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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

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## Supporting Adults with Autism

### Family and Professional Partnerships Optimize Successful Transitions to Adulthood

By Todd Harris, PhD,  
Richard Allen, PsyD, BCBA-D, NCSP,  
Lois Trusler, BSW,  
Kate Langston, MEd, BCBA, and  
Amanda Duffy, MEd, BCBA  
Devereux

The Centers for Disease Control noted that from 1994 to 2005, the number of children ages 6–21 years receiving services for autism increased from 22,664 to 193,637 nationally. This explosive increase in the number of children identified with an autism spectrum disorder sounds a warning for the dire need to implement effective transition services that will successfully bridge school-based and adult services. Pennsylvania, alone, projects 73,593 adults living with autism by 2030 (Shea, 2014).

Much of the success of adult programming will be dependent upon the delivery of quality transition programming for adolescents and young adults. Individuals entering adult systems with increased independence in communication, social, community, and living skills will achieve



**A young adult from Devereux works alongside peers on the grounds crew at a local university**

greater overall independence and lifelong success, allowing adult systems to focus on employment-related performance instead of basic skill development.

The key to success in transition programming is a strong parent/professional partnership that empowers parents and guardians with the skills and knowledge to

be lifetime assets and advocates for their family member with autism (McDonnell and Nelson, 2010). Effective parent/professional partnerships that extend beyond the annually required transition IEP meeting and are focused on person-centered futures planning, coordinated team education activities, and shared ownership of teaching critical skills across school, home, and community settings can result in improved adult outcomes and more effective use of adult programming.

#### Person-Centered Futures Planning

The philosophy of person centered futures planning places the individual at the center of all decision making; treats family members as equal partners in the journey; and capitalizes on the individuals' strengths, skills and aspirations while developing a plan for broad community engagement. This is a change from the previous "services led" way of thinking.

Upon completion of the initial futures plan document, teams typically meet

*see Partnerships on page 16*

### The Unique Interpersonal Demands for Women with ASD *Implications for Gender-Specific Supports for Adults*

By Alyssa S. Milot, PhD  
Licensed Psychologist  
Massachusetts General Hospital  
Lurie Center and Aspire

Over the past several years, there has been increased interest in gender differences within autism spectrum disorder (ASD) and how these differences impact initial diagnosis as well as treatment across the lifespan. According to recent research conducted by Kreiser and White (2014), females diagnosed with ASD present with unique characteristics in each aspect of the diagnostic criteria when compared to their male counterparts. For example, regarding social communication, females tend to engage in imaginative and pretend play from a young age. Their speech also contains more vocabulary words related to emotions, compared to traditional diagnostic criteria of ASD often found in males. It

has also been observed that females with ASD tend to have greater awareness and desire for social interaction, propensity to mimic others in social interactions, tendency to camouflage difficulties by developing coping strategies, and develop one or two close friends compared to their male counterparts. Different than the traditional restricted interests in inanimate objects often described within males with ASD, many females with ASD tend to have restricted interests related to people and animals (e.g., celebrities, pets). Additional characteristics found within women with ASD include perfectionist tendencies and disordered eating (Lai et al., 2015).

One explanation for the varied symptoms of males and females within ASD is our gender-specific societal expectations and norms in the US. Beginning in childhood, female play groups, for example, are often more intimate than male play groups and involve greater expectations for conversation skills, empathy, and emotion-focused

language. These expectations can provide females with ASD more opportunities to observe and mimic socially expected interpersonal skills such as turn-taking and reciprocal conversation during their early development (Kreiser & White, 2014).

At the same time, the social intricacies and demands placed on women with ASD may also be greater than those placed on males with ASD across the lifespan in the US. As a key task of adolescence is gender role development, what it means to be a man or a woman, it is no surprise that differences in societal expectations for males and females surge during this time period (Mahalik et al., 2005). For example, the demands for feminine gender norms in dominant U.S. culture include the importance of developing caring relationships with others, being involved in romantic relationships, investment in one's appearance, modesty, sexual fidelity, and responsibility for and enjoyment of domestic chores and childcare (Mahalik et al., 2005). In the gen-

eral female population in the U.S., conformity to feminine norms (e.g., investment in interpersonal relationships) has been associated with mental health outcomes such as depression beginning in adolescence (Barrett & White, 2002) and continuing through adulthood (Broderick & Korteland, 2002). Since females are expected to value, act nicely in, and be engaged in relationships with family, peers, and romantic partners, they may experience pressure to maintain these relationships at costs to themselves (Fiese & Skillman, 2000). These costs include females silencing their own needs and opinions in order to maintain caring relationships with others (Brown & Gilligan, 1992). While their relationships stay successful, this silencing of one's own needs and opinions is linked to greater symptoms of depression (Danielsson, Bengs, Samuelsson, & Johansson, 2011; Tolman et al., 2006). Males are also confronted with

*see Women on page 21*

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#### Fall 2016 Issue:

“The Unique Needs of Girls and Women with Autism”

**Deadline: September 8, 2016**

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#### Spring 2017 Issue:

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# Leaving the Family Home: Opportunities and Obstacles for Adults with Autism

By Desireé Kameka  
Director of Community Education,  
Outreach & Advocacy  
Madison House Autism Foundation

**W**hen we think about the future of individuals on the autism spectrum, it is easy to feel overwhelmed. Who will help them create their weekly schedule? Where will they work? How will they connect with friends? Who will assume the daily support role once parents can no longer provide care?

Developing a Person-Centered Plan (PCP), which is the adult version of an IEP, helps create structure while shaping an individual's future around his or her life goals, support accommodations, and meaningful relationships. Yet, without access to affordable housing in one's community, all of these plans can be thwarted when the only option available is the "next empty bed."

## Support Funding for Adults on the Spectrum

In the past, individuals with autism were institutionalized in order to receive supports. It wasn't until 1980 that the U.S. created a funding mechanism to "waive" the need for institutionalization. The Home and Community-Based waiver



Desireé Kameka

is now the primary public funding source that allows adults with autism to access supports in a home of their choice. These supports vary by state and may include hours of direct support staff assistance, assistive technology, access to a number of therapies, supported employment or day program opportunities, etc.

While waivers are a fundamental step forward, most states have long waiting lists, and eligibility standards can prevent

individuals on the spectrum from qualifying for benefits. Contact your state Developmental Disability Agency to learn about what waivers are available in your state, to check eligibility requirements, and to get on the wait list: <http://www.nasdds.org/state-agencies/>.

## Overview of Current Housing and Support Models

Once an individual has access to a supports, whether through a waiver or private pay, the next step is finding a home. It is important to understand the distinctions between the various housing models:

**Consumer-owned or Controlled:** Any home that an individual owns or leases. Scheduling and choosing service providers is individualized. The individual can easily change providers and select roommates.

**Provider-owned or Controlled:** Typically called a group home, a service provider maintains a setting where multiple individuals with disabilities live. The provider manages the support staff and offers scheduled outings and activities. If an individual decides he or she would like to switch providers, the individual must move.

**Family Host Home (Adult Foster Care):** A neurotypical individual or family invites a person with autism to live in their home

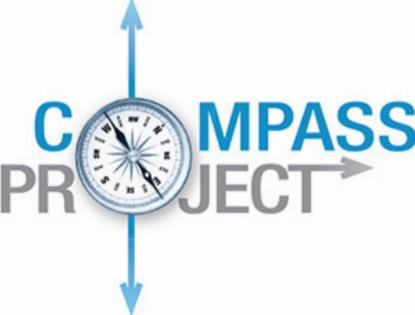
and offers natural supports as part of their family. The state offers a stipend to the family host. If the family decides they can no longer provide these natural supports, the individual must move.

**Shared Living:** An individual on the spectrum chooses to share his or her home with a neurotypical roommate or family. The chosen roommates may (or may not) pay rent and could even receive a stipend as a host family. The roommates, rather than the individual with autism, would have to move if the support relationship changes.

**Campus Setting/Farmstead:** These settings can be either provider-owned/controlled or consumer owned/controlled and are communities within the greater community. Individuals who live there may have pedestrian access to day activities or employment options on the same property as their home. Individuals should have access to their greater community to work, recreate, or volunteer as desired.

With limited access to waiver supports, the National Autism Indicators Report shows that only 19% of young adults on the autism spectrum have ever lived independently after high school (Roux, Shattuck, Rast, Rava, & Anderson, 2015). For

*see Family Home on page 33*



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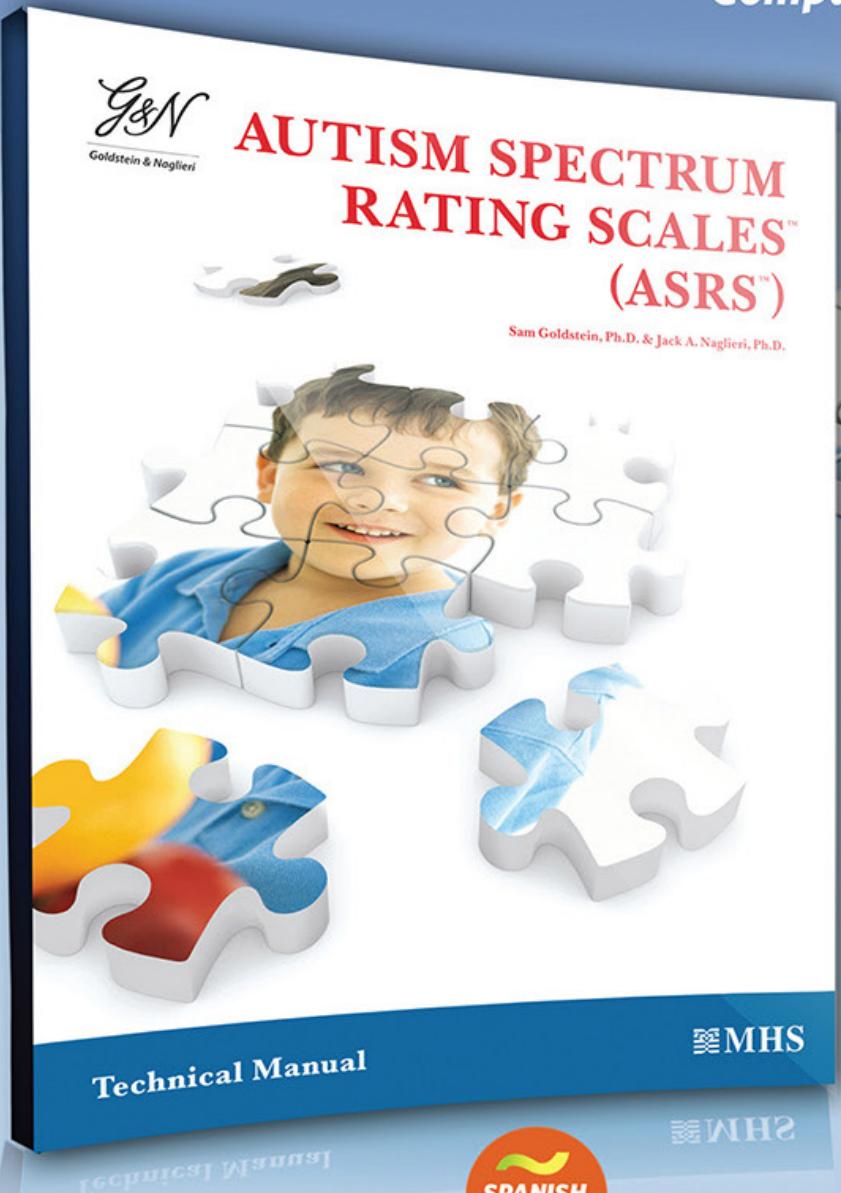
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## How Can College Professors Create an Inclusive Classroom?

