Transitioning into Adulthood: Navigating the Complex Changes Ahead

By Leo V. Sarkissian, MSW

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.

Planning for a Successful Transition to Independent Housing

By Cynthia R. Haddad, CFP

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.

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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.

This is only one of many reports that reference a growing need 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.

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.

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2012/2013 Theme and Deadline Calendar

**Summer 2012 Issue:**
“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”
**Deadline:** December 5, 2012

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“Supportive Housing for Adults with Autism”
**Deadline:** March 5, 2013

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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 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 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
Early Intervention is Key
Focus Should Be on Transition from the Start

Justin DiScaflani, 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” and 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 in results from 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 professionals 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, 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 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.

Transferring 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
The Road to Adulthood

By Carolann Garafola, MA
Executive Director
Mt. Bethel Village

Transition 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 interagency 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 important, 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 the planning process 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 to 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.

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Asperger Center for Education and Training

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

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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). 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 and Adult Autism Services (DJF Ignition Grant). At this year’s upcoming symposium scheduled for April 25th 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 it 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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Early 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 18th and 21st 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 celebrate 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. He needs to balance his strengths, acknowledge his needs, and find accommodations that will assist him in life. The impact of ASD on his life is a fact but what he does to handle it can make a big difference in the quality of his adult life. At a strong transition program, we can navigate these tensions and individualize transition planning to each student’s needs.

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Jacque Murray, MA, MEd
Director
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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 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; Robinson, 2011; Sicile-Kira, 2012). Symptom relief, while essential, is not the equivalent of changing long-term outcome.

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 others. 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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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 individual, 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 filling, 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 to independent living and meaningful work.

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Tackling the Unemployment Crisis for Adults with Asperger’s

By Michael John Carley
Executive Director
ASTEP

Transitioning 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 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 de-mystification.

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, students long related 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 nods and smiles. 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 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.

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

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

Increased 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 school to adulthood. 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 limitations 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 long related 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, age-appropriate functional daily living functional 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 (VABS), a measure of overall independent life skills functioning, are closely related 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 AS 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 positive reinforcement, 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 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,
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

It 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 talking 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
The 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, 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, rereading 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.

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Joe 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 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 departmental 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.

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 
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. 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:

• 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. 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 post-secondary 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?
When 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 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 marriage, we no longer felt like friends. We presented 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...
Positive Psychology Offers Guideposts for Optimism to Young Adults with ASD

By Valerie L. Gaus, PhD
Licensed Psychologist

As young people on the autism spectrum look ahead towards adulthood, 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 realized by many. The very 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 disorder 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

As 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 how 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 coordination, 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 perseverate, 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

Previous 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 (Abbeduto 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 re-framing 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 the end of entitlement programs (e.g., 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.

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 encourage parents to be proactive in maintaining family relationships.

Brian Freedman, PhD

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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 may 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 government 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

By Barbara Bissonnette, Principal
Forward Motion Coaching

Af
fter earning a Bachelor’s degree in political science, Steven turned his attention toward a career in journalism. Tom has solid writing 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 coworkers. He desperately wanted steady income so that he could have his own apartment. Although Steven 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

Barbara Bissonnette, Principal
Forward Motion Coaching

See Jobless on page 37.
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 dianaoma 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@% s!!” turned my head so fast it’s a wonder I didn’t spend the rest of the week in a 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 muttering, “Damn it!” if you didn’t put Scooby Doo on fast enough. I dreaded taking them in public for fear they would belt out something like, “My a-!, the milkshake machine is broken! I want to speak to your d@% manager.” I’ve heard many a mother and grandmother dispense the well-worn joke, “You teach them to talk, and then spend the rest of your life wishing they would be quiet.” No kidding.

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 bringing 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 definitively 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.

Jack’s drawing of Taffi the Turtle

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 children making decisions that others on the young adult’s team are mini-

For 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.

References


From Hopeful Graduation to Hopelessness

The Transition That Many Parents Face

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

Recent 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 parents 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 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 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 reception of services and the scope of services that 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 program director who has the training and expertise 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 the program begins is 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

see Hopelessness on page 36
Newmark Schools for Autism Spectrum Disorders

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Newark freelance writer Robin H. Morris offers insight into the daily experiences of having a child on the autism spectrum:

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.

One thing I’ve learned is that history might actually be taking its toll on my son. 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 answering by a mother in the interview:

Robin’s Voice
A Resilient Mom’s Commentary on 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 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.

