34*

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## Relevance, Safety and Choice are Key to Building Social Skills For Adults with Asperger's Syndrome

By Alex Gitter, MS  
Lead Facilitator  
NIPD/NJ Asperger's  
Skill Building Network

**J**oe is a smart and talented 38 year-old man. But, for many people with Asperger's Syndrome, a form of high-functioning autism, applying these talents in a mostly "neurotypical" (i.e., non-Asperger's) world has been a lifelong challenge.

Navigating the worlds of computers, data, numbers, and statistics has always come easy to Joe; navigating the social world has not. This stark contrast was never more apparent than when Joe was passed over for a promotion.

Joe diligently worked in a company's information technology department for years. But, his supervisor was surprised when Joe approached him about not being considered for a promotion, which went to someone else. The supervisor never saw Joe smile at work, say hello or goodbye to others, sit with others at lunch, or socialize with his colleagues. He figured Joe did not like his job. This supervisor did not know that Joe has Asperger's Syndrome.

Misunderstandings like these are common for people with Asperger's. Interacting socially or on the job can be such a struggle that they may not only lose out



Alex Gitter, MS

on a promotion, but it also may cost them a job, a friend, a relationship or, in some cases, they may become so discouraged that they retreat from the neurotypical world altogether and lose even more.

After eventually losing his job due to conflicts with a new supervisor (this is also quite common for people with Asperger's as they are often unaware of depart-

mental politics and the associated unspoken rules), Joe retreated. He spent most of his time at home, alone, leaving only to get food and visit the local police station to do volunteer work (a longtime hobby). His talents and skills were no longer being put to use, and were completely unknown to most of the outside world.

When Joe's sister suggested he join the National Institute for People with Disabilities of New Jersey's (NIPD/NJ) Asperger's Skill Building Network, Joe passively agreed. NIPD/NJ is a member of the YAI Network. Once he began getting the social tools he had so desperately needed through 10 hours a week of group instruction and practice, he started returning to the world.

He began waking early, arriving first to group, actively participating in discussions and activities, never missing a minute of group from the day he began attending, and thirstily absorbing the information that he had never really realized existed.

His sister reported changes in Joe as well. She noted that he was now talkative in telephone conversations, enthusiastic about what he was learning and the people he met, and showering and grooming regularly. She was thrilled.

The Asperger's Skill Building Network, which began in 2010, is designed to help young adults and adults with Asperger's Syndrome or Asperger's-like features. It

meets twice a week from 10 a.m.– 3 p.m. at William Paterson University in Wayne, N.J.

With the exception of Jed Baker's work focusing on young adults, most existing interventions have been geared toward children. Today, our population also consists of adults. Earlier evidence-based methods and strategies are based on cognitive behavioral principles and can easily be transferred to work with adults. We used the research that was out there and also looked to some additional, maybe out-of-the-box, strategies to construct our programming.

Based on the latest research on social skills instruction for people with Asperger's Syndrome and high-functioning autism, the program's yearlong curriculum focuses on a range of social skills. These include social "building blocks" like recognizing and interpreting social cues, conversational manners, giving and accepting compliments, initiating, maintaining, and joining conversations; complex skills, such as conflict resolution, maintaining and deepening friendships, dating and relationships; and job-seeking and – keeping skills like interviewing, socializing at work, dealing with supervisors, and advocating for a promotion.

Although much of learning occurs throughout the day, a typical day at the Asperger's Skill Building Network "looks

*see Social Skills on page 38*



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***School District from page 1***

It should be the goal of the IEP team to sit down and figure out how all of these moving pieces can fit together appropriately for your child's transition.

**What About Transition Goals?**

Pursuant to federal law, your child's IEP must include measurable postsecondary goals in the areas of training, education, employment, and, where appropriate, independent living skills. Your school district must also develop a statement of transition services (including courses of study) needed to assist your child in reaching his or her transition goals. This requires your school district to report periodically on your child's progress against these goals.

Your child's IEP must include (beginning not later than one year before your child reaches the age of majority under applicable State law) a statement that your child has been informed of the rights, if any, that will transfer to your child on reaching the age of majority.<sup>2</sup> After your child attains the age of majority, if rights transfer to your child, the school district must provide requisite notice (i.e., procedural safeguards notice, notice regarding an upcoming IEP meeting, etc.) to both the student and the parents.

**Who Should Attend Your Child's Transition IEP Meeting?**

As with almost any IEP meeting, your school district must ensure that the IEP team members include:



**Maria C. McGinley, Esq**

- Parents;
- At least one general education teacher of the child (if your child is, or may be, participating in the general education environment);
- At least one special education teacher of the child, or where appropriate, not less than one special education provider of your child;
- A school district representative;
- At the discretion of the parent or the school district, other individuals who

have knowledge or special expertise regarding the child, including related services personnel as appropriate. (It is strongly recommended that you secure the participation of your child's current teachers, therapists and service providers to provide input including after-school or community-based service providers, if any);

- An individual who can interpret the instructional implications of evaluation results.

If the purpose of your child's IEP meeting is the consideration of post-secondary goals and transition services needed to assist your child in reaching those goals, your school district – to the extent appropriate – must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services to the IEP meeting.

Most importantly, for such a transition meeting, your school district must invite your child to attend the IEP meeting.<sup>3</sup> Your child, however, is not required to attend.

**Is Your School District Required to Evaluate Your Child Before Discontinuing Services?**

School districts are not required to conduct an evaluation before terminating special education services for students who are graduating from secondary school with a regular diploma or for students exceeding the age for services in their State. For some students, this could mean that they do not have the documentation of their disability that is needed to

gain access to supports and services in post-school activities, including postsecondary education.

For a child whose eligibility for special education services terminates under the circumstances described above, the school district must provide a "Summary of Performance." This summary must include information on your child's academic achievement and functional performance and include recommendations on how to assist your child in meeting his or her post-secondary goals. This "summary" must include specific, meaningful and understandable information to your child, your family and any agency (including higher education institutes) which may provide services to your child upon transition.

Despite the fact that schools are not required to conduct new evaluations or assessments in generating the "Summary of Performance," the information provided in the summary should adequately describe your child's present levels of performance and individualized needs.

**Topics to Consider Before and During the Transition Planning Process**

As you navigate the transition process, it is recommended you consider the following:

- What additional education options (higher education, vocational, etc.) are appropriate for your child?
- What employment options are appropriate? What supports, if any, will your child need to maintain employment?

*see School District on page 38*

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## Prognosis? The Sky's the Limit

**By David Finch**  
**Author**  
**The Journal of Best Practices**

**W**hen I published my first memoir in January, I expected to receive a fair amount of feedback from readers. I didn't know what my readers would say, exactly, but I assumed that, for the most part, their responses would be positive. I imagined that people would write to me and offer such opinions and observations as "This is a funny book," or "Gee, I think my husband might have Asperger syndrome," or "Thank you so much for flavoring the even-numbered pages."\* What I didn't expect is how many people, both on and off the spectrum, have found the story to be a source of hope: parents of children diagnosed with Asperger's; people whose romantic partners have been diagnosed; people who feel they themselves identify strongly with the parameters of the condition.

This, to me, suggests that people often have concerns about the prognosis of living a fulfilling life with Asperger's. It's understandable. We live in a predominantly neurotypical world, a world full of unwritten and almost universally-understood social methods. (Apparently, 109 out of 110 people learn these methods transparently; the remaining one percent of us need a little help.) School, for its



**David Finch**

part, is a highly social institution, right up there with friendships, marriage, and career. Life is social, and because impaired social instinct is a key characteristic of Asperger's, it stands to reason that the individual with Asperger's will have unique challenges to overcome if he or she wants to be successful in life. (Then again, who doesn't?) As for predicting the likelihood of personal fulfillment, that

depends as largely on adaptability and willingness to adapt as it does on social function and intellect.

The great news for us Aspergians is that what we may lack in social function, we often make up for in spades with intellect and an ability (notice I did not say "inclination") to adapt. That leaves willingness to adapt—a quality one must possess if one wants to be successful, whether they're on the spectrum or not.

Case in point: my marriage of five years, which was in dire straits when I received my Asperger's diagnosis at the age of thirty. Though I had been successful in those institutions in which social instinct isn't formally measured—school (excellent grades) and work (exceeded my objectives)—I could not boast such high performance as a husband and father, roles that require, if not great empathy, then a strong willingness to adapt.

I'd managed to make myself appear to be a worthy partner for my wife Kristen when we were dating, and so it came as a major surprise to both of us when, after we were married, my neurological composition began revealing itself one baffling moment after another: social events rendered insufferable due to my behaviors, my inability to support Kristen emotionally. Oh, and I always hogged all the crab rangoon. After a few years of this, what was there, really, to love? Kristen and I had been best friends since high school, but after only a few years of mar-

riage, we no longer felt like friends. We resented each other.

But with the diagnosis came new understanding; Kristen and I were afforded much-needed insight into how my mind works, and why certain things, such as paying attention to the needs of others and simply going with the flow, posed such a challenge for me.

A diagnosis is not a solution, however; it is only a beginning. It's sort of like being handed a user manual for yourself—whether you choose to use the information to your advantage will determine how successful you'll be in different areas of your life. Again, the prognosis of a fulfilling life depends largely on one's willingness to adapt.

I quickly realized I could learn how to manage my behaviors better and that our best-friendship would come back as a result. And Kristen—a saintly neurotypical who happened to work with autistic children and understood how the autistic mind works—could help me. I had her support; all I needed was a willingness to adapt. And that willingness, fortunately enough, was there.

I wanted to master the behaviors that would make me a great husband—I wanted to adapt—and so I started keeping what I called a "Journal of Best Practices," a collection of personal maxims that I wrote down and practiced (or tried

*see Limit on page 38*

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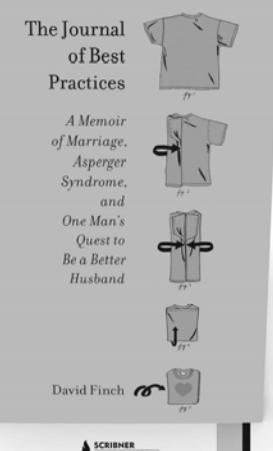
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## Positive Psychology Offers Guideposts for Optimism to Young Adults with ASD

By Valerie L. Gaus, PhD  
Licensed Psychologist

**A**s young people on the autism spectrum look ahead towards adult life, they and their families often feel anxious as they think about entering unknown territory. It can be reassuring to know that having an autism spectrum diagnosis does mean that a person cannot enjoy a mentally healthy life in adulthood. The people who come to see me in my psychotherapy practice, where I serve adults and older teens on the spectrum, have taught me that a sense of well-being and peace of mind can be realized by many. Granted, living with an autism spectrum disorder can involve some pretty stressful situations and that is what often leads people on the spectrum and their families to seek help from therapists. Fortunately, anyone who is working to meet the needs of these young people and their families can find guidance in the literature on both positive psychology and cognitive-behavior therapy (CBT). While both areas of evidence-based practice have their roots in "mainstream" mental health (where research has focused on human beings in general), people on the spectrum can benefit greatly from these approaches that can help them find relief from their daily stress while also capitalizing on their strengths (Gaus, 2007, 2011a, 2011b).



**Valerie L. Gaus, PhD**

### Positive Psychology: Guidelines for a Healthy Adult Life

The very characteristics that can make people on the spectrum vulnerable to stress and at risk for problems in daily living are the very same characteristics that contribute to their talents and abilities. When therapy goals are being set, it is important to not only address the problems that are causing distress, but also to

highlight the assets and coping strategies that the young adult has already developed before coming into treatment. I have marveled at how incredibly resourceful and clever these individuals can be in designing strategies, often without any help, to negotiate their way through a world that is to them very confusing and threatening. A good treatment plan should always include strategies geared toward helping the young person to recognize the things he or she has already done to successfully adapt and to build upon those self-taught skills. This is consistent with the philosophy of positive psychology.

Positive psychology is a growing field that focuses on enhancing the mental and physical health of human beings by highlighting and strengthening assets (e.g., Seligman, 2011). Researchers and clinicians try to understand the characteristics that are associated with happiness as well as resilience and survival through adverse circumstances. While these efforts have been largely geared toward the general population, professionals working with people on the autism spectrum have also found this approach useful (Gaus, 2011b). One important part of this movement has been a focus on defining autism characteristics as *differences*, not *defects*. Autism is not seen as a *disease* but does give a person a unique way of processing information about the world and the people in it. This

philosophy has been helpful to me in my practice with my patients because, while this unique way of perceiving the world does indeed cause some of the problems that bring adults into my office, it also gives them strengths and talents. The positive psychology approach allows me and my patients to use some of the autistic characteristics as tools and assets in the therapy.

One of the most relevant concepts that grew out of positive psychology for adults on the spectrum is the definition of intelligence offered by Sternberg (2003). He suggests that people will be most successful if they possess the skills to do the following:

- Define success in one's own terms, which may or may not correspond to societal or conventional definitions of success
- Adapt to, modify and choose the environments one is in
- Do all of the above by capitalizing on strengths and correcting or compensating for weaknesses

While this definition pertains to all people, it is very useful to young adults on the spectrum in order to help them clarify their goals and identify obstacles.

see **Optimism** on page 32

## Career Planning for People on the Autism Spectrum

By Yvona Fast, MLS  
Support Groups Manager  
GRASP

**A**s autistic kids graduate from high school and enter adulthood, parents ask, "What's next?" Some will go to college, others won't, but many will want to enter the work force.

But what kind of work is the individual suited for? Everyone on the spectrum is different. Deciding on a career path involves learning about yourself: What are your interests? Talents? Skills? Consider temperament, personality, and values. Understanding one's skills and abilities, along with some research of various career possibilities before starting a new job can go a long way towards making it a better experience.

Next, recognize your challenge areas. What do the areas where you are challenged say about you? No two people experience autism in the same way. Accept what can't be changed, and acquire the tools to change what you can. There are strategies, modifications, accommodations and sometimes, medications that can help your strengths to shine above your weaknesses. You may need to try several strategies until you find the ones that work best for you. It's a lifelong process that requires patience and hard work, but does get easier with time. The more you learn about yourself, the easier it becomes.



**Yvona Fast, MLS**

You will also need to research various jobs. Read and talk with people who work in fields that interest you. Arrange information interviews and job shadowing. Your goal is to get to know the occupation.

Then, you must match these vocations with the skills you have identified in the first step. It may be helpful to make a list of your strengths and various areas you find challenging, such as verbal ability, numerical aptitude, spatial skills, motor coordina-

tion, speed, multitasking, organizational ability, social savvy - and rate the requirements of each occupation according to this list. This will enable you to see how your particular abilities/disabilities match those required in the particular job. For example, though I can drive, I would not want a job as a driver. It is too much of a challenge for my spatial skills and would be too stressful. Though I love to cook at home, I don't feel I would be able to perform well on the job, where speed is essential.

Career planning is difficult because it requires dealing with many inferences and unknowns. Even when we find an occupation we think might be suitable, we must consider how our disability will impact it. Books like *What Color is Your Parachute* assume that their audience can do the planning tasks the book recommends. But many individuals on the spectrum have trouble with executive function – the skills needed to organize one's thoughts, tasks, things, and time. These are the abilities that allow you to plan, prioritize, and organize, or to grasp a problem area and come up with feasible solutions. Coming up with goals is very hard for folks with an executive function deficit.

Another issue is the autistic individual's trouble with seeing the big picture. Often, we see the trees but not the forest. We can't see how the various steps add up to the end result. Due to our lack of flexibility and tendency to persevere, those

on the spectrum can easily get stuck on one track and have problems seeing other possibilities.

These questions can help you with the decisions of the career planning process:

- What is the problem? (Answer: To find a suitable career).
- What is my goal...what do I need to accomplish?
- How easy or difficult will it be to accomplish the goal?
- What plan is needed to accomplish the goal? (What materials do I need, who will do what?)
- What steps do I need to take?
- In what order do I need to do these things?
- How long will it take?
- If a problem arises, what new ways should I think to solve the problem?
- Should I ask for assistance? Who can assist me?
- When I'm finished, let's review my goal, plan, and accomplishments.

see **Career** on page 37

## Parental Stress and Family Relationships During the Transition to Adulthood

By Brian Freedman, PhD  
Director, TEEM Unit  
Center for Disabilities Studies  
University of Delaware

**P**revious research has found that parents of children with ASD across different age groups exhibit significant levels of stress and are at greater risk for mental illness. The stress exhibited by parents of children with ASD has been found to be even greater than parents of children with other disabilities (Abedutto et al., 2004). Although less research has been done on the specific experience of parents of children with ASD who are transitioning to young adulthood, some findings suggest that this time period has the potential to be especially stressful. However, by taking proactive steps, developing and maintaining healthy communication patterns, and reframing their outlook and goals for that time period, families can achieve a successful transition.