### *Minor Accommodations to Support Students with Autism*

By Ryan Therriault, MA  
Lead Academic Coordinator  
The College Internship Program  
Brevard Center

**A**s academic coordinator at the College Internship Program for the past 7 years, my main focus has been to help students with learning differences and Autism Spectrum Disorders build social and Executive Function skills in an academic environment. In addition to directly instructing the students, I use real life teachable moments to lead the students to a better understanding and application of the skills needed for independence. Through my journey working with college students on the spectrum, I have developed an understanding of the many challenges the students face communicating with their classmates and professors.

While many of these communication challenges are certainly rooted in the sometimes paralyzing anxiety our students feel, I have noted that many communication errors can be avoided with some simple adjustments to the classroom environment.

#### Creating an Open Line of Communication

Many students are able to produce work, but they may lack the organizational and



Ryan Therriault, MA

social skills to deliver it to the place where it should go at the time in which it is due. When students are unable to figure out what is implied by submission requirements, they can become anxious and irrational and decide not to ask for help. Ultimately, they may not be able to work through those

emotions to turn in their assignments.

In able to reduce this anxiety, it is important to let the students know that you are available to help them. Just stating your office hours is not enough. At some point in a given semester, my students will need to miss a class, ask a question, or point out an error. I sometimes will have lengthy conversations with my students to convince them that it is not a bother to email a teacher with occasional challenges. Instructors can open a line of communication by requiring students to make contact via email or meet in person at least once in a term in order to demonstrate the steps.

#### Building Structure

In order to build a structure for all students, it is important that they know where and when to submit assignments. A good place to build a structure for students is in a syllabus, providing a calendar with clear due dates. Next, state your submission locations in the classroom and online and keep it consistent. Also, clearly state your classroom expectations on the syllabus and the consequences for unmet expectations at the beginning of the term (e.g., Phone must be on silent. The first time is a warning, the second will result in your dismissal). Whether we like it or not, most of our college age students use electronic devices

for everything. This transition to electronics has served my students well during tutoring appointments when we are trying to plan to complete assignments, but they can't remember what the teacher said and may have misplaced the syllabus. By including an electronic compliment, such as Blackboard, Canvas, Angel, or classroom website to the classroom, the students always have access to a planning system that they cannot lose. In addition to the syllabus, video lectures, notes, power points and assignments can be located online. In addition to anxiety, our students may have trouble with attention and fine motor skills which makes it difficult to take notes in class. Posting them online allows the students to take their time comprehending what they hear and also to use assistive technology to create a multisensory study experience.

Feedback is crucial to further explain expectations so that the student can complete the next assignment correctly. Therefore, I highly recommend that professors post grades and comments regarding assignments promptly. When working on assignments with my students, I help them to translate what is meant by what is said, which is especially helpful if I can see it in writing. Reporting attendance is the final

*see Inclusive on page 20*

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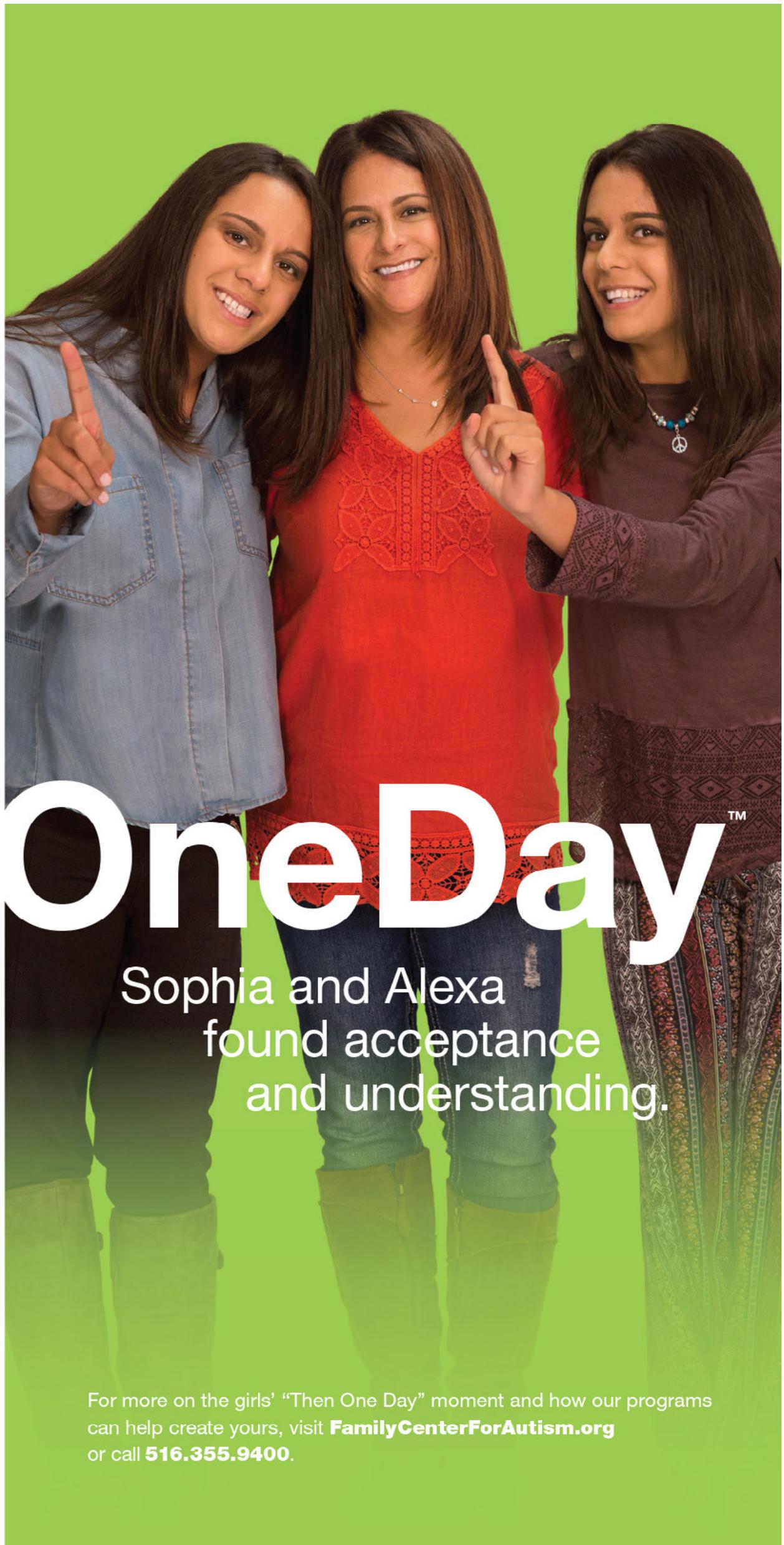
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A photograph of three women standing side-by-side against a bright green background. From left to right: a young woman with long dark hair in a blue denim jacket; a middle-aged woman with long dark hair in an orange patterned top; and a young woman with long dark hair in a brown top. All three are smiling and pointing their index fingers upwards towards the camera.

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# Community Autism Socials at Yale (Project CASY)

## *Developing Group Intervention for Adults Living with Autism*

**By Roger J. Jou, MD, PhD**  
**Assistant Clinical Professor**  
**Yale Child Study Center**

**R**ecommending a “social skills” group is a very common intervention seen in treatment plans of both children and adults living with autism. Despite their popularity, the evidence supporting the effectiveness of social skills groups in children is limited and the situation is more serious in adults living with autism. Nevertheless, many families, schools, and mental health providers remain committed to this intervention presumably due to its potential for and/or perception of effectiveness. Shifting our focus to adults, it might seem reasonable to assume that the group setting is an effective way to improve social interaction skills. In principle, the approach should yield positive results as it uses basic principles of experiential education in which the group leader teaches students through instruction, demonstration and direct experience within the learning environment. Moreover, practically everyone has had the experience being in a group either in the work, school or home settings. From their own experience, parents and professionals may have clear ideas on how groups operate and this can be erroneously gen-



**Roger J. Jou, MD, PhD**

eralized and assumed to be effective for adults living with autism. Even if there is some doubt about the effectiveness, there is a tendency to continue an intervention if there continues to be hope for benefit or assumption that the intervention is not harmful in any way. This is particularly

easy to assume for non-medical interventions because the concept of “side effects” is more closely linked to medication and supplements. However, all interventions have positive and negative aspects, including group interventions.

The best treatment decisions are made by careful consideration of risks and benefits. In group-based interventions for adults living with autism, this process becomes challenging because both risks and benefits may not be clear. The lack of sufficient information to conduct this decision-making process is cause for concern, especially the potential for long-lasting untoward effects of implementing an intervention that has more potential for harm than benefit. For example, if group intervention is recommended as a default treatment modality for adults living with autism and the effects are primarily negative, families and professionals are unknowingly worsening a known problem. In a landscape where resources are already very scarce, there is little room for error. In order to address this concern, the clinicians and researchers at the Yale Child Study Center created Community Autism Socials at Yale (Project CASY) which is an effort to better understand how group processes can benefit the ASD community. Project CASY is sponsored in part by The Daniel Jordan Fiddle Foundation Adult Autism Research Fund

and a generous gift from the Rosen family.