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 Mendoza 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 in supporting individuals in food markets, office settings and delivery positions.

Other agencies are focusing on supporting individuals with skills that are lower 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 cause difficulties 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 of all ages and has leveraged one alternative way of supporting individuals in the community. With their help support their growth and continued integration into the natural communities in which they live and work. It is creative thinking like this along the social and educational placements that may cause difficulties for those with autism.

Across all groups, members were uninterested in more basic material than recognizing that they needed to master these skills. Across all groups, members were uninterested in more basic material than recognizing that they needed to master these skills. Across all groups, members were uninterested in more basic material than recognizing that they needed to master these skills. Across all groups, members were uninterested in more basic material than recognizing that they needed to master these skills.

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 in a way that allows flexibility to incorporate the students’ interests or preferences into the teaching process.

Sexuality from page 17

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 individuals with autism has had results in an increase of the skills that were taught (Banda, Hart, Liu-Gitz, 2010). An additional benefit of using a peer mentoring intervention is that it is more difficult to generalize. Peer mentor 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 to meet the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the 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.

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 individuals with autism has had results in an increase of the skills that were taught (Banda, Hart, Liu-Gitz, 2010). An additional benefit of using a peer mentoring intervention is that it is more difficult to generalize. Peer mentor 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 to meet the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered the material was to role play and take trips to see if the group members had mastered

In the past, the IEP process during their child’s school age years, families can begin to identify with other families who are looking into similar supports and services. Developing a parent network organization can help break the workload of researching available programs. 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 or group home placement. 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 support each other, focusing on keeping each other continuously functioning in the most appropriate ways.

For more information, please visit www.wjcs.com.

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Leaving School Behind - Next Stop, Adulthood

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

T he prospect of adulthood is particularly complex for individuals affected by developmental disabilities, 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, 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.

I assert a trite but I think true summation: nothing worth doing is ever easy! I am privileged to have come to know and to form dedicated relationships and a life of advocacy and promotion for the individual whom I care about. 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 is done with all the skills and care needed 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 thing over and over again; who may have no awareness of danger. On the other hand, they are trained to enable and honor choice-making, respect preferences, and for courage and to promote independence.

As a self-declared professional who cares about them. Like their peers, they must have a history of being eligible for a Developing 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 States for the Education of Children with Disabilities, 2006). The U.S. 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 21st birthday for a CTP, and then, with the recent changes to HEOA the student may be eligible for vocational 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 fundi

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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spectrum. In this manner, individuals, family members and other interested parties can avoid reinventing 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 members 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 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.

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 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.

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, 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

2. The Urban Land Institute, Southwest Autism Research and Resource Center and University of Arizona; www.autismcenter.org/documents/openingdoorsbook/
Worry...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? 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 such, we were 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 the present – utilizing the knowledge of what we’ve learned in the past, not dwell- ing 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.

As difficulties with socialization are at the core of AS, there has been a focused approach to address social issues as ad- vised. 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 socializa- tion opportunities for students in the pro- gram. Based in Social Learning Theory, the primary role of the Peer Mentor is to observe the student’s social behaviors. These may include behaviors as simple as an- swering emails or voice mails, to being on time for appointments, or encouraging the student to participate in other campus activi- ties 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 ca- veat on organized social activities: in my experience I have found that for college students, they may not receive from manualized socialization train- ings have been negated by feelings of hu- manity at being presented information in ways that don’t connect with them or when things received when they were younger. College students often benefit most when they are presented information in more indirect, and mature settings and styles.

As one parent, we have been directly involved in the development of the Adelphi Academy of Letters. Our daughter is 19 years old, a wife, a sister, a friend, an aunt, an employee, etc. A year and a half ago into my life. I’ve known it for some time, 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 adult- hood. For the old me that would be a con- suming 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 differ- ent things happening at school when they’re older, and not pan. 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 hear- ing it from doctors and therapists...now for the learning from 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 nour- ish my relationship with GOD instead of being angry, and it’s so much better. I hope you’ll pray that whoever is reading this; you take my advice and do something for you. Oh yeah, and one more thing...STOP WORRYING!!
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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/networking skills employees based arguably 95% on socialization— that are one of the main reasons our popula- tion slips through the employment cracks; and 3) specific methods for reme- diating some of the issues that may be in the workplace for individuals with AS.