The transition to young adulthood involves new opportunities and challenges for individuals with ASD and their parents. During this time period, families prepare for the end of entitlement programs (e.g., special education) and ready themselves for entry into adult systems that can be incredibly complex. Upon exiting high school, individuals with ASD will typically seek out employment, attend postsecondary



**Brian Freedman, PhD**

education programs, or enroll in day treatment or residential programs. For those who are seeking employment or attending postsecondary education programs, some are able to do so with assistance from specialized programs and services. Unfortunately, the effectiveness of these support mechanisms can vary drastically, since many agencies are not well-equipped with the knowledge and tools necessary to effectively support the unique needs of an individual with ASD. In addition, many students with ASD leave high school lacking many of the critical skills necessary to succeed (Gerhardt & Lainer, 2011), as a result of focusing on traditional academic work. While doing so is very important for preparing students academically for college and allowing them to learn alongside their typical peers, this results in less formal instruction on the "soft skills" that are also necessary to be successful. As a result, many individuals have tremendous difficulty with their initial attempts to seek out employment and attend postsecondary education programs, which may ultimately mean that they spend significantly more time at home (Taylor & Seltzer, 2010).

Throughout this process, families are adjusting to the availability of more limited resources for their child and themselves. If the young adult with ASD is also now home more often, families need to re-adjust to spending more time together, which can impact family relationships. This occurs during a time period when many parents' peers are experiencing a very different kind of transition, as their children are leaving home and spending less time together. This offers an opportunity for parents of typical children to also find new ways of re-connecting as a couple. Families of young adults with ASD do not necessarily have the same natural opportunity, which requires them to become more pro-active in maintaining their marital relationships.

One research study examined the changing relationship of mothers and their adult children with ASD. Taylor and Seltzer (2010) found that these relationships often became more strained over time. This was found to be particularly true of parents of children with ASD who did not have an Intellectual Disability (ID). The authors suggest that, during this time, some families may experience a renewed sense of loss, as they may have had goals for their child (e.g., college) that are seemingly more difficult to achieve than they imagined. Interestingly, Taylor and Seltzer also found that mothers' attribution of their child's behavior changes over time as well. As individuals get older, mothers were more inclined to attribute their child's behavior to the individual's personality or personal choice, as opposed to being symptomatic of the diagnosis of ASD. This causes parents to believe that their children are actively choosing to engage in behaviors that are more frustrating, which leads to greater family conflict.

During the transition to young adulthood, it becomes critical for individuals with ASD to achieve greater independence and increase their self-determination. With that, adult provider systems naturally and appropriately look to that individual as being the key decision maker regarding their own care. While this is an important step for adults with ASD, it also often requires a role-shift for families

*see Stress on page 25*

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## Planning for the Future: Guardianships and Special Needs Trusts

By Susan M. Green, Esq.  
Begley Law Group, PC

**A**s your autistic child transitions into adulthood, you will need to address two very important legal issues: guardianships and special needs trusts. Once your child reaches the age of majority, you must consider whether a guardianship is appropriate. Further, regardless of the age of your child, it is essential to update your own estate plan to ensure your child's well-being long after you and your spouse are gone.

### Guardianships

When your child reaches age 18, you, as the parent, must take action in order to ensure that you can assist your child with medical, financial, and personal decisions. If your child has sufficient capacity, he or she can, and ought to, execute documents, including a will, living will, and powers of attorney. While it is important for everyone to have these documents in place, it is especially important for your special needs child. He or she can name you or another loved one as his or her agent to make decisions in the case of a medical emergency and/or to assist him or her with routine financial and personal decisions. An attorney who specializes in special needs can assist you in determining if your child has capacity to execute these documents.



**Susan M. Green, Esq.**

If your child does not have sufficient capacity, a guardianship will be necessary. Once your child turns 18, you no longer retain the legal right to make the decisions that you have been making for your child up to this point. This situation can be rectified by establishing a guardianship, which is a protective arrangement established by the court system on behalf of an incapacitated individual. In many cases, this process can be simple for parents of children on the autism spectrum,

but it is essential in order to ensure that safeguards are in place for your child. As parents, you can request that a court appoint one or both of you as guardians of both the person and the estate of your child, so that you can make medical decisions as well as control your child's financial assets and deal with advisors, organizations, etc. on your child's behalf. There are two types of guardianships, plenary and limited. A plenary guardian has control of all decisions concerning your child's person and estate. Alternatively, a limited guardianship may be established, which reserves certain decision-making to your child. The type of guardianship that is established will depend on your child's level of independence and capability.

It is also important for you and your spouse to make sure that your wills name your choice of a successor guardian for your child in the event that you both pass away during your child's lifetime. Even though the named person still has the opportunity not to accept the guardianship, you can at least make known your wishes for your child.

### Special Needs Trusts

Most parents worry about the well-being of their children once both spouses have passed away. This concern is especially well-founded for parents of special needs children. You hope to provide for your child throughout the course of his or

her lifetime, even if you are gone. Leaving an inheritance outright to a child with special needs is not the best way to achieve this goal because doing so will jeopardize your child's eligibility for any governmental benefits he or she may be receiving. If you leave assets outright to your autistic child, he or she will lose income- and asset-based benefits, at least for a certain period of time. For example, in order to receive Medicaid benefits, your child cannot have more than \$2,000 of countable assets in his or her name. Your child must utilize any assets in his or her individual name (including inherited assets) for all medical and personal expenses, etc. until those assets have dwindled to \$2,000.

In order to avoid this result, parents and loved ones often establish a third party special needs trust, which is a mechanism through which you can make funds available in order to enhance your child's quality of life while still allowing your child to remain on government benefits. A special needs trust supplements public benefits, such as Medicaid and SSI, without jeopardizing eligibility. The trustee has absolute discretion to expend funds from the trust to purchase things for your child that are not otherwise covered by Medicaid. You can also designate to whom any remaining trust assets will pass upon the death of your child, whether to your other children, relatives, or a charity.

*see Guardianships on page 38*

## The Educated and Jobless

Barbara Bissonnette, Principal  
Forward Motion Coaching

**A**fter earning a Bachelor's degree in political science, Steven\* turned his attention toward a job in public policy. He figured that his knowledge of government, interest in research, and 3.8 GPA would make it easy to find an entry-level position. Instead, he discovered a competitive field where employers expected applicants to have internships or related volunteer experience under their belts. Most of the opportunities were in the Washington, D.C. area, and Steven did not want to move. So he continued visiting job boards, sending out resumes, and hoping for interviews.

Eleven months after graduation, Steven wasn't thinking about a job shaping public policy. His priority (and that of his parents) was *any* job that would provide steady income. Two warehouse jobs were short-lived because he couldn't work quickly enough. Most administrative positions required proficiency with word processing software. There were many jobs in the healthcare field, however they required specific training. Steven was understandably discouraged and concerned about his future.

A life-long fascination with how things work led Alex to pursue an engineering degree. He did well in his classes, but did not develop relationships with professors



**Barbara Bissonnette**

or fellow students, or even try to find an internship. Six months after graduation, he had one telephone screening interview. Alex would not ask his engineer father for contacts, declaring it nepotism. He was not interested in basic networking or in learning how to answer interview questions.

And then there is Tom, who, after majoring in communications, decided on a career in journalism. Tom has solid writ-

ing skills and enjoys interviewing people for articles. He lost a series of jobs because he did not follow instructions, and had conflicts with supervisors and co-workers. He desperately wanted steady income so that he could have his own apartment. Although he didn't want to "waste" his degree, Tom was considering a return to assembly work, which he did part-time during high school. Among the desirable features: knowing exactly what he needed to do.

Early diagnosis and services beginning in grade school are making a college education possible for more and more young people with Asperger's Syndrome. Yet as these stories illustrate, finding a job can be a significant challenge, even with a degree in hand. Increasingly in my coaching practice, I see graduates who are floundering, months and sometimes years after graduation. Some have no idea of what positions they are qualified for. Others discover that they are not suited for jobs in their field of study. Nearly all are anxious and confused about the entire process, from writing a resume to interviewing and creating an effective plan.

Assisting individuals who are seeking competitive (not sheltered or supported) employment requires a pragmatic approach. Personal interests must be balanced with the realities of the job market. Knowledge of a subject cannot be confused with having the capabilities to succeed in a field. Job search strategies must be explicitly

explained before the individual can apply them to his particular situation.

There are people with Asperger's Syndrome who create rewarding careers based on their special interests. However, interest in a subject area doesn't necessarily mean that a person will be able to make a living at it. While this is also true for neurotypicals, the more specialized abilities of Aspergians limit the number of possible career paths.

Holders of liberal arts degrees, in particular, may not know how to sort through the career options to find a good match for their abilities. It was only after Scott earned a Master's Degree in Anthropology that he realized how very few job openings there were in the field, and that most teaching positions require a doctorate. The entry-level jobs that he did get only lasted a few months. Scott was easily overwhelmed and needed explicit directions for every assignment. When stressed, he either became mentally paralyzed or made impulsive, poorly thought out decisions. When we first met he was working as a data entry clerk, frustrated at not being able to use his intellect.

We explored Scott's other interests, which included writing and technology. After several months, he decided to pursue technical writing because the content is highly structured, and he would be able to work alone for extended periods of time.

*see Jobless on page 37*

# the lighter side of the spectrum: a mom's view

By Carrie Cariello



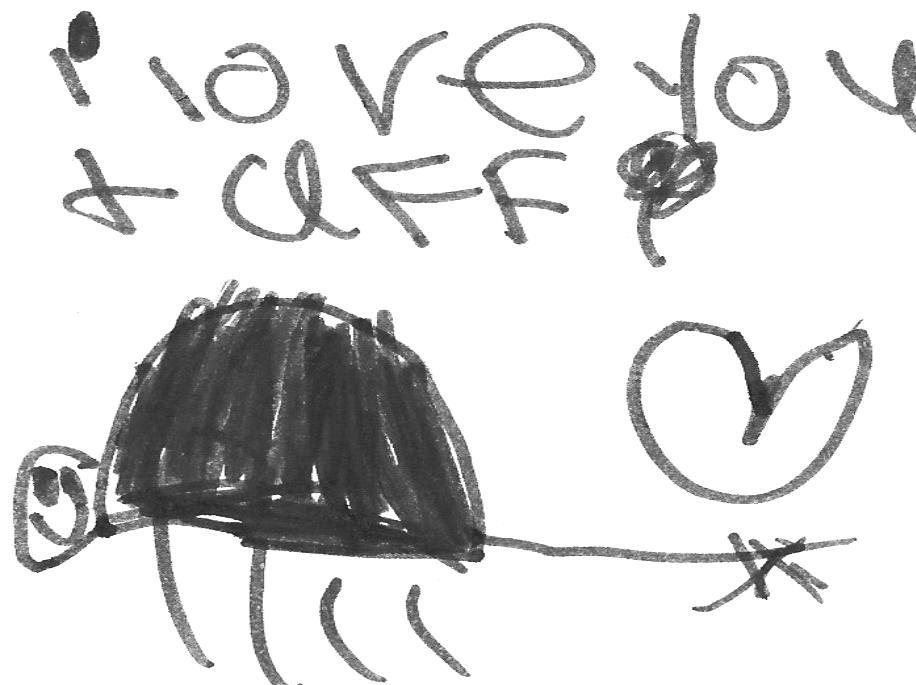
## Taffi the Turtle

[Warning: this article is for mature audiences only. If you're immature for your age you might enjoy it too.]

This fall Jack's second grade class completed a unit about animals in winter. Each student was assigned an animal to study and learn about over the course of two months. The unit culminated with a take-home project of the child's choice; they could make a diorama, poster, or illustrate a book to present to the class and demonstrate their animal's winter habits.

Not being a diorama family (we never have any old shoe boxes lying around), and dreading the idea of helping Jack map out a poster, I went online and found blank books in which he could create a little story with markers. His animal was a turtle.

This project coincided with a new and enchanting behavior of Jack's: swearing. One morning, he went to use the bathroom and noticed that earlier I'd dropped a Clorox tab into the toilet, turning the water blue. His emphatic, "That's a b@%\$#!" turned my head so fast it's a wonder I didn't spend the rest of the week in a



**Jack's drawing of Taffi the Turtle**

neck brace. I asked him where he heard that word and he gave a one-word explanation: "Bus."

In the days following his volatile reaction to blue water in the toilet bowl, Jack expanded his repertoire to include h##!, d-

--, and a\$. He enjoyed experimenting and throwing it out during dinner; "What the h---! Peas again?" Obviously he was a big hit amongst the audience of eight and under in our house, and it didn't take long before our three-year old was mutter-

## Stress from page 23

who have been the central figure in decision-making for their child. For much if not all of their child's life, parents of children with ASD have likely had to fight to ensure that their child was properly evaluated and receiving necessary services. Many parents also had to serve as an all-encompassing resource for their child, acting as their treatment team leader, therapist, teacher, and case worker. As their children get older, due to the decrease in services and resources for adults, many parents then find themselves taking on a greater role as care coordinator. However, their role as a decision-maker diminishes, as it appropriately shifts to the young adult. So, the dynamic and expectations make a dramatic shift as parents must balance the importance of their child's independence while feeling the responsibility of ensuring that they embark on the right path. As a result, some parents might find themselves becoming more stressed, frustrated, and even upset or resentful at this prospect, particularly if they perceive that others on the young adult's team are minimizing the importance of their involvement.

For most parents, the idea of their child getting older and making decisions for

themselves is exciting but also quite scary. They worry about their child being able to lead a successful life and whether they will be treated fairly. They are well aware of the various levels of discrimination, bullying, etc. that their children can (and have been) be exposed to. In addition, parents worry about their children making decisions that may not be fully informed, which may prevent them from gaining access to important services and opportunities. All of these are realistic fears and can create tremendous anxiety for parents and caregivers. Unfortunately, many parents also never receive any guidance or instruction on how to help their young adult become more independent and self-determined, nor are many parents provided with support through this potentially difficult transition process. Research has indicated the importance of helping parents to maintain a confident outlook and reframing their ideas to ensure that they recognize their child and family's important achievements during this time period (Abbeduto et al., 2004).

Therefore, clinicians and practitioners providing support for young adults with ASD should consider how they might offer support for parents as well. They should also be directed to any community resources or

supports for families of transitioning youth with ASD, especially since most typical supports focus on the needs of families of younger children with ASD. It will be critical to listen openly to the concerns of families and avoid immediate judgment. Parents should also be recognized as important members of the child's support team, assuming that the individual with ASD also indicates their preference for parents to be included. They should be engaged and incorporated in decision-making sessions, as well as supported in changing their parental style to allow for their child to become the final decision-maker on the team. Overall, parents would benefit from education and support in assisting their child in becoming more independent: developing and following through with goals, establishing independent living skills, and facing natural consequences. This can be an especially difficult process, as parents may quickly recall past instances in which dealing with natural consequences resulted in a tremendous loss for their child. Nonetheless, it is a critical component of becoming an adult. Finally, in general, parents should be supported in re-examining their communication process with their child in order to hopefully develop a system that allows the child to be increasingly inde-

pendent while ensuring that the parent is kept as informed as is needed.

As a family with four boys and one less-than-ladylike girl, we've gone through the phase of shut-up - and potty, fart, and poop. We've put the kibosh on stupid and dumb, and banned hate altogether. They were even bringin' sexy back for a while, thanks to a catchy little ditty by Justin Timberlake. But Jack's new vocabulary was an entirely new level. This was definitely one of those crossroads parents with autistic children the world over encounter; is this autism or just plain bad behavior? Did we need to add Tourette Syndrome to his diagnosis? Clearly Jack was enjoying his new-found fame as a curse word expert, but given his struggle with language and communication in general, was there more to it?