Much of the benefits and risks of participating in an adult autism group intervention were gathered from interactions with the adults themselves, their parents and other professionals. Not surprisingly, none of the adults were interested in improving their scores on any clinical rating scale which is the focus of practically all clinical trials. Instead, concerns centered around reducing loneliness, wanting friends and starting romantic relationships. This may come as no surprise as these are high priorities for most people in their twenties, yet there are almost no intervention studies with “friend” or “significant other” as primary outcome measures. It was quite concerning to learn about the perceived negatives of group intervention. While most adults were interested or indifferent about attending groups, there was a significant minority adamantly opposed attending a group. Most of the adults in this minority reported having had years of “social skills groups” as children and adolescents and reacted negatively to the mention of attending another group. There was a general consensus that meaningful social interaction was not possible in these groups given the often discrepant verbal capabilities or the presence of disruptive and aberrant

*see Project CASY on page 32*

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## The Direct Care Collaborative

### *Two Populations in Crisis: Adults with Severe Autism and Those That Support Them*

By Cyndy Hayes, DBA  
 President, Aging with Autism  
 and Laurie Sperry, PhD, BCBA-D  
 Assistant Clinical Professor,  
 Yale University

**A**s most of us who are reading this page know, there is a paradoxical relationship between the increasing numbers of people with Autism Spectrum Disorder (ASD) entering adulthood every year and the decline in available services. Indeed, the number of adults (22+) with autism is estimated at 200,000, a number that is projected to increase to 750,000 by 2030 (Khan, 2015). Federally mandated supports end at age 22. Individuals go from well-trained, well-educated staff, often in a 1-1 setting, to living in group homes where the staff ratio is on average 1-3.

The staff facing these difficult challenges is not trained, is severely underpaid and turnover is very high. Approximately 40% of people with ASD do not receive any mental health, medical or speech services once they exit the school system (Shattuck et al., 2011). These factors have created the perfect storm, leaving young adults unprepared for transition and vulnerable throughout their lives.



Cyndy Hayes, DBA

There are over 4 million Direct Care Workers in the United States, comprising one of the largest and fastest growing workforces in the US. Nearly half (49%) receive public assistance to supplement their incomes (Paraprofessional Healthcare Institute, Nov 2013). To put this in perspective, direct care workers are paid



Laurie Sperry, PhD, BCBA-D

a mere 92 cents more than a crewmember at McDonalds (McDonalds Corp, 2015). Demanding work combined with low wages, inadequate training, and limited opportunity for advancement set the stage for high rates of attrition. Staff turnover has both obvious and hidden costs for organizations.

It is important to understand the relationship between the lack of training and support of direct care staff and the quality of life of individuals served. Many leading service providers acknowledge the relationship between the competencies of their direct care staff and the wellbeing of those they support. They further recognize that increases in total compensation, combined with training and growth opportunities for staff, would have a dramatic effect on the cost of turnover and other related expenses. Unfortunately, agencies are managing tight budgets and are focused on short-term outcomes. They are chasing the never-ending challenge of filling these key positions. Operating in this reactive mode has blinded leadership to the insights that would come from taking a longer and more thoughtful view when making important, quality of life decisions.

While leaders agree that better training, compensation and opportunities for direct care staff is the right thing to do, it seems that we will not see any real change until there is concrete evidence that taking a proactive approach is also the smart thing to do. So how do we as a society move from ineffective, high-risk systems and processes to real transformation?

*see Direct Care on page 28*

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 for Pediatric News  
 Author - Coping with a Picky  
 Eater and  
 How to Say No to Your Toddler  
 Brunswick, Maine

## Employment Boot Camp Prepares Job Seekers with ASD

**By Deborah Chin, MA  
and Alexis Bitting, MSEd  
The Daniel Jordan Fiddle Foundation  
Transition and Adult Programs  
University of Miami CARD**

**E**mployment is a socially normative activity that is a key factor in adult life and successful community inclusion (Fussell & Furstenberg, 2005). Paid employment contributes greatly to quality of life outcomes including economic and social wellbeing, enhanced self-esteem, positive health outcomes, and is often a gateway to health insurance (Roux et al., 2013). However, employment is one of the most fundamental challenges for adults with autism spectrum disorder (ASD). While there is increasing focus on the need for more varied employment preparation and vocational options, there is a dearth of programs working to address the need, especially given the many adults who are looking for work. According to the Current Population Survey the employment rate for individuals with disabilities was 18.6%, considerably lower than the 63.5% rate for persons without disabilities (Office of Disability Employment Policy, 2010).

In addition to the lack of training programs for transition age youth with ASD, numerous studies have found that adults with ASD experience unique challenges in gaining and maintaining competitive em-



**After the last workshop, job seekers receive their certificates before heading out for a group social activity**

ployment (Barnhill, 2007). Research has shown that individuals with ASD report difficulty in negotiating social relationships, maintaining jobs, finding a vocational niche, and obtaining work that is commensurate with their ability levels rather than being underemployed (Frith, 2004; Hurtbut & Chalmers, 2004; Tantam, 2000a). In order to provide another option to support adults with ASD in their job search efforts, The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the University of Miami-Nova Southeastern University

Center for Autism and Related Disabilities (UM-NSU CARD) began Project EAARN Employment Boot Camps.

Project EAARN (Employment for Adults with Autism Resource Network) is UM-NSU CARD's employment initiative which includes providing training and assistance to employers, job seekers, and other professionals interested in improving employment outcomes for individuals with ASD. Three years ago, UM-NSU CARD began Project EAARN Employment Boot Camps. These experiences provide one-week inten-

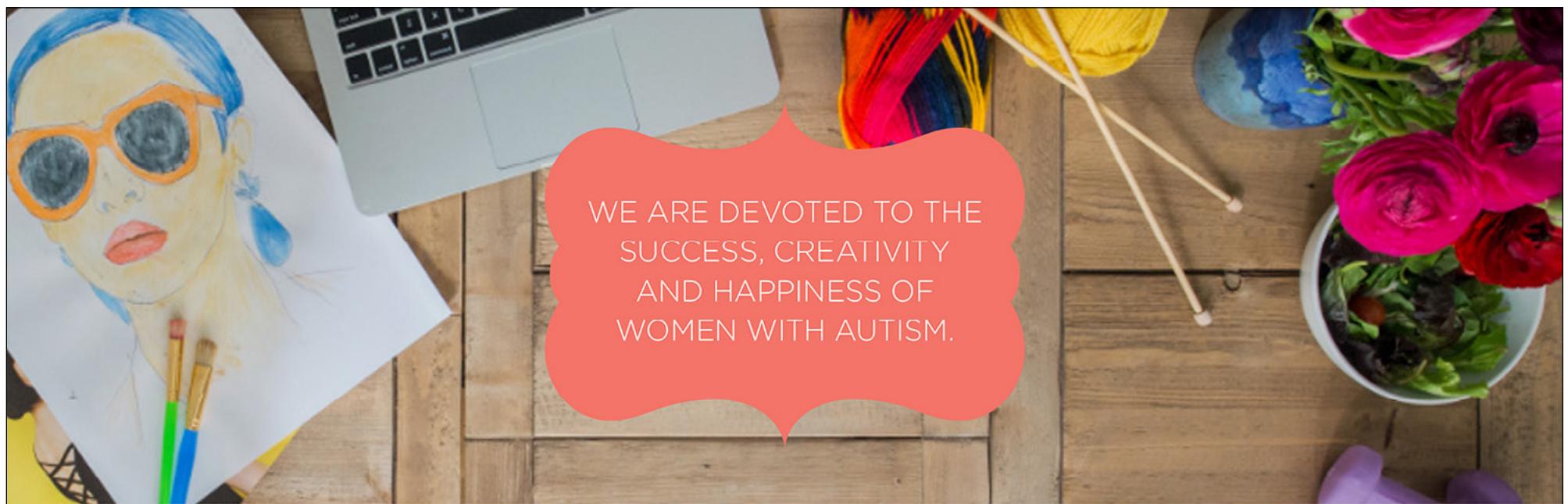
sive programming that focuses on helping adults gain and maintain employment. With support from the Sam Berman Charitable Foundation, clinicians began the process of recruiting and designing a program that would give job seekers the information and experiences they need to be more knowledgeable and successful in their job search.

There are many skills needed to search for appropriate jobs, apply for those jobs, interview with potential employers, interact with individuals at a job site, and follow-up with potential employers. An additional set of skills is needed to maintain a job if one gets a job offer. These skills can include handling feedback, interacting with co-workers and supervisors, asking for help at work, disclosing a disability, and much more. When putting together the curriculum for Project EAARN's Employment Boot Camp, the team carefully chose how and what skills to target in order to truly make an impact for the participants. They ultimately decided to focus on personal care, creating a resume, interview skills, money management, and social skills in the workplace.

Each potential participant was screened for appropriateness of fit to be a part of Project EAARN's Employment Boot Camp. The group is typically about 8-10 adults with an autism spectrum disorder, all of whom are registered UM-NSU CARD

***see Job Seekers on page 34***

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- A community

# The Crisis of Incompetency

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

**D**uring the past several years you have undoubtedly read about what some have called an “autism crisis” or “autism Tsunami” referring to the increasingly large population of children who are diagnosed with autism that are aging to adulthood. Is this the actual “crisis” we should be focusing on or a marketing strategy to create more awareness about adult autism? Much has been achieved in recent years, as more organizations begin to focus on adult life, and new programs relating to residential and employment options are emerging. Whether there are more adults today as in years passed facing the challenges associated with adult autism has not been definitively established, but what is clear is that the general population is more aware that adult individuals require differing and appropriate opportunities to live fulfilling and productive lives.

As an autism community, and as a nation, we must continue to do more to assist



Linda J. Walder

individuals diagnosed with autism achieve their potential, not only in childhood, but throughout their lives. The Daniel Jordan Fiddle Foundation, a pioneer in the creation of programs, public policy, resourc-

es and endowed programs benefiting the diverse population of adults, has led the charge in these areas since our inception in 2002. In 2016, we who focus on adult autism should be asking how we can affect enduring change that enables all individuals to fulfill their potential.