Demyxification

But change, even when it is champi- oned by the D&I and HR departments, is slow. And what is apparent is that compa- nies will likely not commit to hiring people with AS unless they have an opportunity to meet some of them. Call it “kicking the tires” or “testing the waters,” if you will, but companies need to feel confi- dent in their own abilities to make such a relationship work. In short, employers are looking to organizations representing indi- viduals 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. One hundred and 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 compa- nies were then successfully recruited to host, and we had our first session in No- vember 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 an internal way 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 semi- nars are the beginning of building that relationship with these employers to cre- ate the broader awareness and inclusion of individuals with Asperger’s in their diver- sity strategies.

The lessons above are ones that pro- fessionals can learn to modify these strategies 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 of a person with AS mean very little, just as hiring rates alone mean very little. A corporation could have a strong track of hiring under- represented 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.

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Cognitive-Behavior Therapy: Creative Problem-Solving for Adults on the Spectrum

CBT refers to a set of strategies for deal- ing 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 neurotypical patients. This large collection of therapeutic approaches all assume cognitive activity affects emotions and behavior and that peo- ple 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 neurotypical adults, such as major depression and a variety of anxiety disorders (Butler, Chapman, Forman & Beck, 2006). People on the spec- trum 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 ap- proaches 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 neurotypical patient in CBT for a mental health problem, the therapist’s job is to teach the adult with Asperger’s Syn- drome/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 pre- vent symptoms of co-morbid mental health problems, such as anxiety dis- orders and depression

Of the many CBT techniques that are useful for people on the spectrum, prob- lem-solving is one of the better tools. There are 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 can 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 var- iations of the problem-solving steps in the CBT literature, but the general form of the step approach was tailored to meet the needs of adults on the spectrum. When facing an overwhelming situation that, at least ini- tially, seems insurmountable and 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, emo- tional, and sensory/movement differ- ences 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 weight the best against the least feasible.

So how can individuals who are not vocational professionals use this knowl- edge? 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 well-planned support networks.

Secure employment can ease the bur- den 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 em- ployed person is a happier and more con- fident person, making them more attrac- tive 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?

Michael John Carley is the Executive Director of both ASTEP and GRASP. He is also the author of “Asperger’s From the Inside-Out” (Penguin/Perigee), and he has finished a second book, “The Last Memoir of Asperger’s Syndrome.” He was diag- nosed with Asperger’s Syndrome in 2000.

References


A Father’s Experience Accessing Adult Services

By Jeff Stimpson
Journalist

A local advocate called this afflicting me to meet with our well-dressed political to talk about cuts in funding. Everyone swears these are coming downtown 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 politicians 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 much fun for the people who first are to be left out of camp either.

Alex has received services since he was one year old; financial cracks in these 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.

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 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 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 possible, 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, independence in an apartment, by group home or semi-independently in a supported apartment; and how you can focus on reaching that mile marker.

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 coming; 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, “I’m still uneasy on the toilet after hour. I took him out; he wanted to out 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 kids like Alex to a non-descript 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. I decided to wake up with my 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, a 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 re-charge from the drain that is living with Alex as he gets older and bigger. How long, though, before some well-dressed politician 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 overnight through the end of August. Already booked, she said. “What’s Alex’s schedule in February?”

Alex also cramped out of this program last spring by bolting. He ran from the apartment and explored the building. He refused daycare. I was surprised he didn’t run away. 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.jeffjlife.tripod.com/alexetheboy.

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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 and underscoring her ability to aly 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 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 the advice and 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 the summer before their senior semester, since the intensity of the shorter summer courses creates a more difficult adjustment for transitioning students.

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 you do it, you’ll be on your way).

Essay Writing

“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 brain-storm and outline, but now 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 linguistic (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 you don’t believe in. If you’re assigned to write about something that you’d like to read. Write about what you know and relate personal experiences to the prompt. Dare to incorporate humor.

Early Intervention from page 5

Grace Barrett-Snyder has been an intern at the AHA offices twice weekly for the 2011-2012 school year through a program 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 particularly good for students who are 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 programs. She is a helpful writer for 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 a key note speaker. 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.
Mindset from page 12

development and maintenance of friendships, a difficult task for children with ASD. This 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 empathic, especially toward children with ASD, is paralleled by the difficulties these children have in being empathic. 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 learn 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 fear 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 prerequisites 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 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.”

Sam Goldstein, PhD, is an Assistant Clinical Instructor in the University of Utah School of Medicine and Clinical Director of the Neurology, Learning and Behavior Center. Robert Brooks, PhD, is a faculty member of Harvard Medical School. They are co-authors of a dozen books including Raising Resilient Children with Autism Spectrum Disorders (McGraw-Hill, 2012). They can be reached on through their websites: www.sangoldstein.com and www.drroberbrooks.com.