At first I shrugged the swearing off, and figured a kid like Jack didn't understand

*see Taffi on page 36*

**Brian Freedman, PhD, is Director of the Transition, Education, and Employment Model (TEEM) Unit of the Center for Disabilities Studies at the University of Delaware. To learn more, please visit [www.udel.edu/cds/teem.html](http://www.udel.edu/cds/teem.html).**

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## From Hopeful Graduation to Hopelessness

### *The Transition That Many Parents Face*

By Veera Mookerjee  
Doctoral Candidate  
Wurzweiler School of Social Work  
Yeshiva University

**R**ecent updates by Center for Disease Control and Prevention (CDC) indicate that 36,500 children out of the 4 million born in the United States will have an Autism Spectrum Disorder (ASD) diagnosis. An individual with ASD will require care and services for up to 50 years, according to CDC, at a cost of \$3.2 million. This includes early intervention services, ABA therapies, social work services, medical costs, habilitation services and residential services for those individuals in group homes or community residences. The average medical expenses for an individual with ASD exceed those of an individual without ASD by \$ 4,110 to \$ 6,200 annually. Meeting needed expenses is a major financial stress for parents of children with ASD. Planning for the future is not easy. Stress increases as the individual with ASD reaches young adult hood and transitions from mandated school services. Many parents are unprepared when mandated services through the school system cease to exist. Parents are on their own to decide whether to continue services following their autistic child's high school graduation.



**Veera Mookerjee**

#### Details of the Study

A qualitative study focusing on parents of young adults with ASD was conducted by the author while a doctoral student at Yeshiva University's Wurzweiler School of Social Work, New York. The study is unique since it is focused on the phenomena of hopelessness or hopefulness among parents as they face the challenges of their

child transitioning into adulthood. This is an aspect of ASD research that has never been explored before. Twenty participants from New York, Ohio, Texas, and San Diego volunteered to be interviewed for the study. Recruitment of participants was done through agencies serving ASD clients and advertising the study in the Winter 2011 issue of Autism Spectrum News. The participants are all parents of individuals with ASD ages 14 years and above.

The study was designed to identify: 1) What barriers are faced by caregivers during the transition out of mandated educational services to services addressing community inclusion? 2) Has a greater awareness of ASD increased the access to appropriate services? and 3) What kind of necessary supports encourage caregivers to pursue continuing services?

The interviews were audio recorded and the qualitative data that was analyzed by the Atlas-ti software (<http://www.atlasti.com/>) and by identifying inter-linked themes that reflect the phenomena of hopelessness and hopefulness. Seventeen themes were originally identified by the dual process which were later combined to ten themes which were identified as having the highest number of occurrences during the interviews. These themes are: 1) Awareness about ASD; 2) Coping strategies associated with the service structure; 3) Initial confusion related

to the ASD diagnosis; 4) Social isolation; 5) Personal isolation; 6) Inadequate services; 7) Concerns affecting everyday life; 8) Self-guilt and frustration; 9) Social and professional barriers; and 10) Social and professional supports. Each theme is supported with quotes from the interviews.

#### Results of the Parent Interviews

The majority of the parents interviewed expressed feelings of hopelessness when asked, "What does the future of your child look like to you?" While some participants got extremely emotional, others said that they would not think about it as "there is no future." Participants who expressed that they had been satisfied with the school structure are the same caregivers who expressed that they are not prepared for the transition, and did not feel comfortable to move out of their existing mandated services structure to a situation where "nobody is obligated to help." Caregivers found available resources for young adults with ASD to be extremely limited, and the services that were available were not age-appropriate. While all the participants have had to utilize medical services, many still take their children to a pediatrician. Parents expressed that post-school

*see Hopelessness on page 36*

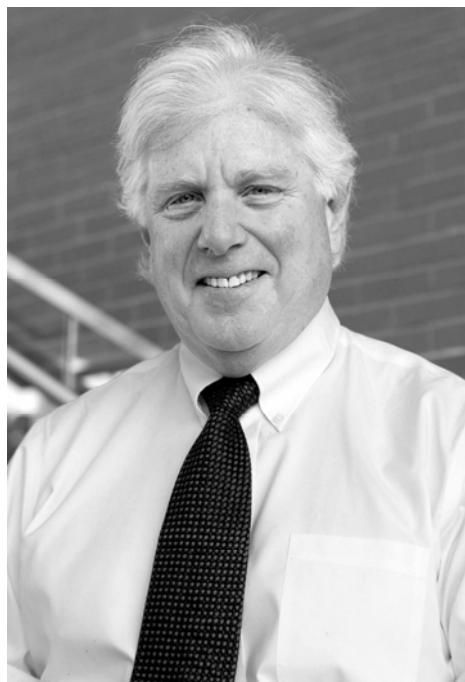
## Blueprint for an Asperger Syndrome College Support Program

By Mitch Nagler MA, LMHC  
Director, Bridges to Adelphi Program  
Adelphi University

In that Asperger Syndrome (AS) was first included as a formal diagnosis in the DSM-IV in 1994, it seems likely that many of the children born after that date who were diagnosed with AS have received academic and social services throughout their school years. These services have enabled them to achieve a higher level of success than was likely before the diagnosis was understood, and individuals with AS were supported in mainstream education. Thus we are now seeing a large cohort of students with AS who are already enrolled, wish to enroll, or who are now preparing to transition to college.

For students with AS, and other non-verbal learning disabilities, the transition to the college experience can be especially anxiety provoking and isolating. Students with AS need different services and supports than students with other disabilities. How can colleges meet the unique and pervasive set of challenges and needs that these students present with? Designing a blueprint for an excellent college support program for students with AS is a complicated process.

One of the most important issues in building a support program for students with AS is understanding the necessity for



**Mitch Nagler MA, LMHC**

an individualized approach that can meet the unique needs of each student in the program. Not only must the program offer a comprehensive array of services, it must also be sensitive and flexible enough to identify and respond to the individual and idiosyncratic needs, thoughts, and behaviors of all students in the program. Because individuals with AS have extremely variable developmental profiles, no two

students will need the same combination of supports. Using a person-centered approach, and "meeting each student where they are," allows for addressing the variations in individual needs. Some students may need extensive executive functioning and academic supports, while others may need more of a focus on socialization issues, and many others likely will need a bit of both. Creating this environment takes good planning, good training, and really good listening.

When building an AS support program, probably the single most important ingredient is working within a welcoming campus culture; which means having administration, faculty and staff support and acceptance for the program. It may be hard to believe, but there are colleges that do not want to be "identified" as being receptive to AS students. If the campus culture is accepting, then deciding what division of the college that the program will be housed in is another important issue. Where it is housed could affect the focus of services, how those services are provided, and who delivers them.

Proper staffing is critical, and like with any other successful project, it starts at the top. Priority should be placed on finding a director who is experienced in providing services, and has a well-developed approach for dealing with individuals on the spectrum and their families. The director must also be qualified to train, support and supervise all program staff members.

Other staffing issues may include whether to use professionals, retirees, or graduate students as staff. The staffing question takes on greater importance when it is understood that in order for the program to be successful, it is essential for the students in the program to develop trusting relationships with the staff. Like other similar professional relationships, trust in, and belief that, the professional can help, are strong indicators for positive outcomes.

In relation to building trust with the students, creating a safe environment for them is important as well. Office space availability can often be a problem on college campuses, so that finding a space that can be used for the safe, quiet delivery of services can be a challenge. Ideally, the space will have multiple individual offices so that services can be delivered privately; and a larger common area for formal and informal socialization opportunities. Creating a space that feels safe and welcoming to the students is important both academically and socially.

Regarding services that are provided, I feel that it is important to place equal focus on academic, social and vocational support issues. Clearly defining these parameters to staff, students and families before they enter the program sets the framework for everyone involved. Staff will know where they are expected to focus, and students and their families will

*see Blueprint on page 31*



## Robin's Voice

### A Resilient Mom's Commentary on Autism



## Transitions Take a Village for Young Adults with Autism

**By Robin H. Morris**  
Freelance Writer

"I'm an adult, I can make my own decisions!" says my 24 year old man/child who has learned the lingo of the grown up world. So is his mantra when he is trying to establish his ground, as he agonizes over choices about a simple schedule change. We, as adults have learned to navigate adjustments, some better than others, but what happens when inflexibility is so paralyzing that it can be a game changer. No question mark here, just a reflection.

Recently we sat around a boardroom table, assessing our son's Individualized Service Plan for the upcoming year. I could read his body language, as he tried not to explode over a suggestion that he try to revisit a possible job opportunity. "Deep breaths." I could hear his internal whisper. It was then that I pulled a prize out of my infinite bag of tricks: "So, I was watching the news this week," I said. "I was shocked to learn that *Citizen Kane* never won an Oscar." He stopped his agony on a dime. "Mom, it was 1941, *How Green was My*



**Robin H. Morris**

*Valley* won that year." Everyone at the table simply paused in awe. How can a 24 year old know such precise information without skipping a beat and share it, when he cannot drop the pervasive occupation of rigidity.

What is even more suffocating for me, as a mother, is the constant nagging that I must be always available with my bag of tricks. That is my problem. Our son has certainly risen above many challenges and learned to assimilate and acquiesce. However, he is still autistic, and while he has tried with Herculean efforts to comply, there must be a balance. Society must comply as well.

We, as parents, recognize that there are significant and complex changes as our children grow into adults. Autism Speaks has authored "The Transition Tool Kit." It is a valuable resource that you can make your own, as it provides questions and food for thought, as you shepherd your child into the next phase of his/her life. Advancing Futures for Adults with Autism has made it a mission to investigate ways for our young adults to become active members of society. There is a light, now it will take a village.

Four years ago, I was preparing dinner while listening to the news. When I heard NBC's Brian Williams I stopped, and noted that history might actually be taking place. It was a story of pride and hope. Randy Lewis, Vice President of Walgreens had implemented a work force

that hopefully would change the face of employment for those with disabilities. Mr. Lewis, prompted by concerns for his son Austin, diagnosed with autism, recognized the vacuum in the arena of jobs for adults with disabilities. He devoted a Walgreen Distribution Center in Anderson, South Carolina to hiring workers with developmental disabilities. Mr. Lewis said that, "Austin's gift to me was to look past the disability and see the person."

The irony here is that this particular distribution center is 20% more efficient than all others in the Walgreen Company, and it is staffed by more than 40% disabled individuals. The building is designed with touch screens and flexible work stations. Randy Lewis's model of "same pay, same job, same performance" would hopefully have been a prototype for future companies.

The most compelling emotion that Mr. Lewis shared was the burning question that we as parents can identify with: "What would happen after I'm gone...could I live that one day longer than my child?" It was answered by a mother in the interview:

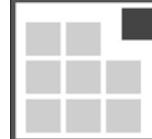
*see Village on page 36*

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### Innovative from page 8

Support Group, one of the four groups in the program, is geared towards young adult participants with an Asperger Syndrome diagnosis. In this group, participants learn and practice navigating social situations such as body and volume awareness, self-advocacy, dealing with anxiety, conversation skills, and developing friendships. Group members have the opportunity to apply the skills discussed out in the community. Participants also receive individualized support within the context of the small group. The Social Learning group now has 12 active individuals with a facilitator from the Mount Sinai Seaver Center and an intern from Adaptations who is with the group for her second year. Additionally, the group has two other interns involved. The group now meets for an hour and a half; thirty minutes are spent discussing a particular lesson with the entire group and an hour is used for small groups discussions. This new Social Learning Support Group has created a space for its participants to socialize, learn and grow together.

The GirlFriends Group is another support group in the program and brings girl-

friends, in this case young women on the spectrum, together to experience the bonds of friendship through laughter, tears and advice when needed. Having a strong network of girlfriends makes women healthier, happier, more successful, less stressed and more confident. The GirlFriends Group helps participants establish lasting friendships. There are currently 9 regular female participants who are benefiting from the group's work on navigating the social complications of female friendships.

The Dating – On and Offline Group has been quite an experience and experiment according to the program facilitators. After several years of hearing about people's desire to date and discussing dating issues one on one with participants, Adaptations is finally able to do so in a group setting. This has allowed participants to receive help in creating their own dating profiles, and explore issues of boundaries and safety when dating online. Participants have expressed that they now feel more comfortable dating on line. This group has also allowed for the creation of a forum for the participants to start asking questions that they have kept inside for so long and to gain support from their peers (e.g. "How

do I ask someone out on a date?" "How do I know if they like me?" or "How do I know when it is appropriate to kiss my date?" etc.). This group is still in its infancy phase where people are just excited to have a place to ask questions, feel validated in not knowing the answers, learn how to better understand social cues and ultimately improve their self-confidence.

The fourth support group in the program, still in formation, will focus on building confidence in dating and social relationships in the context of the larger community outside the program. Other future avenues for this DJF Ignition Grant program include dating and mingling events and the implementation of a safe, secure on-line dating website just for program participants to use within the confines of the program. To achieve this part of the program, a partnership with Pace University and the Seidenberg School of Computer Science and Information Systems has been established. Pace Assistant Dean and Director of Special Programs and Projects has agreed to take on this project and has begun development of the site along with the experts of Adaptations.

The Daniel Jordan Fiddle Foundation and the UJA Federation of New York and

the Hilibrand Foundation are looking forward to the growth of this first Ignition Grant Program and aspire for it to serve as a model for the development of similar programs in communities everywhere.

*Linda Walder Fiddle is helping blaze trails for adults challenged by Autism as the Founder and Executive Director of The Daniel Jordan Fiddle Foundation (DJF). This national Autism organization aims to develop, advocate for and fund programs that create innovative ways for the diverse population of adults living with Autism Spectrum Disorders (ASD) to participate in and contribute to community life. Linda's national, volunteer-driven organization was created in memory of her son, Danny, who passed away at the age of 9. She has dedicated her life to create and bring to fruition a wide range of initiatives that enhance the lives of people on the spectrum and foster awareness about Autism. The recipient of numerous honors, most recently Linda received the "2012 Evangelina Menendez Trailblazer Award" from US Senator Robert Menendez and has been profiled by Redbook Magazine as one of the five most inspirational women who "make a difference."*

***Guiding from page 14***

to possible paid employment. The program, which involves intense behavioral supports within an evidence-based treatment model, has seen success with supporting individuals in food markets, office settings and delivery positions.

Other agencies are focusing on supporting the social and vocational needs of those who are higher on the spectrum in a myriad of ways. Many are utilizing technology as a way to prepare young adults diagnosed with autism for those social situations that may be more difficult to navigate. Still, other programs are creating apartments and alternative living

situations for individuals who do not fit within the system as it currently operates. The ALAW (*Autism Living and Working, Inc.*) program has worked with families on alternative ways of supporting individuals in the community and to help support their growth and continued integration into the natural communities in which they live and work. It is creative thinking like this that will continue to drive the development of services and supports to adequately meet the needs of the most vulnerable individuals.

It is important for parents to advocate for their children early and often. During the IEP process during their child's school age years, families can begin to identify

vocational skills, likes and dislikes. If this process is started early enough, by the time the child graduates, parents will have a good understanding of what vocational opportunities might be best for their child as they become young adults. Additionally, while many families have insisted on intensive staffing for students while in school, it is in their best interest to consider fading that level of support, because staffing ratios in adult programs are typically not as rich as those in school programs. Overdependence on staff prompting and direction can be a detriment to building student independence and can impede the search for appropriate adult settings. Families should also connect

with other families who are looking into similar supports and services. Developing a parent network organization can help divide the workload of researching available supports.

In the end, the most important decision will be a very private one, specific to each family and each son, daughter, sister or brother. For some, this may include residential placement in a group home. For others, it may mean independent living in the community with natural supports. In a system where there is too little support and resources to go around, families must focus on keeping an open mind, supporting each other, and continuously advocating for the most appropriate services.

***Make My Bed from page 16***

parent and school staff collaboration is essential for students to master daily living skills and increase independence. Collaboration with school staff allows parents access to trained professionals who can offer suggestions and adaptations to the teaching process at home if the student is not progressing or is refusing to complete the skill. Training parents on how to implement teaching goals at home allows the skills to be taught in context and in the natural environment, leading to an increased likelihood of the skill being maintained. To increase positive outcomes for students, all daily living skills that are taught should be specific and relevant to the individual's needs. Teaching sessions should be planned and structured, but allow some flexibility to incorporate the students' interests or preferences into the teaching process.

Utilizing peer mentors within an educational setting can provide higher rates of success when teaching these important skills. Current research indicates that the use of typically developing peers to teach skills to individuals with ASDs results in an increase use of the skills that were taught (Banda, Hart, Liu-Gitz, 2010). An additional benefit of using a peer mentoring intervention is that they tend to promote generalization as opposed to adult-managed interventions that are more difficult to generalize. Peer mentoring programs to support the development of adaptive skills have potential applications within high-school settings based on the graduation requirement of many high schools for students to fulfill community service hours. Participating in a peer mentoring program could meet this requirement for students interested in working with peers who have disabilities. Peer

mentoring programs to teach adaptive skills are proactive in that they promote acceptance of those with ASDs in addition to providing skill development.