Ask any adult diagnosed with autism, or in many cases his or her parent, since many cannot advocate for themselves, what their biggest challenge is and they will tell you it is the broken system. When a person transitions from school age entitlements to adult life the system of supports, the stream of information, and the selection of services are incompetently managed through a bureaucratic system that is mind-boggling. Access to information and programs, medical and insurance needs, and the ability to earn income without losing benefits are only a few examples of the areas where change is needed. The broken system is the “crisis” that needs addressing, and this not only affects adults diagnosed with autism, but others diagnosed with a disability. The call to action that needs to be heard is a call to fix the broken system of incompetency.

Please let's not accept that the “crisis” is merely in the numbers of children aging to adulthood. Yes, more programs and community life options are needed to serve adults but the statement that this is the “crisis” we should be focusing on is a shallow statement. The crisis that must be addressed is one of an incompetent system that has been around for decades. The time is now to take action in Washington, D.C. and on the statewide level that will change the systems on which adults diagnosed with autism rely. It is time to address what I call “the crisis of incompetency.” If we do not, only a small, elite group of individuals will have the means to benefit from the newly created residential and employment programs organizations are developing while the majority of adults will continue to remain on waitlists and underserved.

*Linda Walder is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation for Adult Autism whose mission is to develop, advocate for and fund programs, resources and support systems that benefit the diverse population of adults diagnosed with autism. For more information, please visit [www.djfiddlefoundation.org](http://www.djfiddlefoundation.org).*



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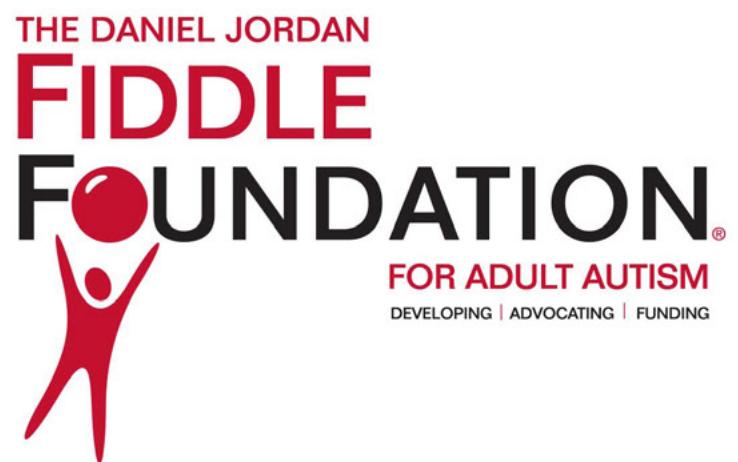
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## Autism and Hospitals: A Difficult Match

**By Eve Megargel and  
Sarahbeth Broder-Fingert, MD  
MassGeneral Hospital for Children**

*As a resident, you always have that one patient who sticks out in your mind—the one who had some profound impact on your practice of medicine and your life outside of medicine. For me, though, it wasn't just one patient. It was one patient after another with the same challenge: autism. Having worked in the school system before medical school, I immediately recognized what was missing in the way physicians and the medical establishment approached children with autism. The hospital staff had no real understanding of these children and how their worlds worked. I first met Billy's mother on a crisp spring afternoon. I had been thinking about and searching for a way to provide the best care for children with autism when in the hospital. I wanted to hear what Eve, the mother of a young man with autism, thought about the issue. The following is Eve's story, in her own words.*

**S**earch-and-find missions are always wrought with unknown dangers. Billy's colonoscopy is complete and Dr D tells us to follow the nurse and attendants who maneuver the bed Billy lies in down the hall. We walk briskly to be next to our son's quiet body. In anticipation that Billy may grab and pull out the IV, his



**Eve Megargel**

left arm is heavily bandaged like a cast. As we enter the intensive pediatric care unit, Matt and I are stopped immediately by a woman who identifies herself as the attending doctor. In a polite but curt tone, she informs us that we must wait outside the intensive care unit while the medical team situates Billy in his new room. We



**Sarahbeth Broder-Fingert, MD**

now enter a new and uncharted territory: a new department with new personnel, new rules, and limited knowledge about autism or Billy. Understandably, the medical team views Billy as a patient. But this 20-year-old young man has autism and a communication system that demands translation. In those short, precious seconds before the

door closes and separates us from Billy, Matt and I try to impress upon the doctor how extraneous noise, light, human movement, and the absence of a communication partner could sabotage the medical objective of completing a virtual endoscopy and that it would be prudent for us to escort Billy. The doctor, however, is not listening and has no questions, only directives. The doors slide closed, and Billy is whisked away.

The medical staff overseeing our son's case informs us that we must follow their protocol regardless of the fallout. This is the policy. But we are not the norm. In those few minutes, while we are barred from being with Billy, I know that even if he only semiwakens, the staff's medical experience will not equip them with the knowledge of how to proceed. Instead, an emergency will unfold as, bewildered and alone, Billy will use his free arm and hand to remove all foreign attachments, tape, and gauze from his body. Physical restraint and medication will likely preempt any effort to communicate because no one knows his language system. This is my nightmare. As these thoughts race through my mind, the nurse arrives and accompanies Matt and me to his room. My instincts are on high alert, and a brief snapshot view of the room compels me to direct. As the autism conductor, I fire out orders. "Close the blinds." "Dim the lights." "Speak softly or

*see Hospitals on page 22*

"An examination of how diverse yet truly unexplored our communication pathways remain" – **David Hajjar, M.S.-SLP**  
Doctoral Candidate in Communication Sciences and Disorders

*Learning to Kiss*

**EVE MEGARGEL**

With commentary from Dr. Timothy Buie and Dr. Christopher J. McDougle  
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## Building Employability Skills in Persons with ASD through Volunteerism

By Liza Jones, MA,  
Patricia Schulman, EdS, BCBA,  
and Mary Jane Weiss, PhD, BCBA-D  
Melmark

Much attention is paid to the educational needs of children with autism. Most of the media exposure on autism emphasizes the power of early intervention and the need for specialized instruction at school. While the media, parents and autism organizations have increased awareness, it remains difficult to secure a job placement for individuals with Autism Spectrum Disorders (ASD) for a variety of reasons. Relatively little information focuses on the needs of adults with autism or the need to prepare learners with ASD for adult life and for the supports available for adults with disabilities. In fact, individuals with ASD will spend the majority of their lives as adults, in environments with fewer resources than educational settings. It is imperative to build strong work skills that can lead to meaningful engagement and employment. In addition, it is important to identify settings, tasks, and activities that are preferred by the learner, to expand and to enhance their work, leisure, and social experiences as adults.

As individuals with autism transition to adulthood, it is important to find valuable and meaningful opportunities based



**Liza Jones, MA**

on each individual's specific needs and interests. The range of skill levels and behavioral challenges associated with autism require a wide array of opportunities and supports. Ideally all aspects of their needs are met within these programs, including providing experiences that lead them to being gainfully employed. In the disability treatment community, there is a strong emphasis on securing employment for all individuals with intellectual disabilities, including those with ASD. A wide variety of employment arrangements can work for individuals with ASD. Great progress



**Patricia Schulman, EdS, BCBA**

has been made in integrating preference into the selection of work tasks and environments. In addition, creative schedules, supports, and arrangements can increase the success of employment placements. Increasingly, employers are being educated about both the needs of individuals with ASD and their potential contributions to the workplace.

In our work at Melmark, however, we have discovered that it is not always easy to secure regular employment for our adults. Employers may be resistant to hiring individuals with ASD due to a lack of under-



**Mary Jane Weiss, PhD, BCBA-D**

standing of their unique abilities and characteristics. As each individual with autism possesses specific skills and strengths in different employment areas, it is important to ensure that the job requirements match the unique skills and capabilities of each individual with autism. For example, individuals initially may only be able to work for 1 hour and manage 1 to 2 tasks, requiring employers to be creative and flexible. Due to the spectrum of autism, some individuals do not have the ability to

*see Volunteerism on page 23*

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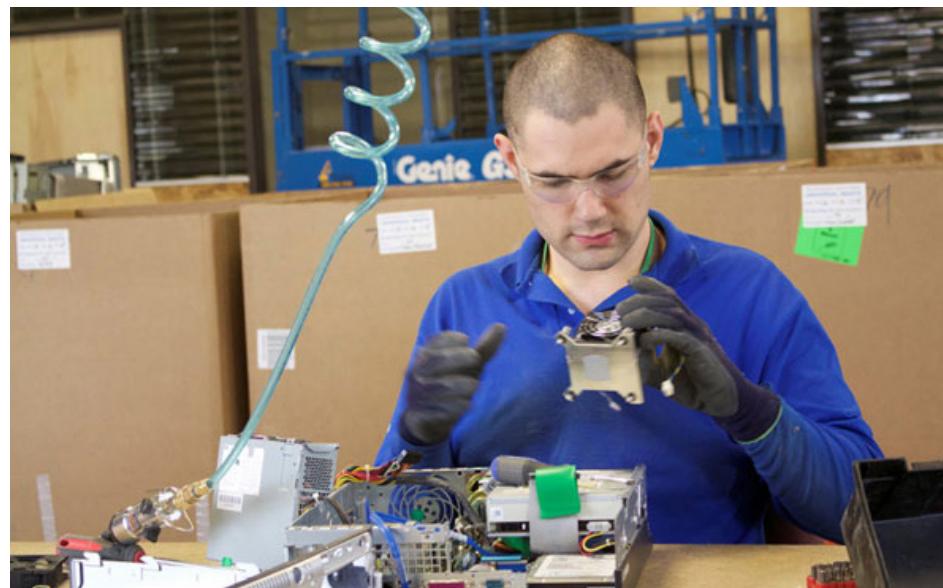
# Employment Opportunities for People with Disabilities

By Laurie Sperry, PhD, BCBA-D  
 Yale University  
 Bill Morris, and  
 Leigh Schilling  
 Blue Star Recyclers

**S**itting in the parking lot of Blue Star Recyclers, I watched as employees arrived by bus and on foot. They ran and skipped into work; each of them 10 – 15 minutes early for their shift. The words of Leigh Schilling, Recycling Technician echoed in my head: “I have the honor of working.”

The number of people with autism spectrum disorder (ASD) exiting the school system and entering the world of adulthood continues to rise. Unfortunately, the development of post-secondary education and employment opportunities has not kept pace with this increase, leaving many people with ASD unemployed and disengaged with their community. Competitive-integrated employment is defined as a job that provides at least minimum wage earnings and levels of benefit comparable to those of non-disabled workers. An integrated setting is one in which the person with a disability has the opportunity to interface with their non-disabled colleagues in the same manner and at the same frequency as their non-disabled colleagues (Fester, 2005).