References


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 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


Westchester Arc

The Gleeson-Israel Gateway Center
265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532
Taffi from page 25

I don’t have to worry about that 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 future. I was enthused by this stunning concept; an auspicious goal, an exemplar for the future. The future is now. Nevertheless, it is four years after, 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 talk about the work 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 7 percent of their workforces be people with disabilities, among other requirements” (www.dol.gov/opa/media/ press/ofccp/OFCCP20111614.htm).

The village starts here.

Robin Hausman Morris is a freelance writer and can be reached at Robin.HausmanMorris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/autism-and-parenting-in-national/robin-hausman-morris.
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 qualitatively different but that doesn’t mean we can’t make a good fit. We need to maximize the probability of workplace success and minimize the possibility of failure.

Brain damage 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 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 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. The 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 may be needed. A 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 communication ability. 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.

Getting a degree does not guarantee a job. What these individuals need to do is learn how to change their 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 test the job skills needed to develop a career or maintain steady employment, so they do not wind up educated and jobless.

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 a sports business management career. 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 genuine business managerial care. Many adults with developmental disabilities are not entitledments. 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 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 Office). DDSO’s have lists of agencies that provide services in their county. The New York City Resources for Children with Special Needs (www.resourceny.org) is also a helpful resource.-reader to learn how to use this tool to ease into the workforce with a part-time job (paid or not) in order to test the job skills needed to develop a career or maintain steady employment, so they do not wind up educated and jobless.

Leaving School from page 29

Access to these services is quite different than accessing education services, which have been developed by and for neurological types. I have found an up-to-date neuropsychological evaluation to be more useful than knowing a client’s personality type. I understand that people have 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 writer. She based the formula 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.

Lateral-mindedness can result in lost opportunities, such as a gain of salt to some clients who volunteered, “I’m not a morning person;” “my self-confidence is low;” and “I don’t know how to ask.” When an interviewer wanted to know, “Why should I hire you?” Lily responded, “I have 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 open job that required specific 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. It is harder to learn about people when the topic is work, one 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? How should one describe the ability to multitask? “good people skills” and the “ability to multitask” – pretty much every job! After defining these as relative, not absolute

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 the federal government. The 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 to family resources. Information about system changes, which will come about due to New York’s application to the 1115 Waiver, is available at Office of Easy Enrollein. 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 delivery 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 website www.parenttoparentnys.org.

Early adulthood marks a major transition; a significant milestone that under scores the lifelong nature of development differences between adults with developmental disabilities and their 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 delivery system may have to be focused on maintaining continuity of 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 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;
    - Collaborate with your child to discuss post-school service options.
- Guardianships from page 24
  - It is also extremely important to inform your relative’s 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 your child’s benefits are preserved.
  - If your child has already received certain asset’s outright and trust of this type of trust can be established, a self-settled (or first party) special needs trust. This type of trust must be established by a parent, grandparent, legal guardian, or the court, but it will be funded with your child’s own assets. This type of trust is less advantageous to your child because it must include a Medicaid payback provision. This means that upon your child’s death, the remaining trust assets must be paid to Medicaid. However, such a trust can enhance your child’s quality of life during his or her lifetime much in the same way as the third party special needs trust.
  - It is important to start planning now for your child’s future. Depending on your child’s unique situation, one or more of the techniques discussed in this article may be utilized. It is important to consult with an attorney who has expertise in both special needs and estate planning in order to ensure the well-being of your child.
- 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 the 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.

Social Skills from page 19

- 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 interact with customers. And so, Kristen realized that she was driving a lot of her frustration with me from not knowing how to engage directly with people. And so, we began a training to learn new skills for socialization.
- 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.

Footnotes

2. 20 U.S.C. 1414(d)(1)(IV)(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).

*Note: Pages are not flavored. That was, as Tina Fey would call it, a joke-ster.
### Deadline Calendar & Ad Size Specifications

#### Deadline Date
- Summer 2012 Issue - June 5, 2012
- Fall 2012 Issue - September 5, 2012
- Winter 2013 Issue - December 5, 2012
- Spring 2013 Issue - March 5, 2013

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### Advertise in Autism Spectrum News

- Business Card - 4 issues ($500)
- Eighth Page (1 issue $300 - 4 issues* $900)
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