When a student with an ASD approaches secondary school, in addition to establishing meaningful academic goals, it is time to address students' needs in terms of daily functioning so they are prepared for the transition post high school. Time spent addressing some of the general education curriculum, (i.e., learning the elements of the periodic table) may ultimately be time lost in gaining meaningful skills that could directly improve adult outcomes. Rather than solely looking at the general education standards, educational goals should be individualized and match plans for adulthood.

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*School Psychology and is a certified School Psychologist. Edel is currently a student in the PsyD School-Community Psychology Program at Hofstra University. Edel has worked with children on the Autism Spectrum and their families for the past 7 years in private and public school settings and is a District Wide School Psychologist with a School District in Nassau County, NY.*

*The Fay J. Lindner Center for Autism and Developmental Disabilities understands the need to teach these important daily living skills to individuals with High-Functioning Autism Spectrum Disorders and offers course sequences in daily living, community, and leisure skills. All courses are supported by typically developing peer mentors from local high schools, and have a parent training component to ensure generalization of taught skills in the home. To inquire about these courses call the Lindner Center at (516) 686-4440.*

***Sexuality from page 17***

or in having a romantic relationship.

With training completed, WJCS staff embarked on creating curriculum and workshops in three specific programs: a recreational/social program for teenagers and their parents, a supported social group for adults age 18-30 with ASD, and to adults in an independent living program. The group members were active participants in the process of identifying their learning needs and priorities. Many were open with their pre-group questions including, "What does a kiss feel like?" and, "Is holding hands dangerous?"

The basic curriculum is broken down into core topics including understanding the body, social communication and relationships, and personal safety and boundaries. Every group covered each of these topics, but relative to the developmental level of the participants. Questions raised by group members were incorporated into the curriculum.

Across all groups, members were uncomfortable yet eager to learn. They were curious about all aspects of dating; where to meet people to date, how to tell if someone was interested, and the logistics of a date. They were more reluctant to work on issues related to hygiene and actual behavior on a date, but were able to recognize that they needed to master these topics in order to be successful in dating. Using television clips and pictures alleviated the pressure of disclosing personal experiences (lack of them).

Lessons learned: The groups tended to be interested in more basic material than anticipated. While the parents of the teen-

agers had anticipated that they would want to learn more about anatomy and sexual activity, the group members actually reported that they were much more interested in dating and felt like they were fairly far away from being ready to be involved sexually with others.

Initially we thought it would be necessary to separate the adult independent living group into those who identified as being sexually involved or wanting to be from those who were not to better address the interests and learning needs of each group. Although some of the group members did identify as not being interested in sexual involvement for themselves, they were interested in learning and talking about safe sexual activity with their peers and felt that it was important to have these discussions as a community.

In each of the groups we also found that prior to any training from us, the group members could verbalize an understanding of some topics, but when asked related questions or to respond to hypothetical situations, their confusion was evident. They may have received some form of education about healthy sexuality in their school programs and from their families, but could not connect the factual to practical application of concepts.

This was especially apparent when talking about boundaries and safety. Many group members could articulate safety rules about how to respond to strangers, but often had an inaccurate and rigid definition of who a stranger was; such as thinking that only men could be strangers. Because we could not anticipate and plan for each of these knowledge gaps or misunderstandings, we found that the only effective way

to see if the group members had mastered the material was to role play and take trips into the community to practice.

We knew there was a need in the community for this special type of education and this was confirmed by parents and participants. A parent of one of the program participants said, "My dream was always for my son to thrive in the community. I always worried about him being safe; I'm grateful to WJCS for providing a group for him to learn and share with others." Another parent stated, "I never realized how uncomfortable I was with discussing relationships and sexuality." A program participant said, "The group helped me handle breakups and relationships and gave me coping skills so when things don't go as I planned I can handle it."

The programs and workshops were well-received by the professional community as well. We were contacted by several agencies about how training for themselves and how they could help parents talk to their children about these issues. In response to these requests and to encourage other agencies in Westchester County and the surrounding areas to do this work, the WJCS Autism Family Center hosted a half-day conference on healthy sexuality and relationships in December 2011 with Dr. Pulver Tetenbaum as the keynote speaker. There were over 100 participants representing the professional community as well as parents/caregivers.

With the support of the ASPIRE Center, WJCS has been able to move from acknowledging the need for a program in Westchester County that addresses healthy sexuality to becoming a lead social agency in providing workshops and groups. To

date, program participants are more comfortable in understanding the complexity of relationships, they have increased their ability to protect themselves from exploitation, they have learned how to make responsible decisions regarding social and sexual relationships. They have been empowered to seek advice and ask questions from others in their trusting circles. They have increased their capacity to become part of the fabric of their communities, living, working, socializing alongside their typically-developing peers.

Transitions in life are often complicated and filled with unknowns. For our clients, consumers, family members with autism spectrum disorders, it is often an overwhelming, and sometimes a scary process. There are so many unknowns, so many decisions to make. With helpful guidance and support, we can make this process more manageable and successful. Transition planning in general, and specific to developing healthy relationships is a long-term process that requires planning and responding to the changing needs of the individual. Successful work in the area of healthy relationships incorporates a strong knowledge base, comfort with the topic(s), and a person-centered approach. As did WJCS, creating the opportunity for individuals with autism spectrum disorders to learn, think aloud, share with others, question and experience helps ensure the safety and well-being of our clientele.

*Patricia L. Grossman, LCSW, is Director and Kari Y. Phillips, LCSW, is Assistant Director of Outpatient Services for Persons with Developmental Disabilities at WJCS. For more information, please visit [www.wjcs.com](http://www.wjcs.com).*

## Leaving School Behind - Next Stop, Adulthood

**By H. Laurie Yankowitz, EdD**  
**Vice President of Individual and Family Support Services**  
**HeartShare Human Services of NY**

The prospect of adulthood is particularly complex for individuals affected by developmental disability, their families, and the people who care about them. Like their peers, they have accumulated two decades' worth of experiences, their bodies have matured, and they are considered to be autonomous citizens with rights and responsibilities governed by the law of the land. Unlike their peers, they have not outgrown significant reliance on others to navigate the demands of adult independence – accessing health care, productive engagement and gainful employment, money management, self-direction – due to a host of limitations that impact the ability to take care of oneself.

Today's adult service delivery system for people with developmental disabilities strives to honor their status as full-fledged citizens who have reached the age of majority. They are "grown-ups" who want to make lifestyle choices in keeping with their individual preferences and desire for independence. To this author's mind, there is no more noble task than supporting this basic desire. Associated challenges are numerous and wide-ranging—making for an extraordinarily stimulating mission. Professionals and parents, some-



**H. Laurie Yankowitz, EdD**

times in partnership, sometimes with opposing views, are presented with ongoing issues requiring a delicate weighing of protective oversight vs. dignity of risk in the essential effort to assist an especially vulnerable human being in living a rich and self-actualized life.

Family members are particularly challenged to make identity adjustments, both in terms of their grown child and their own role in their grown child's life. It is suffi-

ciently daunting to grant autonomy to any human being who you have fed, clothed, consoled, counseled, cajoled, disciplined, cheered, and housed for twenty years. How do you "let go" when that person is someone who rarely makes eye contact, makes loud, odd vocalizations and flaps their hands every time they change location, and if left to their own devices would eat only pizza, water crackers and grape jelly? How do you switch gears from being that child's caregiver and protector to that adult's supporter and advocate?

Professionals, too, are confronted with seemingly dichotomous responsibilities. On one hand, they are charged with insuring the health and safety of every individual for whom they have oversight. This includes folks who want to escape environments that may, for them, be too bright, too noisy, too crowded, or too unfamiliar; who may provoke aggression in others due to a compulsion to repeat the same word, phrase, or snippet of a commercial again and again and again; who may have no awareness of danger. On the other hand, they are trained to enable and honor choice-making, respect preferences, and encourage and promote independence.

I assert a trite but I think true summation: nothing worth doing is ever easy! I am privileged to have come to know many families whose diligent efforts and dedication to bringing their children up to "be all they can be" have resulted in many successes. One young man who comes to

mind, who has an intellectual disability in the mild/moderate range and is prone to high anxiety, has successfully learned to use the New York City subway system, is holding 3 part-time jobs, and lives semi-independently in an apartment where he enjoys both privacy and company.

I also have the good fortune of working at an agency with colleagues who thoughtfully toil to do right by the people entrusted to our care, while complying with ever-increasing demands from various authorities for meticulous documentation and budget matters. Individuals who started services with us by attending a school holiday respite program have transitioned to our day habilitation and residential services, followed by service coordinators who strive to insure that outcomes important to the individual are identified, pursued, and achieved. These goals can include being able to hand a cashier the right amount of money to purchase a favorite CD, cooking a favorite meal from their country of origin, or simply selecting and wearing fabrics that maximizes their comfort because they are highly sensitive.

When working with people who have very limited communication skills and do not initiate activities or interactions, staff need to be extremely attentive to body language and facial expressions, and provide a wide variety of activities to discover what interests and pleases the individual.

*see Leaving School on page 37*

### Post-Secondary from page 4

college or vocational training. Students frequently struggle with setting an alarm clock, managing their time, traveling independently to and from classes and home, organizing their room and possessions, money management, and laundry. Finally, students with ASDs struggle with vocational skills such as job search skills, interviewing techniques, dressing appropriately for work, and work place decorum.

Comprehensive Transition and Post-secondary programs are designed to help students with an Intellectual Disability address their impairments in executive functioning, as well as their social, independent living, and vocational skills. This is all done within the context of the college environment. Students in a federally approved CTP are expected to spend over ½ of their classroom and experiential time alongside their neurotypical peers. This can be done on a class by class basis, semester by semester basis or over the course of the entire program. CTPs structures will vary from college to college. The college will determine not only the structure of the program, but also what constitutes an Intellectual Disability (ID) and what documentation the student must provide to establish evidence of an ID (within certain limitations established by the legislation). The student however, must have a history of being eligible for a Free and Appropriate Public Education (FAPE) under the Individuals with Disabilities Education Act (IDEA).

Parents working collaboratively with school districts have the opportunity to create an Independent Educational Pro-

gram (IEP) with a transition plan that can incorporate a Comprehensive Transition and Post-secondary program as an end goal for a student with an ASD. As the student progresses through their high school years, IEP goals should target social, independent living, and vocational skills acquisition. These goals are often very difficult for school districts to attain. They require a substantial amount of time and require hours of practice that are not always feasible in the confines of a school day. CTPs can help school districts with these goals because they provide an environment in which the student must practice these skills on a daily basis. Living in a residence hall requires a student with ASDs to interact and practice social skills. Being away from home requires the student to practice managing his or her own time and money, cleaning his or her own room and doing his or her own laundry.

Under the Individuals with Disabilities Education Improvement Act of 2004, Congress specified what qualified as transition services, which included college based transition programs. During the commentary process, The U.S. Department of Education staff also clarified that funds from parts A & B of IDEIA can be used to fund community or college based transition programs. (Please see Assistance to the states for the Education of Children with Disabilities, 2006). The US DOE went on to clarify that IEP teams have always had this ability. It is the IEP team, with the parents and student as members, who determine how to attain the IEP goals. If the IEP team determines that a CTP is an appropriate means to

meet the student's IEP goals, then funds from the school district can be used to support the program.

Students with ASDs and other Intellectual Disabilities (ID) may have a longer trajectory than their neurotypical peers in transitioning into adulthood and reaching independence. A well-conceived transition plan for a qualified student with an ASD can provide funding through the school district through the student's 21<sup>st</sup> birthday for a CTP, and then, with the recent changes to HEOA the student may be eligible for Federal Student Aid if he or she is enrolled in a federally approved CTP.

It is important to note that Funds under IDEIA and HEOA may not be used simultaneously. It must also be noted that funding for a CTP under HEOA is limited to Federal Pell grants, Federal Supplemental Educational Opportunity Grants (FSEOG) and the Federal Work Study program. Currently, students with ID are NOT eligible for federal loan programs. The funding under title IV of HEOA may NOT be used by a student who is currently being funded by a school district under IDEIA. To complete the FAFSA, students must go to [www.fafsa.gov](http://www.fafsa.gov) and enter a federal school code for the college that has an approved CTP. All students must obtain a Personal Identification Number (PIN that serves as the student's electronic signature at [www.pin.ed.gov](http://www.pin.ed.gov)). If the student is a dependent (under the age of 24), the student's parent must also obtain his or her own unique PIN and is required to provide an electronic signature for the FAFSA. So far, no States have developed comparable tuition assistance programs in response to this new legislation.

As of February 1, 2012 only 10 colleges in the United States have been approved by the U.S. Department of Education to provide Comprehensive Transition and Post-secondary programs to students with Intellectual Disabilities. For an updated and complete listing of federally approved CTPs, please visit: <http://studentaid.ed.gov/PORTALSWebApp/students/english/CTPProgramList.jsp>.

New York Institute of Technology is proud to announce that its Vocational Independence Program (VIP) is the first CTP in the State of New York to receive this prestigious distinction and only the second college in the entire Northeast to receive this designation. For more information about the Vocational Independence Program, visit: [www.nyit.edu/vip](http://www.nyit.edu/vip).

### References

Assistance to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities, 71 Federal Register, 46668 (2006)( to be codified as 34 CFR Parts 300 and 301)

*Authors' Note: the author would like to thank Dr. Judy Shanley, U.S Department of Education, Office of Post-secondary Education, for providing the technical information contained in this article.*

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**Housing from page 1**

spectrum. In this manner, individuals, family members and other interested parties can avoid re-inventing the wheel, taking advantage of service models and planning tools that already exist for persons with developmental disabilities while addressing specific needs that they or their family member may have.

The following are key components to consider in building a framework for housing beyond the school years.

**A Person Centered Approach And an Individual Plan**

*A Person Centered Approach and an Individual Plan* should be the foundation of the framework. It's important to assess any housing options through the lens of what the individual's needs, skills and desires are. There are tools on the web which can guide an individual/family through this process. An individual plan should consider the whole life of the individual, not only housing. Can he/she be alone during the day? What are his/her employment possibilities? Is further training needed or job supports? How will he/she maintain a social life and other interests such as religion, hobbies, family get-togethers, sporting events, etc.

Requesting a *person centered transition plan* during the school years is strongly recommended. This is a resource that is a right as educational services (See IDEA, Individuals with Disabilities Education Act) are an entitlement. At age 16 years, school systems are required to develop a transition plan for adulthood or adult life. Too few people take advantage of this requirement.

**Government Benefits and Programs**

*Government Benefits and Programs* for funding sources can make a difference in your plan. Researching and understanding government programs such as social security or funding through state specific disability agencies are critical. Social Security provides adults with disabilities a monthly benefits payment and health insurance if they meet a low income threshold. Keep in mind the \$2,000 asset limit for Supplemental Security Income. For more information visit [www.ssa.gov](http://www.ssa.gov).

Each state varies in how services and funding to individuals are provided despite national legislation and regulations which guide the delivery of services such as health care, education and long term care. In some states there may be specific programs for adults with ASD while in other states one has to go through one or more state developmental disabilities agencies. For example, residential services may be possible through one state agency but employment training or support may have to be accessed through the state vocational rehabilitation agency. As soon as you identify the agency that is relevant, and which provides services you require, ask for an application to begin the process.

**Financial Planning**

A family's personal *Financial Planning* will have a large impact on the

**Cynthia R. Haddad, CFP**

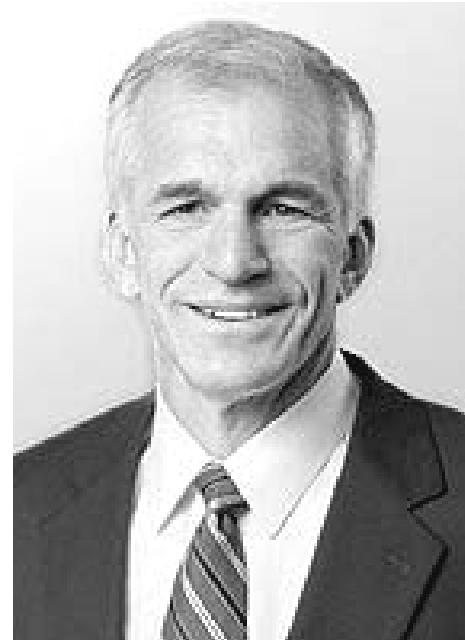
ability to continue to pay for the housing model both during the life of the parent(s) and upon their death. Since government resources are continuing to shrink and the need for services is continuing to increase, obtaining public funding for residential supports in non-emergency situations will continue to get more difficult. Because of this it is important to build a plan that involves personal resources. Since parents have to plan for both their own financial security as well as the security of their child it is important to prioritize your goals.