It is estimated that over 80% of people with developmental disabilities are unem-



Ian is dismantling a computer at the Blue Star Recyclers Denver location

ployed (U.S. Department of Labor, 2014). In addition to the increase in the number of people without work, the Labor Department reported an increase in the number of people with disabilities who stopped looking for jobs. A study by Eaves and Ho (2008) revealed that nearly half (45%) of people with ASD had never been employed and of those who had been employed, only 4% of the participants had employment that met criteria for being competitive. In a study examining post-secondary outcomes

for young adults with ASD, only 6% were engaged in competitive employment and none of these jobs were full time. A minority of participants (12%) in the study were receiving services from job coaches with the vast majority spending their days in sheltered workshops or day centers (Taylor & Seltzer, 2011).

A cost-benefit analysis of employment and the support required to sustain employment found that for every dollar earned by a person with ASD, the services required

to earn that dollar cost \$26.74. Compared to other disability categories, people with ASD had the most expensive support needs (Cimera & Cowan, 2009). This begs the question, is this expense related to trying to fit a square peg in a proverbial round hole? In other words, what happens when the special interests and abilities of the person with ASD are capitalized upon? Is the need for support and resultant cost as great?

An 80/20 Problem with a 100% Solution

Blue Star Recyclers is a 501(c)(3) non-profit organization established in Colorado with a mission of ethically recycling electronics to create local jobs for adults with ASD and other disabilities. This mission helps solve two totally unrelated problems. The first is wasted talent. It is inconceivable that over 80% of adults with ASD and other disabilities are unemployed when a portion of this workforce is custom made for repetitive, systematic, procedural, and tactile tasks. The second is wasted resources. Less than 20% of electronics are ethically recycled in the U.S., yet every element can be recycled, reused and/or repurposed (US Environmental Protection Agency, 2014).

The fulfillment of Blue Star’s mission to date has produced significant triple-bottom line results, including 25 permanent part time and full time jobs for people with ASD

*see Opportunities on page 18*

## Accommodating Communication Difficulties

By Yvona Fast, MLS  
 Author and Advocate

**C**ommunication issues are common because most on the spectrum have difficulty reading body language and interpreting facial expressions or tone of voice – and 90% of interpersonal communication is nonverbal. Words can have different meanings depending upon tone and emphasis. This means the person may not understand their boss’s or colleague’s expectations and desires. If they’re around people for any length of time, they will slip up and cross an invisible (to them) boundary, causing offense. Often they never learn what it was they did or said that turned the other person off. While friends may in time come to understand this behavior isn’t intentional, this rarely happens at work.

Those on the autism spectrum often take things at face value and fail to see shades of gray. They tend to be frank and straightforward, and may want to get down to business. They might have difficulty understanding humor and figurative speech. For many, acknowledging, cheerily greeting and saying goodbye to people just doesn’t come naturally.

Other communication issues for those with autism spectrum disorders include taking things literally; they may not be able to tell when someone is joking, and thus take



Yvona Fast, MLS

teasing seriously, alienating the teaser. Lack of eye contact is perceived as appearance of dishonesty, boredom, inattentiveness, or rudeness, and can cause misunderstanding, offense or aggression. Many neuro-typical individuals (NTs) intuitively distrust someone who doesn’t look at them directly.

Conversations are tricky. Many find it difficult to approach people and don’t know what to say. They may have trouble

separating details from essential points in a conversation, so they may ramble, providing a myriad of details without stating their ideas clearly. Since words are their only method of communication, their words are much more emotionally loaded than for NTs, making it more difficult to accept criticism without getting upset. Often someone on the autism spectrum will keep speaking regardless of the listener’s interest, because they are unaware when their incessant talking becomes annoying and can’t read the signs of impatience on the listener’s face. How does one tell when he is rambling on with too much information? How does one know when it’s her turn to speak?

Here are some techniques to make your communication more effective:

- Try to communicate with people via methods that minimize body language, such as e-mail or telephone.
- Tell people that you have difficulty with nonverbal communication. Most people won’t get it, but some will.
- Let them know they must verbalize EVERYTHING, including their feelings; you just don’t “get” it otherwise. This works with people who understand you and know you well.
- ASK what’s going on; this also works better with those you know well. For

example, you could ask, “Do you think I’m angry?” and, if he says yes, reply, “I’m not angry at all. What made you think I was?”

- Realize that you’re not good at anticipating another’s feelings. That way, you can remind yourself to ask follow-up questions in a conversation and to respond with empathy.
- Explain that your face doesn’t always show your true feelings. For example, say, “I have a tendency to look angry when I am not, so I appreciate you seeking clarification.”
- Know when it is better to be less candid and honest. In social or employment situations, it’s often better to dodge questions about such hot button topics as religion and politics in order to avoid conflict. It’s usually best to avoid telling your boss exactly what you think of him or her. Otherwise, you may suffer the consequences.
- Watch and listen to people. For example, if you trust person A but then see that she hangs around with person B, who is definitely a jerk, you may reconsider your decision about putting too much trust in person A. Why is she

*see Accommodating on page 32*

# 8 Things I Wish I Knew Before My Autism Diagnosis at 22

By Taylor Raines  
College Student and Writer  
University of Central Florida

**A**t the age of twenty-two, I was diagnosed with high-functioning autism, commonly known as "Asperger's Syndrome." On the autism spectrum, high-functioning individuals with autism generally don't have developmental delays that are common in other parts of the spectrum. High-functioning autism is marked by difficulties with social interaction, sensory sensitivities, repetitive routines, and difficulty reading social cues. Many children are diagnosed at a young age, allowing parents and teachers to provide those children with tools necessary for development, and provide assistance with learning "normal" social behaviors. For many women, like myself, diagnosis doesn't come until much later in life – sometimes into late adulthood. Many psychologists and sociologists believe this is primarily because girls are socialized in society much differently. Girls and young women are better at masking their atypical behaviors and are better verbal communicators, allowing for better interactional skills.

I am one of many women diagnosed with high-functioning autism in adulthood — far outside my developmental years. For me, my diagnosis (and my "new" life) came at



Taylor Raines

the age of 22. For some women, it doesn't come until late adulthood, if at all. These are some of the things I wish I knew before I received my diagnosis later in life. They're also the things I want my friends and family to know now, because I was never able to express them effectively before.

1. You know just how much other people mean to you — but they don't.

Before receiving my diagnosis, my close friends and family had a negative image of me. In their eyes, I was sometimes rude,

I said inappropriate things at the wrong times or I said something honest when it was best to tell a little lie. I've been told that I don't care enough about my friends, that I push people away and even that I don't love my family. This couldn't be farther from the truth. In reality, I love and appreciate most of the people in my life to an almost unhealthy extent. My diagnosis gave me the life-changing reminder that you need to tell people you love them and to show as much appreciation as you feel.

2. You'll find an amazing companion to share your life with, but it'll take time and effort.

I was lucky enough to have my loving, neurotypical boyfriend at my side before, during and after I received my diagnosis. As one may imagine, we have a lot of struggles that are directly linked to my autism: communication issues, sensory difficulties and sometimes needing time to myself. As I mentioned above, I also have to remind myself to show my appreciation for him, which is sometimes as simple as remembering to ask him how his day was. However, our problems aren't so unlike other couples' that we can't work through them — it just takes more consideration and effort. You'll find someone, too, if you're romantically inclined (but you might not be!). You're just as capable of finding love as anyone else.

3. If you never reach out to your friends, your friends will never reach out to you.

When you're feeling overloaded and just need time to yourself, it's really easy to skip out on plans. You never want to disappoint your friends, so sometimes you don't reschedule... because you might have to cancel again. Before you know it, it has been years since you last spoke to them. Be honest and upfront if your plans change, and put effort into connecting often.

4. You're not "crazy."

I suffered with mental health concerns for most of my life before receiving a diagnosis. I struggled with suicidal thoughts, self-harm, mood swings, debilitating depression and even health problems brought on by stress. I was previously misdiagnosed with a myriad of mental illnesses and medications never worked. I thought I was a lost cause until I received my diagnosis. Now I have coping strategies and a community of people to turn to when I'm feeling overwhelmed or depressed.

5. You're not weird.

Are you obsessive? Super into animals or classical literature? A band most of your friends don't care about? You're not weird.

*see Wish I Knew on page 26*

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# Empowering Young Women with ASD to be Successful in the Workplace

By Marjorie Madfis  
President  
Yes She Can Inc.

Like their neurotypical peers, young women with autism spectrum disorders (ASD) truly desire to be independent. To seek her potential and independence, most women with autism need to work for money, even if it is for 15 hours a week. Women transitioning from school to adulthood need to stretch, take risks, try and possibly stumble, and learn how to recover. They need to discover their inner strength and build resilience. They need to transform from dependent students and social service "consumers" to confident problem-solving women. But given their social and emotional challenges, they need a supportive environment to begin their exploration of their capabilities. They also need an environment where they can connect with other women who share their challenges - where they can "be themselves" while learning to stretch. They need a workplace where they have interest, if not passion for what they are doing to motivate them to keep trying.

Yes She Can, a White Plains, NY-based non-profit dedicated to helping young women with autism develop job skills, opened Girl AGain, a resale boutique for American Girl dolls in February 2014. We



**Trainee working with peer mentor to research merchandise**

have served 16 women so far, and we have capacity for more trainees.

Many of our young women who are in the training program offered by Yes She Can had no idea what is required to be a good employee. They need a training approach that educates them about what is necessary to be a good employee and helps them develop those traits so they can increase their chances of finding and keeping a job. The following traits frequently show up on lists describing characteristics of suc-

cessful people: responsible and motivated, strong communicators, conscientious, and flexible. This list highlights why people on the spectrum, in particular, have difficulty obtaining and sustaining employment. The characteristics that are necessary are often those that they struggle with the most.

## Adaptable and Flexible

Employees need to recognize priorities, be able to shift from one task to another

## *Partnerships from page 1*

annually to update the plan. However, the plan is a living document, so additional meetings in response to emerging issues should be an accepted part of the parent/professional partnership. Optimally, the planning process begins as early as when an individual is 12 years old, allowing more time to work collaboratively to develop a plan designed to fully prepare an individual and their family for adult life.