What makes residential planning for an individual with special needs particularly challenging is that until the person reaches the age of 22 it can be difficult to project the exact dollar needs. It might help to break down the need into three components; day services, residential supports and the cost of the physical structure. Then attach income sources for these estimated expenses where possible.

Working with a Certified Financial Planner™, who is knowledgeable in special needs planning, will help you to identify what it takes for you to achieve your personal security and then overlay the needs of your child on top of your plan. The key is, simply begin to save! As basic as this sounds, we find that all too often parents plan on paying for their child's college educations, and ignore saving for their son or daughter that has special needs.

**Legal Planning**

There are several *Legal Planning* possibilities here that can protect the individual with ASD while maintaining as much independence as possible. When the child reaches age 18, there must be consideration for guardianship, or the less restrictive alternatives such as limited guardianships, conservators, representative payee, health care proxies and power of attorney. Beyond the well-known special needs trust planning, there is a continuum of safeguards that can be utilized in decision making. The decision of home ownership, i.e. the parent, individual, trust, or other entity should be considered carefully and with consideration for protecting and accessing government benefits.

**John W. Nadworny, CFP**

Working with an attorney who is knowledgeable in disability law will be beneficial.

**Housing Services Agency**

The *Housing Services Agency* that will provide services should be an experienced agency who has demonstrated a commitment to supporting individuals with ASD. This should include specific training programs for staff with a well-documented understanding of the unique needs of adults with ASD.

Using the person centered plan to compare options and alternatives, visit a few homes to get a sense of what might be available. This includes different types of housing (condominium, apartment, and house), the size (number of roommates) and the level of support needed (24 hours, part-time, drop in) and special requirements for medical needs, transportation, and social activities.

**Employment and/or Day Programs**

Explore *Employment and/or Day Programs* that might be appropriate to the abilities. What are the possibilities of employment? If not full-time, what are the activities during the day that will complement or take the place of employment? In the transition plan, the choice of a secondary school has a big impact on preparation. If someone is interested in a technical career he/she may want to choose a secondary school that has that type of curriculum.

**Health Care**

Consider *Health Care* needs including behavioral health needs of the individual and roommates. Is there a specific plan in this area so that the adult can either manage his/her health care or has the support to do so? This includes prevention strategies as well as the ability to address illnesses or health conditions in the future as they arise.

**Social Needs**

Beyond the physical home, incorporating the *social needs* of individuals helps to build a full life. Supports for unique lifestyles, friendships, families,

**Leo V. Sarkissian, MSW**

social/leisure, recreation, hobbies, religion, traditions and the like should be incorporated in the planning and budgeting process.

This outline is a beginning step in development of a framework for planning. Without a guide, persons with ASD and families are leaving the future to chance. Although planning cannot eliminate all the unknowns that exist, it can provide a solid foundation for a good life in the community.

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**Footnotes**

1. 2004, IDEA, excerpted from regulations on transition, [www.idea.ed.gov](http://www.idea.ed.gov); choose Part B

2. The Urban Land Institute, Southwest Autism Research and Resource Center and University of Arizona; [www.autismcenter.org/documents/openingdoorsebook/](http://www.autismcenter.org/documents/openingdoorsebook/)

3. News story 11/8/2010, rtv6-IndyChannel; [www.theindychannel.com/news/25688588/detail.html](http://www.theindychannel.com/news/25688588/detail.html) and cited by Disability Scoop,

4. 2010, Advocates for Autism in Massachusetts with research by the Lurie Institute for Disability Policy, Heller School for Social Policy and Management at Brandeis University, [www.afamaction.org/AFAMASCReport2-10-10final.pdf](http://www.afamaction.org/AFAMASCReport2-10-10final.pdf)

## Will We Ever Stop Worrying?

**By Debbi Hudak**  
Parent

**W**orry...it's a real feeling, but, I've come to learn, a big waste of time. How I wish worry was not a real thing. How I wish I could start every day with a clear head and just deal with things when they happen. I guess people like that really do exist out there...but I'm not one of them, yet.

I didn't know it then, but looking back when I was a child, I had anxiety. I can't believe that all I had to worry about was if my hair looked good that day or if I could fit into a favorite pair of jeans. Sounds real worrisome, huh? But, it was real for me. Will I get all my homework done fast so I can play basketball with the guys? Again, hard to believe, but these were real worries. They were different, however, from the worries we feel as adults.

How is it possible that we really didn't know how good we had it, worry-wise, when we were kids? I'd say it's because, as kids, we lived in the moment and as adults we're always thinking ahead and anticipating everything that "might" happen. It might sound impossible, but we can get a handle on our worry. I've learned that we seriously need to live in



**Debbi Hudak**

the present – utilizing the knowledge of what we've learned in the past, not dwelling on it. Dwelling on anything just isn't healthy. Replaying in our heads events that have happened and worrying that they might happen again is not good. We should only look back briefly, in a reflection kind of way, but not dwelling. We're

human beings, we were actually born with everyone knowing we'd make mistakes, but we're all so afraid to do just that. We can reflect, and learn, then move forward.

I tell you this, because I believe that my worry over my autistic daughters' life is what caused a malignant melanoma to manifest in me. My daughter, Alicia, is 18 years old and was diagnosed with autism at age 2 ½. I was a wreck, not to mention, heartbroken, blind-sighted and overwhelmed...any of this sound familiar? So, of course, as we all do as parents of autistic children, I dove full speed ahead into learning all I could to help her. I was also trying to be good at being a mother to a typical 4 year old, a wife, a sister, a friend, an aunt, an employee, etc. A year and a half into Alicia's diagnosis, I noticed a spot on the back of my left thigh. I mentioned it to a friend, who turned pale and said, get it checked out immediately. If not for her, I'd be dead. It was caught early, so I needed no chemo or radiation, just a direct order from the doctor to stay out of the sun. So, see if you can guess what I did...BINGO, I started to WORRY about how I was going to be able to let the kids swim and do outdoor things, if I couldn't go in the sun. (I have a feeling some of you thought I'd say, "I stayed out of the sun"...he, he, he...gotcha!) Of course, we figured out how to make it work and I completely wasted my

time by worrying about it.

Alicia is 18 now and many things need to be considered as she enters into adulthood. For the old me that would be a consuming world of worry; luckily, I've learned from the past. I can wake up and see the mounds of paperwork from social security benefits, to guardianship, to different things happening at school when they're older, and not panic. I can make a phone call a day to tackle these projects, instead of worrying that they all had to be done yesterday. Folks, it's a process to get where I am and I work on it every day!! It's never too late to start to live in the moment. We need to take care of ourselves now and stay healthy for our kids. And, as much as we don't want to, we have to be a little selfish. Take that exercise class, read the book you've been wanting to, it's healthy to have "me" time. I know you've been hearing it for years, but you've been hearing it from doctors and therapists...now you're hearing it from a mom of an autistic child, who learned how to stop feeling guilty, and it really works. My faith has been my strength...I took the time to nourish my relationship with GOD instead of being angry, and it's so much better. I hope and pray that whoever is reading this; you take my advice and do something for you. Oh yeah, and one more thing...STOP WORRYING!!

### *Blueprint from page 26*

know what to expect from the program. In addition having different staff members with different skills sets responsible to provide service in each area is advised.

A few more words on trust and safety. Client trust is built on their belief and feelings of being understood and valued. Because our population has struggled with these issues so often in the past, it is essential to address them directly. I train staff to try to "see the world through the eyes" of each student that they work with, and to let the student know that they are trying to do that. As well, I encourage staff to "listen to the music, not the words." That is, to try to understand what message each student is trying to tell us. For many students, this is the first time that anyone has communicated these wishes to them, and they find it exciting and hopeful. By taking this approach, I am attempting to begin to challenge the negative thinking style that individuals with AS often manifest, which includes the belief that others cannot, or will not, understand them. These beliefs often stand in the way of students disclosing problems and challenges to staff members, and therefore, getting the help that they need.

Because of its importance to student success, and its multiple challenges, I suggest dividing academics into separate service providers; whom I will refer to as the Academic Coach and the Learning Strategist. Both will focus on the cognitive disabilities that often cause students with AS to struggle academically. Because of transition and anxiety issues that are common at the beginning of each semester, placing increased focus on academics at that time is advised.

The Academic Coach is trained in, and responsible to, monitor executive function-

ing issues and to take the global view of student status. Academic Coaches not only monitor class syllabi, time management, and organization and planning; they also monitor self-management issues such as sleep and waking management, personal hygiene, and medication management. By working with the same students over the course of their enrollment in the program, the Academic Coach learns areas of strength and weakness, and the unique issues that need attention for each student, which enables trust to build and be maintained. We have been most successful when these meetings occur at least twice weekly. Students leave each meeting with their Academic Coach with a printed document of assignments, exam preparations, or other scheduled support sessions that should be completed before the next meeting with the Academic Coach. As another form of communication and documentation of the upcoming tasks, the Academic Coach emails this information to the students.

The Learning Strategist is trained in, and responsible for, working with students to address typically occurring academic problems including procrastination and avoidance. The Learning Strategist focuses on helping students understand and complete assignments, develop, produce and convert thoughts to cohesive text or narratives, and prepare for exams. As with the Academic Coach, the Learning Strategist works individually with the same students so that they can come to understand each student's areas of strength and weakness, and become aware of the unique issues that need attention for each student, which also enables trust to build and be maintained. These meetings occur at least twice weekly. If the student needs more specific specialized tutoring help, a referral is made to the university Tutoring Center.

As difficulties with socialization are at the core of AS, there has been a focused approach to address social issues as advised. We have utilized a multimodal approach, which includes Peer Mentoring, social support groups, and group outings. Peer Mentors can be student volunteers from the university that are trained and supervised to provide weekly socialization opportunities for students in the program. Based in Social Learning Theory, the primary role of the Peer Mentor is to model appropriate social behaviors. These may include behaviors as simple as answering emails or voice mails, to being on time for appointments, or encouraging their student to participate in other campus activities which the Peer Mentor may be involved in.

Social groups and group outings provide opportunities for students to socialize and get to know each other in small and large settings, on and off campus. Weekly or bi-weekly open groups, run by members of the program's staff, encourage friendships within the program, and offer students the opportunity to safely discuss problems that they may be having in school, at home, or with peers. Planning group activities, both on and off campus, can also be a goal of these meetings. In both cases, students have the opportunity to practice brainstorming and problem solving techniques. One caveat on organized social activities: in my experience I have found that for college students, any benefits that they may receive from manualized socialization trainings have been negated by feelings of humiliation at being presented information in ways that remind them of previous trainings received when they were younger. College students often benefit most when they are presented information in more indirect, and mature settings and styles.

One reason that vocational services are included in the program design is that it is all too common to see students successfully complete their college careers, only to move back home to live with their parents, ill-equipped to become employed. Additionally, having a vocational goal can help to motivate and shape academic efforts. Therefore, having an experienced vocational counselor on staff is an important element. This person can offer vocational testing and interpretation for the students, as well as develop on and off campus job opportunities, provide job coaching, and resume writing and job interview skills support. These services can be provided individually and in group settings.

Efforts to create and maintain college support programs for students with AS are hard work, but they are important and can be successful. Because individuals with AS see the world differently, their creativity and thinking styles can be an asset on any campus. As more students with AS become successful in college because of support programs, and their positive contributions to campus communities become recognized, we should see programs offered on more campuses.

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***Unemployment from page 16***

through a company's intranet system, as well as live training customized to an employer's needs. The video based training teaches: 1) how to identify (though not diagnose) employees that may require different management strategies, and what those strategies are; 2) how to modify traditional recruiting methods—strategies based arguably 95% on socialization—that are one of the main reasons our population slips through the employment cracks; and 3) specific methods for remediating some of the issues that may arise in the workplace for individuals with AS.

**Demystification**

But change, even when it is championed by the D&I and HR departments, is slow. And what is apparent is that *companies will likely not commit to hiring people with AS unless they first are provided with an opportunity to meet some of them*. Call it "kicking the tires" or "testing the waters," if you will, but companies need to feel confident in their own abilities to make such a relationship work. In short, employers are

looking to organizations representing individuals with AS to demystify what that means from an employment perspective.

In 2011, ASTEP launched a Corporate Lecture Series. The concept was simple – ask 6 large employers each to host one two hour session for a group of young adults with AS where the employer talks about the job search process, their corporate culture, and networking skills. A group of twelve young people with AS—all of whom who are recent, or soon-to-be recent college graduates—was chosen from a pool of thirty applicants. Six Fortune 1000 companies were then successfully recruited to host, and we had our first session in November 2011. Not only do these sessions allow companies to meet a group of young adults on the spectrum, the attendees are also provided with a learning experience where they can ask questions they might not have felt comfortable asking otherwise. As the seminar series is not a job interview, but instead an educational forum, the group is able to both share and resolve some of their confusion over job-related issues, such as what exactly "conservative attire" means, or how internal promotions are actually facilitated in large companies.

The real benefit of course, is the strong impression the attendees are leaving on the company representatives. These seminars are the beginning of building that relationship with these employers to create the broader awareness and inclusion of individuals with Asperger's in their diversity strategies.

The lessons above are ones that professionals working to increase employment statistics for individuals with AS need to know. But another lesson learned in our first year is one that anyone who knows an individual with AS can use. For employers, retention rates alone mean very little, just as hiring rates alone mean very little. A corporation could have a strong track of hiring underrepresented communities, but if those new hires all leave within a year, the company has failed in its D&I efforts, yet can still boast a high minority-hiring rate. And if a company does everything in its power to keep their one minority hire, then that company has a 100% retention rate. *Hiring and retention rates work in tandem*, and everyone working in the employment field needs to operate on this principal.

So how can individuals who are not vocational professionals use this knowledge? Everyone - parents, other family members, and friends - can advocate within their own companies for increased hiring practices of people with Hidden Disabilities, diversity training, Employee Resource Groups (ERGs, or interior support groups within businesses for minority employees), and awareness campaigns.

Secure employment can ease the burden of so many transition issues. Finding a place to live is so much less stressful when you know you'll be able to pay for that first apartment. A successfully employed person is a happier and more confident person, making them more attractive to others for all types of relationships. In the best-case scenario, how glorious are those feelings inside when you are paid to do something that you enjoy?

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**Optimism from page 22****Cognitive-Behavior Therapy: Creative Problem-Solving for Adults on the Spectrum**

CBT refers to a set of strategies for dealing with mental health problems that has existed for over 40 years and has a huge empirical literature supporting its validity as a psychotherapy approach with neuro-typical patients. This large collection of therapeutic approaches all assume cognitive activity affects emotions and behavior and that people can learn to monitor and alter that activity in order to bring about changes in mood and behavior. CBT has been shown to be effective for a wide variety of mental health problems seen in neuro-typical adults, such as major depression and a variety of anxiety disorders (Butler, Chapman, Forman & Beck, 2006). Because people on the spectrum are at best, not immune to the mental health issues that can affect any adult, and may, in fact, be more vulnerable to some (e.g., Attwood, 2006; Gaus, 2007, 2011a; Ghaziuddin, 2005), they should be offered the same evidenced-based therapeutic approaches that might be offered to anyone.