Key considerations throughout this process include discussions of post-21 employment and/or education options, levels and types of desired community and social inclusion, and strengths and needs related to independent living (Polychronis and McDonnell, 2010). Depending upon the type of process used, the outcomes may vary, but those in our own process include:

- A personal profile on the individual, including preferences related to social interactions and relationships, employment, and community inclusion;
- The individual's and family's vision for post-21 employment and where the individual will live;
- Supports required for successful employment, community, and independent living activities (including behavioral, medical and physical supports; staffing supports; and environmental considerations);
- Ideas for goals and objectives for employment preparation; and

- A detailed action plan for the upcoming year that identifies items that the individual, the family, and the school staff are all responsible for completing (such as exploring available funding streams, investigating and visiting adult program options, arranging community-based employment experiences, and identification of additional skills that need to be targeted to support the shared team vision of post-21 living).

Additional information on person centered futures planning can be found in The PATH & MAPS Handbook: Person-Centered Ways to Build Community (O'Brien, Pearpoint, and Kahn, 2010) or at: <http://pcp.sonoranucedd.fcm.arizona.edu/resources/person-centered-planning-tools?destination=node/170>.

## Team Education Activities

A recent survey of over 200 families revealed that many families lack adequate knowledge regarding post-21 employment, residential, and adult programming/college options (Harris, El-Attar, Albertson, and Bonn, 2010). Results also indicated that many families (61%) were unaware that mandated services end upon graduation. Moreover, many families had limited knowledge on how to access possible funding streams as well as what supports for adults with autism were available in their area.

Given this reality, it is crucial that school teams and families begin planning for post-21, life no later than when a student is 14 years old. Key information gathered

include what funding streams are available for an individual and how the family can begin the process of applying for these funded services; what type of appropriate services are available in the area and who are the providers; how to set up tours of potential programs; and how to collect information on other important considerations (such as issues related to guardianship, SSI and medical assistance, selective service, and so on).

A timeline that may be helpful for organizing this planning can be found in the online Autism Transition Handbook ([www.autismhandbook.org](http://www.autismhandbook.org)). Another helpful tool is the Autism Speaks Transition Toolkit ([www.autismspeaks.org](http://www.autismspeaks.org)).

Unfortunately, many adults with autism face long waiting lists for services funding, which can be further compounded by strict eligibility criteria, leaving them without needed supports and services for multiple years upon graduation. By linking to funding streams and adult providers at or before the age of 14 years, families can increase the likelihood that they will have access to the planned services in adulthood.

## Shared Ownership of Teaching Critical Skills

Too often individuals learn skills at school, but without collaboration with families, these skills infrequently generalize to home and community settings and/or are often not maintained into adulthood. Therefore, teaching critical transition skills and achieving generalization to other settings requires a shared responsibility among families, school staff and other professionals.

as priorities change (set by manager or demand by customer). As we know, "go-with-the-flow" is especially challenging for people with autism, who tend to be rigid and rule-bound.

Recently, one of our most capable trainees was completely focused on her data entry work in the store and did not notice that customers had entered the store. She did not realize that customers are the priority and that data entry work can wait. She could not sift her attention to the customers because she was worried she would lose her place in Quick Books. After being coached she was able to assist the customer in selecting a doll to purchase (which she usually loves) but was not able to give the customer her full enthusiastic attention that is typical because her mind was on her data work. This is something we will continue to practice with her, even creating artificial interruptions.

Another trainee was using an iPad to do research but the iPad was needed to conduct a customer transaction (our usual device for transactions had a malfunction). That trainee could not relinquish the iPad because she said she was not done with her work. When she was told that the customer transaction was the priority she still resisted. So two problems: she refused a request from the manager and she could not adjust, nearly having an outburst.

*see Empowering on page 24*

As part of a person-centered futures planning process, the team can identify which communication, social, community, and living skills need to be targeted to help an individual achieve their goals into adulthood (note: this would not necessarily be all skills identified within the IEP, but rather key skills that have been selected as most important for a successful transition). Within each domain, the team must select which specific skills need to be initially targeted based upon assessment data. For example, Bondy (2011) has identified the most critical communication targets that serve as a foundation for effectively communicating across home, community or employment settings. Among these skills are requesting preferred items, asking for help, asking for a break, following directions and following a schedule. There are multiple resources and assessments available to teams to help identify what skills should be addressed in other domains as well, such as Skillstreaming the Adolescent (McGinnis, Sprafkin, Gershaw, and Klein, 2012) for social skills and the Syracuse Community-Referenced Curriculum Guide (Ford, Schnorr, Meyer, Davern, Black, and Dempsey, 2010) that can assist in assessing employment, community, independent living, and recreational skills.

Instructional procedures utilized to teach these identified critical skills must also be evidence-based (i.e., interventions that have strong research support and thus, are more likely to be effective). In the field of autism, interventions based on the principles of applied behavior analysis have

*see Partnerships on page 25*



# The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

## Will He Live on His Own?

**R**arely a week goes by when I don't wonder if my son, Jack, will ever be able to live on his own. I mean, that's what kids do, right? They keep you up at night and drink all your milk and leave their wet, muddy boots all over the kitchen floor and cost you a **bajillion** dollars and then, at some point, they move out.

And you cry and cry and mourn the missed opportunities and the time you yelled about the boots and griped about the milk, but eventually, you both realize it's for the best. Parent and child are not meant to live together forever.

Before I was a mother, I thought that one of the hardest things in the whole big entire world would be to have a child who couldn't live independently because of a disability. I'm not even kidding. It's like I wrote my own script.

And now, I have a child who may not live on his own.

Ever since Jack was about eighteen months old, I've alternated between two phrases; *he can* and *he can't*.

Oh, there's some variation on the wording—*he won't* and *he will*, for example—but it's really just a running tally of all the



**Jack at eighteen months old**

things he does and does not do.

*He doesn't point his finger, but he can change the DVD player.*

*He can turn the key in the ignition to start the car, but he has trouble tying his shoes.*

*He knows the capital of all fifty states,*

*but he doesn't understand what the word "float" means.*

Then, on a fairly regular basis, I take my imaginary tally sheet and use a weird algorithm in my head with a very convoluted formula to try and answer one simple question. Will he ever be able to live independently?

Can I say it? I'll just say it. One day, I would like to be independent too. One day I would like to be independent of **Redbox** and **Oreo cookie challenges** and autism. I would like a little breathing space.

It is a two-way street, this independence thing, and some days it feels like nothing more than a dead-end, or a really long detour with a lot of orange cones and flashing lights and constant, ongoing construction.

I know, I know, there are all sorts of assisted living places and group homes and condominiums where they mow the lawn and shovel the snow and fix your faucet if it leaks. We can set him up in an apartment that we pay for and I can stock it with pancake mix and Frosted Flakes and frozen chicken fingers, and then I can check in on him every day—or every other day, if he seems calm.

But this is not what he wants for himself. He wants to live on his own, in a house, in California. I don't really know why Cali-

fornia, seeing as he's never been there, but there you have it.

He wants a wife, and a family. He wants to be a father, and drive an SUV like his own dad.

I'm not sure I can adequately describe what it feels like for me to hear him talk about his own future. It is equal parts thrilling and alarming, like I'm driving a car very fast, and I just realized the street isn't paved and the steering wheel is broken.

*He can tell me the shortest route to the mall, but once we're there he might wander away and get lost.*

*He will talk about Disney movies with anyone, but he has no interest in what the other person has to say.*

*He knows the population of Zimbabwe, but he gets confused if someone talks too fast.*

I know, I know, he's not even twelve yet and there's plenty of time and it's too soon to worry, why just *look* at all the progress he's made!

But if there's anything an **autism mama** knows, it's that time is not on our side.

*He can, but he won't.*

*He should, but he doesn't.*

*He has, but he never.*

Whether I have realized it or not, every

*see His Own on page 34*



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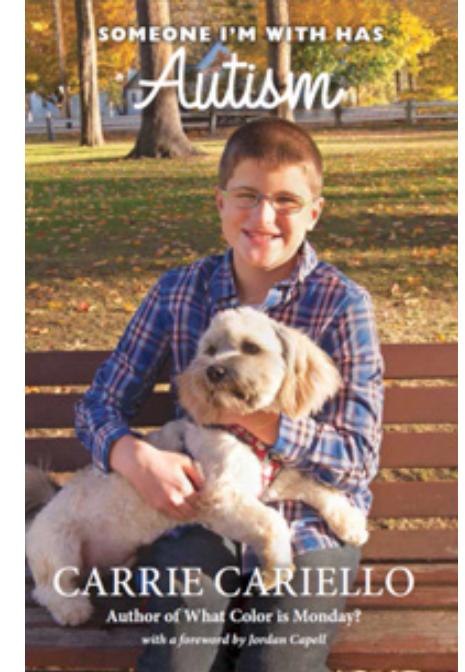
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# Adults on the Autism Spectrum: An Unidentified and Forgotten Population

By Karl Wittig, PE  
Advisory Board Member  
GRASP

**A**mong all those on the autism spectrum, adults get the least media attention and receive the fewest services, supports, and resources of any kind. This is ironic when one considers that adulthood constitutes most of the human lifespan, so that the vast majority of individuals with autism clearly are adults. Unfortunately, since most of the autism spectrum was not recognized in the U.S. until 1994 and there was hardly any public awareness until the mid-2000s, very few of today's adults with autism over the age of about 35 were ever identified, let alone diagnosed. They constitute a substantial population largely unknown both to society and to themselves. Until recently only the most severely impaired were recognized, and of those only a minority received appropriate services or supports of any kind. For younger adults, who are more likely to have been diagnosed, the situation is not as dire but still leaves much to be desired. The fact that, in most states, benefits and services end upon reaching adulthood (usually at age 21) means that adults on the spectrum are often left without supports.

The bad news is that, with improved diagnostic methods and increasing public



Karl Wittig, PE

awareness, the number of adults identified on the autism spectrum is rapidly rising, and will continue to increase dramatically. In the U.S., with a population of 320 million, an incidence of 1 in 68 results in about 5 million individuals with autism, most of whom are adults. As they get older, many will have greater need of benefits and services at a high cost to society. The good news, however, is that a high percentage (probably a large majority) who are less

impaired can attain the levels of skill that they need to live in the world independently with fewer supports and much lower costs to society and the taxpayer. I strongly believe this to be the case.

Many challenges adults on the spectrum face occur in daily living. For individuals with autism, who often have trouble with changes in routines, the transition to independent living can be very demanding. Learning the requisite skills may be difficult, and incorporating them into their lives can be a substantial hurdle. What is usually overlooked, however, is that most activities of daily life are periodic routines which are performed daily (e.g., food preparation, personal hygiene), weekly (laundry, housecleaning), monthly (rent, bill-paying), annually (filing tax returns), or at a regular interval as is necessary. One thing that individuals with autism are usually very good at is following repetitive routines. Once a person on the spectrum learns these routines, chances are high that they can maintain them for the rest of their lives. This makes the dream of independent living more likely to be reality. I am reminded of the old Chinese proverb, "Give a man a fish and you feed him for a day; teach a man to fish and you feed him for life."

Early intervention in childhood is considered the most important factor in attaining positive outcomes for individuals with autism. I believe this is also true for adults

in that early preparation, for some aspects of life that are usually ignored in the educational process, needs to be provided to young individuals with autism before they reach adulthood. In particular, issues of socialization and daily living need to be explicitly addressed by the time a person with autism is in high school, if not middle school. Education in many aspects of daily life is nothing less than essential. These include personal hygiene, clothing and dress, food and diet, household maintenance and housekeeping, financial management and budgeting, and other practical matters. Social skills and socialization issues include getting along with others, being part of a group, meeting people, making friends, and finding and maintaining romantic relationships. Most importantly, this needs to be done for *everyone* on the autism spectrum, regardless of academic or other ability, and with *all* degrees of autistic impairments ranging from the mildest to the more severe. The level of instruction can be tailored to the abilities and challenges of an individual, but it *cannot* be neglected in *any* case. The costs involved will be minuscule compared to the later costs of providing services to adults who are not able to do these things for themselves.

There is a common belief that people "pick up" these things naturally and that there is no need for explicit instruction in

see *Forgotten on page 31*

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## Opportunities from page 14

and other disabilities, 10 million pounds of electronics ethically recycled, and \$5 million in combined earned income and taxpayer savings. While these are impressive outcomes for a small nonprofit, it is the workers who have posted the greatest accomplishments at Blue Star: Zero turnover, zero absenteeism, and zero lost-time accidents. These results demonstrate that the unemployment rate of people with ASD and related disabilities is tied to the lack of opportunity, not the lack of ability.

The idea behind Blue Star surfaced in 2008 when founder and CEO Bill Morris discovered a small group of adults with ASD dismantling electronics as unpaid volunteers in a day habilitation program. Bill was impressed by the level of innate

skill and proficiency these unpaid workers demonstrated, and became convinced their aptitudes were worthy of paid employment. He helped create an employment enclave through a partnership with an electronics recycler in Denver who offered to pay five cents per pound to disassemble computers into their constituent base materials. The first four employees started work in October 2008, and almost immediately another discovery was made: In their new workplace setting (away from the day habilitation program) two employees with seizure disorder stopped having seizures, and one nonverbal employee became verbal. It was evident their entire overall state of well-being improved by having a purpose to their day and meaningful work where they could apply their talents. Capitalizing on these propensities

obviated the need for job coaches. Blue Star is not a supported employment setting. The employees, who represent the full range of the autism spectrum, all work independently in a variety of positions alongside their colleagues without disabilities making this a truly integrated work setting.

Leigh Schilling, a Recycling Technician at Blue Star Recyclers, joined the organization in 2012 as a volunteer, and was later hired to join the production team. It was soon evident Leigh had a special proclivity for very precise manual tasks involving the disassembly of hard disk drives. At Blue Star every employee is accountable to achieve a daily production goal, and like the entire team, Leigh takes her team contribution seriously. She has set numerous record goal achievement levels, yet

continually strives to improve upon them. Leigh reports that her job "allows me to give back to my community. I break down electronics and that keeps them from going into a landfill."

Old electronics are often thrown in a drawer or put on a shelf and forgotten. What a troubling parallel to the potential employee with ASD. When I asked Leigh what the best part of her job was she replied, "I love to work. It gives me a purpose. I've found what I love to do AND I'm a contributing member of society." Capitalizing on the special aptitudes and interests of people with ASD results in a motivated and highly skilled workforce. That's enough to make any prospective employer want to skip into work.

see *Opportunities on page 32*

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# Next Stop, Adulthood: A Framework for Effective Transition Planning for Students with Severe Disabilities

By Lauren E. Andersen, MA  
Doctoral Student  
Teachers College,  
Columbia University

**I**t is imperative for school professionals such as special education teachers, general education teachers, guidance counselors, and other school personnel to be knowledgeable of the secondary-transition planning process for students with severe disabilities to better meet the needs of their students and to assist in creating a plan. Throughout a free and appropriate public education, school personnel work relentlessly to help students with severe disabilities develop skills that will enable them to be as independent as possible. And yet, upon graduation, it is still possible for a student with a severe disability to graduate from high school and have no formal plan for his or her adult life. With no plan for the future, the skills that took minutes, hours, and years for an individual to master may quickly fade away. There may be no body of peers to socialize with, no yellow school bus waiting outside the house, and unfortunately there may be "nothing to do" at all. In order to sustain the continued efforts of school professionals, family members, and more than anyone,



Lauren E. Andersen, MA

individuals with severe disabilities themselves, we must take the steps required to develop a realistic and effective plan for the future. The intention of this article is to familiarize practitioners with the transition planning process through a proposed framework to assist in creating effective transition plans for students with severe disabilities.

## Who is Responsible for Transition Planning?

It is the shared responsibility of the school district to ensure transition planning is adequately being practiced. Stakeholders such as general education teachers, special education teachers, transition specialists, and employment specialists must be prepared to participate in an ongoing collaborative process and offer their expertise to drive best practice in transition planning for each individual student (Holthaus & Smith, 2002). According to IDEA (2004), the term "transition services" means a coordinated set of activities for a child with a disability that: (1) Is designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and (3) Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and,

if appropriate, acquisition of daily living skills and functional vocational evaluation [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]. Local education agencies have some flexibility in regard to carrying out the federal law and state interpretations. For example, the "buy out option" is a practice in which school districts can contract directly with private adult service agencies to provide transition related activities. This may include services such as job development and on-the-job support in the form of job coaching (Sailor, 2002). School districts can meet the federal and state mandates of IDEA by entering contracts with adult service agencies and forming partnerships with the existing school personnel team.

## From School to the Adult Service System

For students with significant disabilities who will continue to need support after high school, the transition from high school into adulthood is stressful. For many years the school has acted as the coordinator of services, working collaboratively with parents/guardians of students with severe disabilities to individualize educational plans and provide related services to target areas of need. Once the student finishes out the school year in which he/she turns

*see Transition on page 38*

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# The Importance of Community Social Participation for Adults with ASD

**By Mary Riggs Cohen, PhD  
and Brittany Lyman, PsyD  
Autism Spectrum Diagnostics  
and Consulting**

Over the past ten years, researchers have been investigating the quality of life and overall functioning of adults with Autism Spectrum Disorders (ASD) (Orsmond, G.I., Shattuck, P.T., Cooper, B.P., Sterzing, P.R., Anderson, K.A., 2013; Billstedt, E., Gillberg, I.A. & Gillberg, C., 2011; Robertson, S.M., 2010; Renty, J.O. & Roeyers, H., 2006). A consistent finding across these studies is the importance of social participation and its correlation with improved quality of life. These studies describe the negative impact of social isolation and lack of community integration for adults with ASD, emphasizing the need for more social support resources.

## Transition to Adulthood

The transition to adulthood brings new challenges for maintaining and developing social relationships. Friendships formed in elementary or high school may be difficult to maintain due to less frequent contact (Orsmond et al., 2013). Many adults with ASD do not drive and may become isolated after graduation if they do not have access to transportation. Data from the National



**Mary Riggs Cohen, PhD**

Longitudinal Transition Study-2 revealed that young adults with ASD are more likely to experience social difficulties than other special needs groups. They are less likely to see friends, be called or invited to social activities (Orsmond et al., 2013). Young adulthood is now seen as a high-risk period for the development of mental health conditions, particularly anxiety and depression in this population.



**Brittany Lyman, PsyD**

## Lack of Social Experiences

Billstedt et al. (2007) found that fewer than half of adults with ASD participated in any social events (attending church, special interest groups, concerts, recreational activities) in their respective communities. While many adults with ASD use social media and have social interactions online, they do not typically have relationships

with individuals in their community to engage in shared activities, recreation or community volunteer involvement. For many the internet is their only link to the outside world and they do not receive the social cues necessary to decode social behavior. It is important to recognize that face-to-face social interactions are essential in helping adults with ASD learn to navigate the social world and provide a sense of belonging and inclusion in the community at large.

## Social Support Models

Two examples of successful social support models in the Philadelphia region are the “drop in” format and the scheduled “meet up” organization. The first example is exemplified by the Coffee House Center, which is directed by the Family Services Association of Bucks County (<http://www.fsabc.org/program/aaces/>). Founded in 2009, the Coffee House provides organized activities, discussion groups, guest speakers and casual conversation. Members can drop in for social experiences and are encouraged to attend frequently. They can meet other “like-minded” individuals with ASD from a wide geographic area who may share their interests. Unstructured social time and structured social activities are available. The second model is

*see Community on page 35*

## Inclusive from page 6

component of feedback for the students. Many of my students don't realize how many classes they have missed or that it even mattered that they were not there. I have had many students that did not meet their own expectations and then went underground emotionally. They needed help working through the situation before they got to the point of an administrative withdrawal for non-attendance. Therefore, it is important to state attendance expectations explicitly.

## Comprehending Expectations

In order to ensure that the students comprehend your expectations, require students to take a syllabus quiz and a quiz regarding any accompanying online component. Even more engaging might be a group activity where the students work in groups of four and each student reads their assigned number of paragraphs with a certain category. After a period of time, they share with their group. Next, an appointed group member shares what they learned with the class. Finally, a group discussion or pop quiz can ensue. This activity can be used with regular course content as well.

For students with social and Executive Function challenges, small group activities in class are easier than out of class group activities because they receive constant feedback from peers and the instructor. Although, my students (who are given explicit instructions on how to interact with others) still falter in this area. There

have been countless times when I was tutoring a student and the student mentioned an out of class group assignment of which they were unaware of their part. In addition, even when prompted, they may not ever come to our session with contact information. Of those who did, some took over the group and others were totally aloof. If their groupmates tolerated their social oddities, then they might be given a task. If there must be out of class group assignments, then allow the students some class time to connect, exchange information and schedule in-person meeting days and times.