CBT teaches people to monitor their own thoughts and perceptions with the hopes that they will become more aware of their interpretive errors, but *not to change the individual's entire personality*. As with any neuro-typical patient in CBT for a mental health problem, the therapist's job is to teach the adult with Asperger's Syndrome/High Functioning Autism (AS/HFA) to identify and modify the cognitive activity that is causing problems in living. For people with AS/HFA, this means to:

- Teach new cognitive and behavioral skills that were never learned
- Teach compensatory strategies for deficits that cannot be changed
- Facilitate self-acceptance
- Teach strategies to decrease or prevent symptoms of co-morbid mental health problems, such as anxiety disorders and depression

Of the many CBT techniques that are useful for people on the spectrum, problem-solving is one of the most versatile sets of tools for a young person to take on the journey into adulthood. Growing out of traditional CBT (D'Zurilla & Goldfried, 1971), problem-solving skills can help people cope with a multitude of stressful events and pitfalls that come at any point across the lifespan. Armed with this step-by-step formula for thinking objectively about dilemmas and conflicts, a young person can manage more independently the complex and often overwhelming world of adult life. There are many versions of the problem-solving steps in the CBT literature, but the following 8-step approach was tailored to meet the needs of adults on the spectrum. When facing an overwhelming situation that, at least initially, seems insurmountable and/or leads to a surge of intense emotions (e.g., "meltdown"), a person who is working on problem-solving skills will be asked to go through the following steps in order to address the issue:

1. *Identify and define your problem.* Ask, "What is bothering me in this situation?"
2. *Define your goal.* Ask, "How do I wish it could be different?"
3. *Identify the obstacles in the way of your achieving your goal.* Ask, "What is getting in my way?" and identify ASD thinking, social, emotional, and sensory/movement differences that might be involved.
4. *List several possible solutions to address the obstacle(s).* Ask, "What are the possible solutions for the obstacle(s)?" List as many as you can think of, no matter how silly some may seem (some psychologists call this step *brainstorming*).
5. *Consider the consequences of each solution.* Ask, "What are the pros and cons of each solution?" and weigh the best against the least feasible.
6. *Choose the best solution(s) to try out first.* (Please note that reference to psycho-educational and self-help materials on autism characteristics is often needed for a person to independently consider specific thinking, social, and emotional management strategies.)
7. *Implement the solution and track your progress.* Put the solutions in place and come up with an objective way to measure your progress. Remember to measure the goal you set in step 2.
8. *Evaluate the solution to see if it met the goal you defined in step 2.* Ask, "Did the solution meet my goal, or do I need to try a different solution?" Rate how close you got to your goal (stated in step 2) on a scale of 0–100 percent. Celebrate if you met your goal or came close, modify the plan if needed, or go back to step 3 if you have had no progress.

Using this formula to solve problems effectively takes practice. Like any skill, most people need guidance or coaching through many rounds of examples before it will become "second nature." Therapists, teachers or patient family members may be a good source of this support. Combined with the philosophy of positive psychology, problem-solving skills help young people on the spectrum become active participants in planning their future. Through the approaches described here, these individuals can define their own goals, become more knowledgeable about their own strengths and weaknesses and then use that information to increase life satisfaction.

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*and "Cognitive-Behavioral Therapy for Adult Asperger Syndrome."* For more information, you can contact her through her website at [www.drvaleriegaus.com](http://www.drvaleriegaus.com).

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# A Father's Experience Accessing Adult Services

By Jeff Stimpson  
Journalist

**A** local advocate called this afternoon asking me to meet with our well-dressed politicos to talk about cuts in funding. Everyone swears these are coming down the pike for people like me and my family. I'm still unsure of the dollars involved, but what I hear – what I've heard my whole adult life – is cuts, cuts, cuts. Thing is, I haven't had a 13-year-old with autism my whole adult life.

My son Alex is now shaving; he's broader now in the shoulders than he was long when he was born premature. He uses roll-on deodorant. He's coming into the age when I have to think about day programs, guardianship, residences and other grown-up stuff in the years ahead that will require big bucks that might not be there.

Here in New York State, they're dressing up proposed cuts as "changes to a waiver" and calling them part of a "People First" initiative, which makes me wonder where politicos placed "people" before. Alex's Medicaid Service Coordinator reports that some men and women in day programs have had their summer camp funding cut and that residence managers must cherry-pick who goes to camp. Doesn't sound like a fun job for the managers. Doesn't sound like much fun for the people who are first to be left out of camp either.

Alex has received services since he was one year old; financial cracks in those services have begun to appear like fissures in a warming ice field. Higher fees for summer camp. Twenty bucks for field trips that used to be free. Soon it'll be \$50, \$100.



**Jeff Stimpson**

We're happy to pay – I'm grateful to my aging bones for "services" – though I do wonder where it'll end. "Everybody writes fundraising letters about kids," says my wife Jill. "It's the grown men who don't get to go to camp I'm thinking about."

For more than a year, we've flirted with adult stuff for Alex. School transition coordinators have mentioned job training; "vocational" has begun to appear on Alex's IEP. The faces of educators light up in a new way when I mention that Alex likes to arrange store shelves or do laundry or empty a dishwasher. Last Thanksgiving break, because autism doesn't take a four-day weekend, was tough. By that Saturday morning Alex was saying, "David's com-

ing? Rosa's coming? David's coming?" as he slipped on his shoes, hoodie and backpack. "Take a walk! Wanna walk!" David and Rosa are, well, "companions" I guess you'd call them if, like us, your son is too old to hang around with a "babysitter." By the morning of Black Friday, Alex was bored out of his mind. He didn't want to do letters with me, didn't want to pick up his room or put laundry away. He yelped into his iPad. He wanted to go out hour after hour. I took him out; he wanted to go again immediately after we came home, and I could tell he wanted to go out with anybody besides mom and dad.

I have tried to get him into overnight respite, a terrific program in which parents like me take guys like Alex to a nondescript apartment building on the other side of Manhattan. There we walk past the doorman who glances at Alex and knows to say, "Sixth floor," and we go up to a three-bedroom where Alex could stay for scattered days and nights for years to come, gaining his independence while his mom and I catch up on our sleep. The program is mostly for adults. Some live for days in the apartment, buses picking them up for school or their day programs right at the door and dropping them back off at the apartment at day's end.

We hope that when this program is humming in our lives, it'll help get Alex out of the house, which he wants to do (a 13-year-old who wants to get away from his parents now and then: somebody call "60 Minutes"), and it will help us recharge from the drain that is living with Alex as he gets older and bigger. How long, though, before some well-dressed politico decides that funding for overnight respite simply isn't important enough?

"The holidays book up well in advance," said the lady who coordinates the program. "Parents jump right on those school holidays." I called her late last September about overnights through the end of 2011. Already booked, she said. "What's Alex's schedule in February?"

Alex also crapped out of this program last spring by bolting. He ran from the apartment and explored the building. He refused to listen to the staff. He hogged the TV. The staff's response was to let him get his feet wet by the half- and then full-day stays at the end of August, instead of staying overnight; they helped arrange for a 1:1 para, too. "If you took me to a strange place where I didn't know anybody I wouldn't know what to do, either," the coordinator told me. "Tell him he's going to have fun."

During the last week of August, Alex did well. So well, I guess, that the second morning the supervisor called me and said they could take him for *four days*, until Labor Day eve. I was tempted but he wasn't ready, I told her. From that offer I came away with the idea that holidays are clear for vacancies in overnight respite; I came away with the idea that adult programs for guys like Alex will be as wide open as those for children.

*Parents jump right on those school holidays.* I can see plain as the fuzz on Alex's upper lip that stuff for grown-ups is going to require thought, planning, more thought, more planning, and a scary amount of plain old luck.

*Jeff Stimpson's books are "Alex the Boy: Episodes From a Family's Life With Autism" and "Alex: The Fathering of a Preemie."* Visit his blog is at [www.jeffstimpson.com/alextheboy](http://www.jeffstimpson.com/alextheboy).

## Road from page 6

and/or background information to make "accommodations" on the spot.

The following is a list of action items to ensure the road to transition is as smooth as possible:

- Begin the process of planning at 14 years of age and review that plan every year;
- Begin the guardianship process at least by 16 years of age so that guardianship is in place at 18 years of age;
- Obtain SSI benefits and/or where appropriate SSDI benefits;
- Register with your state's Developmental Disabilities Agency, read online and go to the office for a one-on-one meeting with a counselor;
- Access whatever behavioral, medical and advocacy supports you can while under the school district's responsibilities;
- Begin your estate planning now, no matter how young or old your child is, so that you can begin to plan for where your son or daughter will live; and where appropriate bring family members into that process;
- At least 12 months to 18 months ahead of the time that your adult child is going to leave the cocoon of the school, call for a meeting with not only the school officials, but also any state agency officials who may be supporting your son or daughter after 21 years;
- As a part of that process, consider a Person-Centered-Planning review at least a year before exiting the school. This consists of what your adult child wants to do for work or for volunteering, where he or she wants to live, who will be a support on a daily basis, what community experiences will support community integration, how your adult child reacts when unhappy, angry, upset, what is considered a good day, a good week, a good weekend. Consider what your adult child likes to do for fun, what are the self-help skills that are still in need of support, what are the social and personal arrangements that work and how do a variety of people "view" the adult with ASD.
- Consider a Vocational Assessment to help to determine a direction, not only while in school but also once the adult child with ASD steps into the post-secondary world;
- Uncover the unexpected skills and talents of your child as early as possi-

ble, and build on those through school and subsequently into adulthood;

- Considering the long term goal for your adult/child with ASD, and that of the adult/child to live a safe, happy and meaningful life, whether it is at home, independently in an apartment, in a group home or semi-independently in a supported apartment; and how you can focus on reaching that mile marker.
- Network, network, network with other families; they are your allies and sources of information to unlocking the vast array of information that will help you and your adult child with ASD;
- Consider all the alternatives for living semi-independently or supported within your community or your state and how you can make that happen.

Once the elements are in place, the most difficult and challenging road to navigate is determining where your adult child will live. The living options include: at home with parents and/or another sibling; a group home, which may include people not on the autism spectrum and may be miles from where the immediate family lives; an independent living apartment, which may provide weekly visits from a counselor and/or support staff member; or a very unique set-

ting that is under construction in Warren, NJ. This facility, Mt. Bethel Village, is a supported apartment complex with professional staff and direct care staff 24 hours a day, seven days a week. This professionally staffed complex will offer on-site activities and supports including: art, music, library, exercise classes, a computer room, video-game room, social groups, transportation, behavioral intervention support, medical oversight for medications, and transportation to outside jobs and recreational experiences.

The first of its kind on the east coast, Mt. Bethel Village is an alternative to traditional housing for adults on the autism spectrum and will open in October 2012. Many of its design features are based on recommendations made in the 2009 report *Opening Doors* by The Urban Land Institute (ULI), the Southwest Autism Research & Resource Center (SARRC) and the Arizona Board of Regents for and on behalf of Arizona State University. Under the direction of highly trained staff, adults will be grouped in neighborhoods based on their unique needs, age, and their cognitive capabilities.

Families will need to consider what the best residential option will be, as their adult child is expected to live way beyond the years of the parents. In conclusion, the road to adulthood will take many twists and turns, will be bumpy and confusing, but it is a road that must be traveled. By planning early, the individual's future will be secure and supported as they age into adulthood.

**Dedicated from page 10**

Rather than give up on his dream, his teachers identified a less strenuous vet tech program at a local vocational-technical school and prepared him to enter it. After completing that program, he entered his local community college and took additional academic coursework. With a record of success and experience handling college coursework, Henry was then admitted to the originally desired, competitive vet tech program, where he has been highly successful and received awards for his performance. The transition program staff's knowledge of the reputations, entry requirements and demands of the various programs made it possible for Henry to find a path to achieving his dream.

In another case, "Emily" hoped to receive a degree in childcare in order to work in a childcare center. She applied to her local vocational-technical school but her application was denied. The teachers at her transition center were able to successfully advocate for her admission by arranging a meeting with educators at the school for her, at which she was able to allay the school's concerns about her ability to meet the requirements. She completed the program successfully and has since transferred to a 2-year college, from which she plans to eventually transfer to a 4-year college. Had she and her family accepted the original "no" decision from the vocational-technical school, Emily's future would look quite different.

**A Network of Support**

In advising students, transition educators

often have valuable information to share from their contacts at local community colleges and through experiences shared by former and current students. This can supplement and expand beyond the advising services offered by the colleges themselves. For example, educators at a strong transition program may know from experience that it is best if students begin college coursework in the fall rather than the summer semester, since the intensity of the shorter summer courses creates a more difficult adjustment for transitioning students.

**An Emphasis on Self-Advocacy**

One of the goals of any strong transition program should be helping students develop the self-advocacy skills they will need throughout their lives. Post secondary education and vocational training offer many opportunities to practice self-advocacy. For example, in a community college setting, "class participation" requirements can pose a problem for students with autism, who may find it difficult to express themselves in front of a group. A transition program can advise students on self-advocacy strategies to proactively address this issue. One strategy would be for the student to write a letter to the professor at the beginning of the course asking if he/she can turn in written notes or responses to fulfill the participation requirement. Often, once a student has made the professor aware of the student's challenges, the professor will make an effort to elicit comments and provide encouragement and support in class discussions. Writing letters to professors which explain challenges or differ-

ences and offer alternative solutions is a powerful strategy for managing issues before they arise.

**Addressing the Needs of  
"The Whole Person"**

Our job as educators of students with ASD is to prepare our students for the future, which encompasses so much more than academics. For example, some students may have poor hygiene or dress messily, which may be incompatible with being hired or holding a job. A program addresses important unwritten work skills like appropriate behavior in the workplace and important details like clothing choice, hygiene, and hair style. Looking clean, neat, and appropriate to the situation is a crucial skill for school or in the workplace.

In addition, social support and contact with peers is important and motivating to many students. The existence of a peer cohort gives students social support, familiar faces, and "strength in numbers." At many transition centers, there are opportunities for socialization, recreation and friendship including holiday parties, dances and casual recreational opportunities. Skills such as developing friendships, self-control and regulation, communication, problem solving, and developing interests and hobbies will enrich their lives as adults, and since students do not intuitively pick up these skills, they must be taught.

**Summary**

Strong transition programs should help a student and his or her family set realistic

goals, figure out how best to achieve them, provide support and self-advocacy training along the way, and address the student's social, emotional, and recreational needs. Adult agencies are for the most part underfunded, overwhelmed, and do not offer the support that has typically been offered to students while in school. This means that taking advantage of the time in school during the 18-21 period is absolutely necessary to a successful transition. Programs offered by schools that meet the tenets described here are usually far superior to the types of programs that can be accessed as an adult, and for many families the cost of well-developed post-21 programs is prohibitive. The 18-21 period is a critical time for shaping a student's future, and a strong transition program can be a powerful ally in that process.

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*The Vanguard Transition Center ([www.vanguardschool-pa.org/vtc](http://www.vanguardschool-pa.org/vtc)), a program of Valley Forge Educational Services, offers opportunities for post-secondary education, career development, and social and life skills development to adults ages 18-21 who have been diagnosed with autism spectrum disorders, mild emotional disturbance, and/or neurological impairments. Students receive continuing education, counseling, self-advocacy training, therapies, and career experience.*

**Advice from page 18****Personal Hygiene**

In high school it's very important to take care of yourself. That means brushing your teeth, washing your face, taking a shower every day, wearing clean clothes, changing out of your gym clothes, using deodorant, etc. Have a routine. Lay out your clothes the night before so you're not rushing in the morning trying to get ready. If you often forget to brush your teeth, maybe brush your teeth in the shower (it sounds weird, but if it works for you, you can get two things done at the same time). If you have clothes lying around on your bedroom floor, don't use your nose as your best judgment. Throw them in the laundry! You'll feel clean and people will be more likely to talk to you.

**Clubs/Extracurricular Activities**

After school activities is your place to reach out and meet new people. You'll be able to connect with your classmates that have similar interests to you. I'm sure they'll be welcoming, too. Find out what clubs your school has and when they meet. Try a variety of activities and see which one(s) work for you. Maybe sports? Key club? Newspaper? There are

so many, but pick one or two you want to keep up with. Keep it simple and don't overload your schedule. If you have no idea which club or activity you want to try, ask a classmate about which ones appeal to them. Suggest attending a club meeting with them. If you're not ready for that yet, don't worry about it. Start small by asking someone you know. Do you have a sibling in the school? A cousin? A teacher you like? Ask them about extracurricular activities and you'll be on your way.

**Essays**

(groaning) "Do I really have to write another essay on *To Kill a Mockingbird*?" Don't look at it that way! With every new task, you have to approach the assignment differently. Yes, you should still brainstorm and outline and draft and edit, but you should change your mentality. Have a positive outlook and make it interesting for yourself. Think outside the box. Use your voice in your writing, not one of a Shakespearean linguist (unless that's really how you write). If you're asked to support or refute a position, try refuting it. Write about what you believe in, not what your teacher does or what you think they'd like to read. Write about what you know and relate personal experiences to the prompt. Dare to incorporate humor.

Get out what you want to say and worry about how to say it later. Have someone help you edit. If you're happy with your essay, that's great. If you're not, fix it so you are. See, I didn't think this at first, but believe me when I say this it's possible to have fun writing an essay. As long as it's not a DBQ (Document Based Question). Those are the worst.

Now I know I couldn't tell you everything about high school in this article (trust me, I wish I could!), but a lot of it is stuff you learn along the way. You figure out a lot of things in high school, whether it be about yourself, your relationship with others, who your real friends are, or how much you despise macroeconomics. I ask you to stay true to yourself and find what you enjoy and who you can spend time with. If you do the best you can and realize all that you're capable of in these four years, you will excel in high school and that success will carry you into adulthood.

I wish you all the best!

*NOTE: For information on transitioning from high school and the Summary of Performance (SOP) Student Exit Summary requirements, go to our website and click on: [www.ahany.org/re\\_trans.htm](http://www.ahany.org/re_trans.htm).*

*Grace Barrett-Snyder has been an intern at the AHA offices twice weekly for the 2011-2012 school year through a pro-*

*gram at her high school. The Senior Experience Internship Program is a course that combines 12th grade English and social studies curricula and provides students with the opportunity to explore a variety of career options through out-of-school internships. This internship is a particularly good fit because Grace was diagnosed with Asperger Syndrome in elementary school. Because Grace is so able in so many areas, she is part of the AHA team, helping with our many projects. She writes beautifully, helping with publications and AHA eNews; creating professional and creative artwork as well as having a side business of designing sneakers; created the Save-The-Date postcard for our annual fundraiser; and offered some great suggestions to the committee. She attended our fall conference where she had been a teen panelist and wrote a blog entry. She continues to write excellent blog entries which get great feedback from the public (read them at: <http://ahany.org/blog/>). It has been special to all of us to experience her senior year, her humor, contagious smile and her all around terrificness! We will miss her next year, but she will continue to be part of our team.*

*This article was originally published in the spring 2012 issue of Asperger Syndrome and High Functioning Autism Association's (AHA) publication *On The Spectrum*.*

**Early Intervention from page 5**

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***Mindset from page 12***

development and maintenance of friendships, a difficult task for children with ASD. They can be reinforced by parents, therapists, teachers and other professionals. Briefly, the guideposts are as follows. Please note that in our new book, *Raising Resilient Children with Autism Spectrum Disorders* (McGraw-Hill, 2012), we elaborate and outline these Guideposts as well as provide parents and educators with reasoned and reasonable strategies together with case material to help their children.

**Guidepost 1: Developing strategies to teach and convey empathy.** A basic foundation of any relationship, parent-child, teacher-child, therapist-child or child-child, is empathy. Empathy is the capacity to put one's self inside the shoes of other people and to see the world through their eyes. The struggle for adults to be empathetic, especially toward children with ASD, is paralleled by the difficulties these children have in being empathetic. Empathy involves both perspective taking and the ability to identify and recognize emotion, skills that typically lag in children with ASD. Thus, it is important for parents to model and teach these skills to their children.

**Guidepost 2: Developing strategies to help children with ASD learn to communicate and listen effectively.** Combined with the first strategy we refer to this as empathic communication. Empathic communication has many features. It is not just speaking to another person with clarity. It also involves actively listening to others, understanding and validating what they are attempting to say.

**Guidepost 3: Accepting our children for who they are and conveying unconditional love in the context of setting realistic expectations.** To truly nurture a social resilient mindset requires that we love our children unconditionally and help them feel appreciated. To accomplish this we must learn to accept children for who they are, not necessarily what we hope or want them to be.

**Guidepost 4: Nurturing islands of competence or areas of strength in every child.**

While it crucial to address problems, we have come to recognize that to place the emphasis on analyzing pathology and fixing deficits limits our ability to assist children with ASD and their parents lead more satisfying, resilient lives. The metaphor of islands of competence is the embodiment of a strength-based approach. To apply the essence of this metaphor in our clinical and parental practices, we ask parents to look within themselves as well as within their children to identify such islands, to reinforce and nurture them.

**Guidepost 5: Helping children with ASD learn from rather than feel defeated by mistakes.** There is a significant difference in the ways in which resilient children view mistakes compared with children who do not possess a social resilient mindset. Resilient youngsters perceive setbacks as opportunities for learning. In marked contrast, children who lack confidence and hope attribute mistakes to variables that cannot be corrected or modified. In reaction to this pessimistic outlook they are vulnerable to retreating from challenges, experiencing feelings of inadequacy and/or projecting blame on others for their problems. It is imperative that children with ASD learn to develop a healthy outlook about mistakes from an early age. They must learn that mistakes are both expected and accepted and are important experiences for learning.

**Guidepost 6: Teaching children how to solve problems and make sound decisions, particularly in their relationships with others.** The attitude of resilient youngsters is that mistakes serve as catalysts for problem solving. Such youngsters believe they have control over what transpires in their lives rather than being victims of events. The process of solving problems includes identifying and acknowledging those problems, articulating short and long-term goals, considering several possible options for dealing with each problem and reaching those goals as well as selecting and applying options that appear to have the greatest probability for success. Children then need to learn how to assess their progress and learn from the outcome if changes have to be made to the goals or the strategies used. Very clearly,

children on the ASD spectrum struggle with problem solving. They lack many of the prerequisite skills required to engage in this process. Though teaching problem-solving skills to children with ASD may at times feel like a Herculean task, it represents one of the most important responsibilities we have as caregivers and educators to help children with ASD develop a social resilient mindset.

**Guidepost 7: Developing strategies to discipline in ways that promote self-discipline and a sense of self-worth.** One of the main responsibilities of parents and educators is to model and teach discipline. The word discipline relates to the word disciple and is best understood as a teaching process. Additionally, an often under-identified goal of discipline is to nurture self-discipline and self-control. Self-discipline implies that a child possesses an internalized set of rules so that even if a parent or other adult is not present the child will act in a thoughtful, reflective manner. Self-discipline may be understood as a significant component of a social resilient mindset in which a sense of responsibility for one's behavior flourishes.

**Guidepost 8: Helping children with ASD develop responsibility, compassion, and a social conscience.** A frequently asked question from parents of children with ASD concerns how to teach their children to be more caring and responsible. We have asserted that there appears to be an inborn need to help others (Brooks and Goldstein, 2001). Observe young children, even those on the ASD spectrum; they take great pleasure in helping as evidenced by their smiles when we compliment and appreciate their contributions. Given the lifelong influence of contributory activities, having children help others is a strategy we consistently recommend to parents and teachers of children with ASD.

Parents of children with ASD as well as therapists, teachers, and other professionals are in a powerful position to have a significant impact on the present and future lives of these children. When adults provide this kind of nurturance, they assume the vital role of what Segal (1988)

called a "charismatic adult," a person from whom children "gather strength."

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

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

**For more information, visit our website [www.FAAHFA.com](http://www.FAAHFA.com) or contact the facilitators:**  
**Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com**

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

Focused on: Employment & Vocational Issues, College Coaching & Supports, Socialization Self-Advocacy, Dating, and Relationships

**For further information contact the facilitators:**

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

**Upcoming Meeting Dates: 2012 - 4/22, 5/20, 6/10, 9/23, 10/28, 11/18, 12/16    2013 - 1/27, 2/24, 3/17, 4/28, 5/19, 6/9**

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

**Taffi from page 25**

the concept of context and the idea that what you hear on the back of the bus should stay on the back of the bus. But then he started using the expletives at school and when he was frustrated. One week during religion class, the teachers turned the lights out unexpectedly to show a movie and Jack went haywire. When they turned the lights back on they found he'd written "This is so stupid" on the wall in crayon. That same week we were visiting my in-laws for Sunday dinner and after a long winter afternoon cooped up inside, Jack sauntered up to his college-age cousin Jenny and blurted "b&\*%\$." Although he didn't say it aggressively or in a name-calling manner, it was still exceedingly inappropriate. We were mortified.

Oh we chastised him. We took away the Wii, we roared parental messages like, "We don't talk like that in this house!" We made him wash his artwork off the church wall and apologize to Jenny. And still Jack remained unfazed and as determined as ever to pepper his speech with profanities. Stubbing his toe could result in a loud "What the h\*&%!" and he would bray "Shut up!" at something as innocuous as taking a shower. For a child who struggles so much to communicate, these words sure were coming easily. We were really at a loss.

And so, back to turtles. I sat Jack down and explained his turtle project was due and went through the directions for illustrating his little book. I cheerily suggested he create a turtle to write about and he

agreed, titling the story "Taffi the Turtle." In the spirit of working independently, I left him alone in the kitchen to pen his chronicle about Taffi's winter habits. I returned about twenty minutes later to check his progress and discovered he'd finished the book and wandered upstairs to play the Wii. Flipping through the pages nearly turned my hair white. His charming little novella read something like this:

### Taffi the Turtle

By Jack Cariello, age 7

*Page 1: Taffi the Turtle he says a lot of bad words and good words.*

*Page 2: "Is dumb all right for me?" Said Taffi. "Hmmmm." said Taffi's mom.*

*Page 3: "Dam it." said Taffi. "I love you." said Taffi's mom.*

*Page 4: "Can I say bich?" said Taffi. "Hmmmm." said Taffi's mom.*

*Page 5: "What does ass mean?" said Taffi, "Hmmmm.", said Taffi's mom.*

*Page 6: "How about sucker?" said Taffi. "Hmmmm." said Taffi's mom.*

*Page 7: "Oh, shut up" said Taffi's mom. "Hmmmm" said Taffi.*

*Page 8: "OK, do you still love me and my badness?" said Taffi.*

The End

Cute story, huh? And notice, not one single word about Taffi's activity during the winter months!

With a lump of despair in my throat, I read it through a few times before calling Jack downstairs to talk about it. As I expected, he really couldn't explain what his motive was for creating such an unsavory character. He simply shrugged and said, "Taffi is bad sometimes."

I have to admit, there are elements of this little book that I find hysterically funny, and I'm guilty of having described parts of it at more than one cocktail party. (And whenever I recount the book, I always insert a world-weary voice during my part at the end; "Oh, shut up.") Autistic or not, there's just something comical about a kid cracking off curses. But I was also very sad.

I was sad to see that underneath the tale of Taffi lurks Jack's own emotional dilemma about his behavior and unconditional love. He wrote the words for concepts he couldn't verbally articulate, and through this school project demonstrated that he – like most typical kids – is concerned about whether people will love him in spite of his "badness." I worried that I hadn't been able to make him understand that I will always, always love him – no matter what his choices with language or anything else. I love him because beneath that badness is yet another example of his extraordinary, tender struggle to parse the world as he understands it with the world as it really is.

Slowly, Jack has started to alter his

behavior when it comes to bad language, and these days he'll warn us if he's on the edge and about to shout out something naughty. The stomach bug was making its rounds through our house, and he cautioned me, "If I throw up I'm going to say a lot of bad words because I hate when my throat is sick!" A teacher told me she overheard him in the hallway in the throes of a tantrum, and he said, "I'm so angry! I want to say bad words!" What initially began as an antic to make people laugh became a red flag for Jack's distress, and has now blossomed into a way for him to communicate something he feels very, very strongly about.

I decided to give the turtle project a few days of rest. At the end of the week I brought it up to Jack and we both agreed this was not the best material to bring to school. Although he didn't provide me with much more insight as to his original work of art, he didn't protest when I suggested a do-over. Once again I left him alone to work and within a few minutes he presented me with a book about Taffi asking his mother to go sledding and drink hot chocolate. I consider that a success. (Still nothing about how turtles survive during the winter. How the \*#@# do they get by when it snows?)

*Do you have a story of your own to share or want to comment on this article? Email me at carrie@dovetaildental. Carrie Cariello lives in New Hampshire with her husband and five children.*

**Village from page 27**

"I don't have to have that worry anymore...as long as he does his job; he'll have a home at Walgreen."

The reality is that autism does not fit into a neat package. I don't know that a person with autism will always "do his or her job." However, it is the commitment and understanding that Randy Lewis has

pioneered that will be a catalyst for change in the work force.

I was enthused by this stunning concept; an auspicious goal, an exemplar for the future. The future is now. Nevertheless, it is four years later and, given the turbulent nature of the economy, our children face further challenges. However, Randy Lewis' model is the quintessential village and role model. Advancing

Futures for Adults with Autism talks about our children being productive members of society. They need respect, coupled with patience and understanding.

It was announced last year that, "The U.S. Department of Labor is proposing a new rule that would require federal contractors and subcontractors to set a hiring goal of having 7 percent of their workforces be people with disabilities, among other re-

quirements" ([www.dol.gov/opa/media/press/ofccp/OFCCP20111614.htm](http://www.dol.gov/opa/media/press/ofccp/OFCCP20111614.htm)).

The village starts here.

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**Hopelessness from page 26**

services are expensive, are deemed experimental, or are not covered by insurance. Some participants have enrolled their adolescent sons and daughters in continuing services are not satisfied, but are accessing these services just for the sake of maintaining a structured schedule for their children. Participants requested that professionals be better trained to ensure service efficacy.

These findings are explained in part by social capital theory. Social capital is the form of social, personal, financial, and professional resources created by people to ensure help when in need. Based on the experiences they have had, parents develop their identity, enhance their role of being a primary decision maker for their child, and develop optimism and hopefulness as they see their child growing and learning new skills at school. Parents start to expect that these skills will help their child progress into future areas such as vocational training, a community college for further studies, and a better life in the larger social community with family and friends who provide care and encouragement. As for professional services, parents strongly believe that they will be available and remain supportive after they reach

adulthood, and that they are entitled to this professional care. Interestingly, caregivers develop their coping strategies based on the associated service structures, and as a result isolate themselves from traditional support systems including family, friends and even spouses.

Caregivers do not identify their isolation until the associated service structure disappears and they find themselves both socially and personally isolated. The reality starts to occur when, by policy mandate, parents are told by their child's school that they need to have a transition plan, as services will change after their children age out of school. For many others, the collapse of the school structure hits harder when they realize that post-high school professionals are not obligated to help and such services are not mandated. The social capital that the parents had invested in and had while their child was enrolled in school, their established coping strategy, which counted well while their child was in school, as parents see it, turns into an illusion. The social investment that parents had made of their time, finances, and emotions in building resources and helpful connections are lost immediately after the adolescent with ASD graduates from high

school. Parents are left in a state of social bankruptcy that is losing their social capital. The participants shared their concerns of everyday life which included: fear about the safety of their children and reluctance about asking others to care for the adult with ASD once the parents were gone. As social capital resources dwindle, it is interesting and disappointing to note that the experience that had initially lead to the development of hopefulness takes a sharp turn pointing towards hopelessness.

When the school support structure collapses, parents confront problems associated with inadequate services. When they have to compromise with what they get as a replacement, they get frustrated and feel guilty that they are not doing enough for their adolescent child. To these parents, it would seem that awareness about ASD has become meaningless as it cannot be appropriately used. It is hard for them to identify new social and professional supports but is common to identify social and professional barriers. The resulting chaos is similar to the initial confusion parents had encountered when their child was displaying unusual behavior and a diagnosis had not been made. The difference being, at that time the individual was a child and the parents were relieved to get a

diagnosis since it provided direction for action. Now the diagnosis is still there but the child has become an adolescent with increasingly complex behaviors and associated problems. Caregivers expressed feelings that they are stuck in time and are able to visualize the virtual dead end in their lives as their autistic children fail to carry their legacy to the future.

**Summary**

With more serious challenges for parents and caregivers of young adults with ASD, these parents need to develop a new decision making capability. The transition challenge leaves all parents with a serious question: "What is the future of my child when I am no longer around?" It was difficult to see parents cry and express concerns about the future. This study demonstrated the unspoken psycho-social and emotional involvements that parents face.

The study identifies how parents invest their social capital to ensure a better and productive future of their child only to lose it as their child reaches adolescence. The hopefulness that nurtured parents from professionals and mandated services over the school years; it is now replaced by hopelessness.

**Career from page 22**

Remember that the goal of all this is to find a suitable work environment. Finding that good fit for people on the spectrum can be very difficult. We may be qualified, but that doesn't mean it will be a good fit. We need to maximize the probability of workplace success and minimize the possibility of failure.

Because autism is neurological, rather than physical or even psychological, it's not a cookie cutter diagnosis. It affects everyone differently, in different areas and to different degrees. Self-assessment means finding a balance between knowing about your limitations, learning what to do about them, and not letting them run you into the ground. Aptitude tests can help you recognize your strengths and your areas of weakness as well as the degree of impairments in those areas. It's imperative that the individual finds a vocation that suits his or her interests and personality style. It is best to avoid jobs that emphasize your weaknesses and find jobs that focus on your strengths.

In order to achieve success in employ-

ment, it's crucial to have a good grasp of individual strengths and weaknesses. This knowledge is vital to choosing an appropriate career direction, and is the first step in developing strategies for success in the workplace and knowing what accommodations will facilitate success. A thorough psycho-vocational assessment is an important step towards self-awareness.

The autistic stereotype describes common characteristics, but not all autistic adults exhibit the same attributes. Not all have problems with social interaction to the same extent. Not all have the same degree of executive function impairment. Not all have the same degree of clumsiness. Therefore, it's important to know yourself. One tool can be a personal profile, where you list strengths and weaknesses in four areas: cognitive, physical, emotional and social.

Most of us have some idea of what we're good at and not so good at. There are some things that we just can never do, no matter how hard we work at them. I'll probably never be a ballerina or a professional athlete. I'm too uncoordinated and slow. But that's OK. The important thing

to remember is that we are all individuals with a unique set of interests, skills, talents, abilities, and challenges. So the most important thing you can do is to dig deep for information about yourself before going out into the world of work.

ASDs make some things very hard or even impossible. For example, I would never consider becoming a neurosurgeon, a professional ball player, or even a hairdresser (just ask the remains of my Barbie dolls). If a goal is important enough, with time, patience, compensations, and remedial help, it can be achieved. We can learn things that are difficult for us, although they often take us much longer – sometimes ten times as long. So we must save that energy for things that really matter and forget about the rest. The effort may not be worth the output. It can be a tough decision, because it feels like you're giving up.

The problem faced by many on the spectrum is that our weaknesses are more pervasive than our strengths. Writing is my strength. But not every job allows me to use this skill. The fact that I have social problems on the job, however, crosses all career fields. I can try to find jobs where

I'm more likely to work independently. Yet within every company there are organizational politics to navigate. The same is true when I think and work slower than others. I can avoid jobs where my motor slowness and clumsiness will be an issue, like factory labor. But every job requires one to handle some objects, such as file folders, making copies, and sending faxes. It all requires handling papers, picking them up, laying them down... And those lost seconds add up to minutes and sometimes hours, until I find I simply can't do the expected amount of work in the allotted time.

Remember, we're not all alike. We all have personalities, interests, and abilities in addition to our disability. It's really important to look at all of those things in choosing a job.

*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. She has spoken to autism and disability groups around North America about these issues.*

**Jobless from page 24**

It can be quite instructive to ask an individual what he envisions himself doing once he is employed. When I ask this question, many say that they don't know. Others reply with inaccurate ideas about job qualifications and their own abilities. Jim wanted a job related to his love of sports. He spent months interviewing for sales positions, the usual entry point for sports business management careers. When we met, it didn't take long to see why he wasn't getting offers. Jim spoke in a monotone and showed almost no facial expression. He initially did not want to accept that he needed to work on his non-verbal communication, and even with that, might not be suited for a job in sales.

Career assessments should be taken with a grain of salt, since they have been developed by and for neurotypical people. I have found an up-to-date neuropsychological evaluation to be more useful than knowing a client's personality type. Understanding cognitive abilities in areas such as attention, memory, and visual-spatial processing can steer individuals toward occupations that emphasize areas

of strength, and away from those that emphasize weaknesses. Despite her intellect, Suzanne lost a customer service job because she could not simultaneously listen to customers and type their comments into a database.

The job search itself can be fraught with confusion, particularly when the focus is on the wrong details. Laura developed a mathematical formula to determine whether she was qualified to be a technical documentation writer. The formula was based on statistics about the average number of resumes that must be sent to get an interview, and the average number of interviews it takes to get a job offer. Laura concluded that if she sent a certain number of resumes and did not get an interview, it would mean that she was not qualified.

Literal-mindedness can result in missed opportunities. Adam couldn't seem to find any jobs to apply for, even though he had skills that were in demand. When we reviewed some job openings together, I discovered that he disqualified himself from positions that called for "good people skills" and the "ability to multitask" – pretty much every job! After defining these as relative, not absolute

terms, many more possibilities appeared. In a similar vein, Josh didn't apply for an opening requiring 2 years of experience because he had worked for 19 months.

Interviewing is a complex social event infused with subtlety and nuance. Simply greeting the interviewer involves making eye contact, smiling, shaking hands and delivering a friendly greeting all within the space of a few seconds. There is small talk to make on the way to the interviewer's office; a decision to be made about where to sit. One man, who has a Master's Degree, was confused about why he should be prepared to discuss previous jobs, since they were listed on his resume.

Even interview questions can be ambiguous. Does, "Where do you want to be in 5 years," refer to geography? How honest should one be when discussing weaknesses? Definitely not as candid as these clients who volunteered, "I'm not a morning person;" "my self-confidence is low;" and "I can't make small talk." When an interviewer wanted to know, "Why should I hire you instead of the other candidates?" Bill said, "I don't know how to answer that, because I haven't met the other candidates."

Getting a degree does not guarantee employment. What these individuals need is specific guidance on how to choose realistic jobs or careers, understand the perspective of an employer, communicate their capabilities, and follow through on a plan. Some will need to improve critical skills, such as those related to interpersonal communication, before they are ready to pursue employment. Others need to ease into the workforce with a part-time job (paid or not) in order to learn the job skills needed to develop a career or maintain steady employment, so they do not wind up educated and jobless.

\* Names and identifying details have been changed, and in some cases composites have been used, to protect the privacy of individuals.

*Barbara Bissonnette is the Principal of Forward Motion Coaching ([www.ForwardMotion.info](http://www.ForwardMotion.info)) and author of the Asperger's Syndrome Workplace Survival Guide. The College to Career: Asperger's Syndrome Employment Intensive is an 8-week program she developed to guide individuals through every step of the job search process.*

**Leaving School from page 29**

Access to these services is quite different than accessing education services, which are mandated by law. Services for adults with developmental disabilities are not entitlements. They must be requested and pursued by the individual and their advocates.

Families should not assume that if their child has been in special education they will automatically be determined to be eligible for adult services. There are very specific documentation requirements and an enrollment procedure that must be followed to be able to access services funded through the Office for People with Developmental Disabilities (OPWDD), which contracts with New York's vast network of non-profit providers.

Every county in NY State currently has a local branch of OPWDD called a DDSO (Developmental Disabilities Service Of-

fice). DDSO's have lists of agencies that provide services in their county. The *New York City Resources for Children with Special Needs* ([www.resourcesnyc.org](http://www.resourcesnyc.org)) is also an excellent place to learn about agencies and services.

The first thing the parent of a student close to graduating needs to do is find an agency that provides Medicaid Service Coordination, and work with that agency to apply for that service. The DDSO or non-profit providers can make referrals to families for obtaining the right type of evaluations needed to apply for eligibility, which often are not available from school.

Using family support services, such as respite, a social skills program, or parent training from an agency prior to graduation is an excellent introduction to services in the adult service delivery system while "John or Jane" is still a minor.

It happens that New York State's service delivery system is on the cusp of some major changes. The system will, however, continue to be largely funded by Medicaid. Individuals reaching the age of majority will not have their parent's income counted toward eligibility, and should be enrolled in Medicaid as soon as they turn 18 if they have not been eligible prior due to family resources. Information about system changes, which will come about due to New York's application to the 1115 Waiver, is available at OPWDD's website [www.opwdd.ny.gov](http://www.opwdd.ny.gov).

Parent-to-Parent of New York State is another organization that can be contacted for assistance with the transition process. It can be overwhelming to navigate the adult service system and decide which agencies to contact, all while adjusting to your child leaving school – and childhood – behind. Information about Parent-to-Parent can be obtained from their web site

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

Early adulthood marks a major transition; a significant milestone that underscores the lifelong nature of developmental disability. Differences between affected individuals and non-disabled peers may have become increasingly evident, and some goals may need to be adjusted. Adulthood may also bring unexpected maturity, improvements in adapting to environmental expectations, and most importantly, ongoing skill development. Today's adult service system is focused on supporting continued personal growth, respecting individual rights and preferences, and the rewards of contributing toward enriching each person's quality of life.

*For more information, contact the Vice President of Individual and Family Support Services at HeartShare, Laurie Yankowitz, at (718) 422-3271.*

**School District from page 20**

- What living supports and services, if any, will your child require?
- What social supports will your child require to effectively integrate into the community? What recreation and leisure options are appropriate for your child?
- What income support opportunities are available for your child?
- How will your child's medical needs be cared for?
- How will your child be able to self-advocate and seek help when needed?
- Will your child secure a driver's license? What travel training, if any, does your child need in order to effectively navigate the public transportation system?
- Does your child know how to appropriately utilize the world wide

**Guardianships from page 24**

It is also extremely important to inform your relatives about the existence of this special needs trust. Grandparents and other relatives may wish to provide for your child through their estate plans. If they leave money outright to your child, the same issue with benefits eligibility can arise. Instead, these other parties can make lifetime gifts or leave inheritances directly to your child's trust in order to make sure

web? Have you had discussions regarding the hidden dangers of web-browsing?

- Does your child need information regarding romantic and intimate relationships?

**Tips for Parents Preparing for the Transition IEP Meeting**

If you find that your child is facing this critical transition period, consider the following tips:

- Advise your district, in writing, that you are interested in discussing transition at the next meeting;
- Take note of your child's work product, daily living skills, behaviors (if any), social abilities, goals and desires;
- If feasible, discuss your child's disability with your child and provide guidance on how your child can be a self-advocate and ask for what he or she needs;

• Discuss transition services with your child's teachers, therapists and providers;

- Familiarize yourself with agencies and organizations that provide transition and post-secondary services to determine what information and resources are available.

**Conclusion**

The goal of transition planning is to collaborate with your school district to develop an individualized post-education plan. Creating an individually tailored transition plan for your child is not a simple task. Due to the fact that post-school services are not mandated by federal law, it can be difficult to timely secure post-school services and programs as many agencies have long waiting lists. It is essential to thoroughly research available agencies and services that might be able to provide your child with post-secondary services. Remember, you are always your child's best advocate. As a transition team member, you must remain open-minded

and patient on the journey to creating a plan that will enable your child to live as independently and happily as possible.

*Maria C. McGinley, MST, JD (New York Law School, '10) is an Associate at Mayerson & Associates, a New York law firm dedicated to representing children and adolescents on the autism spectrum, and assisting families in accessing the education and related services necessary and appropriate for students. Prior to practicing at Mayerson & Associates, Ms. McGinley taught students with autism spectrum disorders when she was a special education teacher for the New York City Department of Education.*

**Footnotes**

1. See 20 U.S.C. § 1401 and 34 CFR §300.43(a).

2. 20 U.S.C. 1414(d)(1)(A)(i)(VIII); 34 C.F.R. 300.320(b).

3. 34 CFR 300.321(a) and (b)(1); 20 U.S.C. 1414(d)(1)(B).

to ensure the well-being of your child.

*Susan M. Green is an attorney with Begley Law Group, P.C. in Moorestown, New Jersey. Begley Law Group, P.C. specializes in planning for disabled individuals and families. The firm's services include, but are not limited to, estate planning, special needs trusts, and guardianship proceedings. To contact Susan M. Green, please call 856-235-8501 or visit the firm's website at [www.begleylawgroup.com](http://www.begleylawgroup.com).*

\*Note: Pages are not flavored. That was, as Tina Fey would call it, a joke-lie.

*David Finch married his wife, Kristen, in 2003, and five years later he was diagnosed with Asperger syndrome. David's essays have been published in The New York Times, Huffington Post, Slate, and Psychology Today, and he is a blogger for Psychology Today. His debut memoir, The Journal of Best Practices (Scribner, January 2012), is now a New York Times bestseller. David also lectures on the topics of relationships and living successfully with Asperger's. Please find more information about David on Facebook at [www.facebook.com/DavidFinchWriter](http://www.facebook.com/DavidFinchWriter), and on his website: [www.davidfinchwriter.com](http://www.davidfinchwriter.com).*

**Limit from page 21**

to practice) every day, with help from Kristen, my window to the neurotypical world: "Don't change the radio station when she's singing along," "Be present in family moments," and "Go with the flow," just to name a few. Some of my Best Practices helped me to bridge the neurological gap that had separated Kristen and me. But many of my Best Practices—ones like, "Better to fold and put away the laundry than to take only what you need from the dryer"—had nothing to do with Asperger's. Many of them were simply things that any married couple needs to work on at one point or another.

Renewing my commitment to self-improvement every morning was not easy. But it was very clear to me that if I wanted achieve real transformation in my marriage and in my life, this was the only way it was going to happen. And so I did.

Kristen had to adapt as well. She had to learn how to engage with me in constructive ways. Most wives, for example, don't need to coach their husbands on how to communicate or to listen effectively. (Then again, perhaps they do.) She learned how to pick her battles and stay patient whenever I was doing something outrageously annoying, such as using all the hot water for my daily required morning shower, sixty minutes in duration. She

learned new methods for socialization, such as explaining to me exactly what an evening with friends would look like before they came over, so that I wouldn't feel anxious.

Together, with our commitment to each other and to these best practices, we are making it work. I'm happy to say that our neurologically-mixed marriage is now stronger than it ever could have been without these tests, and best of all, I have my best friend back.

So, I'd say the prognosis can be great. Living a fulfilling life with Asperger's (or otherwise)—living the life you want to live—is without question a possibility. The path you take to get there is entirely up to you.

**Social Skills from page 19**

nothing like a typical day in any school I know," says Nancy O'Reilly, Program Supervisor, who has a background in special education (as well as, rehabilitation counseling). A typical day can include acting games, role playing, art, game shows, in-vivo social skills practice during lunch and monthly community outings, team building activities, and didactic instruction with a sprinkling of stress reduction strategies (e.g., deep breathing, meditation, yoga) throughout the day to minimize anxiety in the moment and help the participants develop coping skills to use outside of group.

Joe was hungry for these social skills, and he wanted to learn, but one reason

he participated so enthusiastically is likely because he felt safe and comfortable doing so.

The people in the program not only struggle with navigating the social world, but they also often face bullying, criticism, and rejection whenever they even attempt to.

After repeatedly getting negative feedback it makes sense that, like Joe, people with Asperger's retreat and are hesitant to try new things (especially in a group setting).

Much time and energy is spent on creating a safe and trusting environment for participants to give and receive feedback from one another. As a result, they are able to try out different behaviors and hear what their peers and the staff have to say without feeling judged or hurt. And

they may even apply the feedback.

Affording participants the opportunity to choose when and if they want to use the skills presented also seems to work. Or, as I like to remind families, we meet each individual wherever they are in their life, presenting various skills as tools to be used when, and if, he or she so chooses.

Showing how things are related also helps participants realize how a certain social skill might be helpful when it comes to making friends or getting and keeping a job.

Joe, who attended the program two years ago, still enjoys connecting with his fellow alumni at a monthly dinner at the Wayne Hills Diner, near William Paterson University. He's always the first to arrive and the last to leave.

He longed for information that could

help him in his life. Having never been diagnosed with Asperger's until he was an adult, Joe didn't have the benefit of services and supports that children on the spectrum have today. The program helped open Joe's eyes to a new world.

Today, Joe has returned to school and is finishing up his master's degree in computer sciences at New Jersey Institute of Technology. NIPD/NJ's program helped him realize that he has value and can do more with his life; And he has formed friendships along the way.

*Alex Gitter is the Lead Facilitator at the National Institute for People with Disabilities on New Jersey's Asperger's Skill Building Network. For more information about the program, contact Alex at 973-720-3762 or [Alexandra.Gitter@yai.org](mailto:Alexandra.Gitter@yai.org).*

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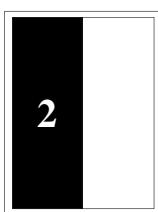
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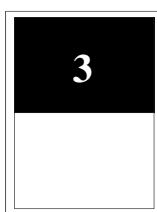
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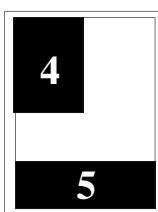
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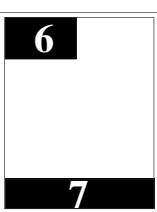
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