## Understanding Assignments

Students can become overwhelmed easily in any subject, especially when it is not an area of interest. When requiring a student to complete assignments, be clear and concise with directions. If the class is online, be sure to separate the lecture from the assignment. I had a student writing with graduate level writing skills panic and cry for days when she saw two pages of requirements. She couldn't even read it. I extracted the lecture and outlined the requirements. She sat down and made a plan to complete the assignment and was able to complete the assignment unassisted from that point. It was helpful that she knew way ahead of time when her assignment was due so that she could plan to complete it early. As a result, she was able to get it reviewed by the writing lab before her final submission. She went to the writing lab because her teacher offered extra credit if her paper was signed

by writing lab staff. Another technique that is helpful is when instructors offer specific feedback in the areas that need work and demonstrate what it looks like. The instructor may also require students to demonstrate where they went wrong and allow them the ability to correct or have the student's grade, check and critique each other. The classes can be structured to encourage several submissions to allow students to get it right.

## Using Assessments

Assessments allow the students to know in which area they need to improve. It also gives them an opportunity to prove their knowledge. Unfortunately, I have witnessed on multiple occasions students who understand the material but get hung up on the details of the assessment. When writing tests, it is important to have someone proof your tests for spelling and grammar errors and avoid negative statements like, “Which selection is not the answer?” You are testing for knowledge, not attention. Stick with one style of test or let the students know if you are going to change your style. A sudden change could cause a rigid student to panic and not complete the exam. Also, giving assessments often presents more opportunity for feedback and practice understanding your expectations. Consider using other methods of assessment like crossword puzzles, hangman, games, portfolios, and presentations. This will allow students with test anxiety and other testing issues to show you what they know.

## The Grand Design

When designing your classroom environment, consider what you are trying to accomplish. Many instructors have asked me, “If I hand them everything, then how will they be able to function in the real world?” My response is that the students with learning differences that I have worked with were almost always intelligent enough to handle the course content. However, they struggled because of issues with note taking, time management, organization, study strategies and anxiety. These are all areas that students can work on with college student support services such as writing labs, math labs, accessibility services, counseling and peer mentors, etc. Recommend and require your students to at least try out these services so they are comfortable going through the process. As an instructor, you teach the student the content of the course. If you offer your students support, deliver your course content in an engaging manner by facilitating learning and they will remember it forever.

*Ryan Therriault serves as the Lead Academic Coordinator for all six sites of the College Internship Program (CIP). CIP ([www.cipworldwide.org](http://www.cipworldwide.org)) is a comprehensive program serving teens and young adults with Asperger's, Autism and other Learning Differences. CIP offers year round and summer programs. Autism and Learning Differences (An Active Learning Teaching Toolkit), by Dr. Michael McManmon EdD (CIP's founder), published by Jessica Kingsley Publishers, London 2015.*

# Extraordinary Ventures Creates Extraordinary Opportunities

By Gregg Ireland and  
Melanie Schaffran  
Extraordinary Ventures

**G**overnment is an important employer in our economy, but by far the largest source of jobs is the private sector made up of hundreds of thousands of small, medium and large businesses. But neither government nor private enterprise has done a very good job incorporating the skills and talents of adults with autism and other intellectual challenges into American mainstream economy. Unemployment facing adults on the spectrum remains at an alarming rate of 80-90%! It is a shame and we can do better.

Turning the situation around is not easy. It requires new ways of thinking and renewed focus and commitment of the parties involved - government, business, families, individuals. It will take risk taking, and who is better for that task than the American small business community or the great American entrepreneur? We need new ideas and business models to tap into the strengths of what to date is largely an ignored, disenfranchised group in our society. One such promising new entrepreneurial model that has come on the scene in recent years is Extraordinary Ventures.

In Chapel Hill North Carolina, Extraordinary Ventures (EV) owns and operates a portfolio of five small business platforms:



EVNY successfully launches its candle business

laundry, office services, pet services, transit bus cleaning and gifts. The businesses are organized and managed by a team of young start-up artists whose goals are to develop sustainable businesses and provide ideal employment opportunities for people with autism. EV makes liberal use of behavioral techniques from the University of North Carolina TEACCH Autism Program including job flow diagrams, colorful work charts and picture schedules.

The jobs are inclusive. The employees are responsible for many tasks that keep them active in the community—for example, picking up and delivering laundry to customers, working alongside bus drivers and maintenance personnel in the cleaning operation, and running errands such as picking up finished jobs at the printer and delivering batches of letters to the Post Office in office services. The result is a happy, prosperous and growing workforce of

55 individuals, ranging from age 18 to 65.

Extraordinary Ventures in Chapel Hill (EVNC, [www.extraordinaryventures.org](http://www.extraordinaryventures.org)) is in its eighth year. While it is no longer a pure startup, every facet of the business continues to grow and develop. Importantly, the capital requirement is modest and while the enterprise is not yet profitable as a whole, donations for this non-profit operation account for around 20% of the revenues needed to meet the budget. After 8 years, the total investment made to create 55 great jobs amounts to less than one-half of a year of college tuition per employee. It's a great value for the people and for society.

Turning their attention to the rest of the country, EV has formed partnerships with organizations in New York, Michigan, California and Atlanta. A New York based group, founded over twenty years ago by a group of parents was one of the first to sign up.

The Foundation for Empowering Citizens with Autism (FECA, [www.fecainc.org](http://www.fecainc.org)), located in Westchester County outside of New York City has for over two decades been fulfilling its mission of providing programs for children and adults with autism, often by working through partnerships with area service providers. FECA's educational conferences in the early days introduced the evidence-based and

*see Extraordinary on page 35*

## Women from page 1

their own masculine gender norms including that they must control their emotions and rely solely on themselves to solve life's problems. Masculine gender norms also include taking risks and competition, placing priority on work over family, and exhibiting power and even violence over women (Mahalik et al., 2003). Given that the fact that many feminine gender norms focus on interpersonal relationships, while masculine norms favor reliance on one's own skills and resources, it is no surprise that this creates a challenging and unique crossroads for females with ASD, who face complex social challenges.

Some women with ASD may be interested in developing and navigating these roles, but find the inherent social demands of these multiple roles (e.g., friend, romantic partner, mother, daughter, caretaker) to be overwhelming and unattainable. Other women may not be attuned to and/or interested in investing in these roles. Additionally and unfortunately, statistics continue to show that women, due to a variety of factors including gender norms for both men and women, are more likely to be victims of intimate partner abuse and violence. Young women diagnosed with ASD may be even more susceptible to these dangers due to their difficulties both in recognizing social cues and engaging in self-advocacy (Willey, 2012). Because of the increasing social demands and complexity of interpersonal relationships during young adulthood, some studies have shown that young women diagnosed with ASD are more susceptible to anxiety, depression, somatic



Alyssa S. Milot, PhD

symptoms, eating disorders (i.e., anorexia nervosa), and difficulties with sleep (Kreiser & White, 2014).

Therefore, to help women with ASD understand, navigate, and make informed choices regarding how they want to successfully live their adult lives, gender-specific supports and interventions are necessary and required in today's society. What might these supports look like? Beginning in adolescence, females with ASD (and females in general) would benefit from direct exposure to societal expectations and norms regarding expectations for investing in interpersonal relationships (e.g., friendships, romantic partnerships, children) and one's

appearance, as well as showing modesty towards others about one's strengths and accomplishments (Mahalik et al., 2005). Female adolescents, including those with ASD, would benefit from viewing examples of societal attitudes in everyday media (e.g., television shows, commercials, magazines, etc.) to help build their awareness of these topics. Exposure to these societal norms helps to develop greater awareness and conscious-raising of societal attitudes and its impact on everyday life. After females have been exposed to these societal gender norms, it is important that they be provided with opportunities to discuss their own goals and values and how they relate to societal norms. For females with ASD, it is important to provide explicit discussions of both the costs and benefits of choosing to abide by or reject traditional female role norms. Their impairments in perspective taking may limit their ability to understand these social consequences. These discussions can be completed in psychoeducational support groups that provide a safe place to discuss one's perspectives, ideas, and concerns as well as opportunities to gain peers and learn skills.

For those women with ASD who choose to conform to feminine norms, valuing an investment in interpersonal relationships (e.g., friendship, romantic partnership, motherhood, caregiver), it is essential that they have lifelong access to support groups to obtain social support and skills instruction regarding the unique demands (and benefits) of these varied interpersonal relationships. For example, direct skill instruction regarding communication skills necessary for each interpersonal role

through discussion and role plays would be helpful. Example themes include honest communication with one's romantic partner, self-disclosure of one's challenges to a new friend, and limit setting with one's children. In addition, specific examples presented through sharing of personal experiences, vignettes, or media images of both healthy and unhealthy interpersonal relationships (e.g., when a partner is taking advantage of another) would help to illuminate key signs to observe in one's day-to-day interactions as suggested by Willey (2012).

In addition to direct skill instruction and social support around the development and maintenance of interpersonal relationships, women with ASD need opportunities to discuss and practice self-care practices as a means of relaxation as well as to treat co-occurring mental health symptoms such as anxiety and depression. Furthermore, there has been increased discussion of the need to more routinely discuss and utilize the strengths of women with ASD within social and mental health supports and interventions. More specifically, Australian psychologist Tania Marshall views women diagnosed with ASD as possessing an abundance of strengths that she describes in her popular book series *Aspie Girls*. Some examples include creativity, strong will, keen attention to detail, honesty, and special interests in areas such as nature, animals, children, and art that have the potential to yield activism and prosocial involvement with others in one's community (Attwood, et al., 2006).

*see Women on page 36*

# College Supports for Students with ASD: Now and Looking Forward

**By Diane Slonim, PhD**  
Speech-Language Pathologist

The necessity of a college education as an entrant to anything but a minimum wage job is well documented (Farrington, R. 2014). With the increasing number of students entering college with Autism Spectrum Disorder (Pinder-Amaker, S. 2014), professionals have begun to turn their attention to the needs for special supports to ensure successful outcomes. Beginning in 2010 or 2011, these programs have begun to take root across the country. It is important to take a look at some of the successful programs currently in operation on college campuses, how they are funded and sustained, and how they demonstrate that there is evidence that they are succeeding. There is an ever increasing need to demonstrate that these programs are "evidence based" if they are to continue to succeed and expand.

## ASD Program at Purchase College

Dr. Lauren Greiner, clinical psychologist, is the driving force behind the ASD program at Purchase College, State University of New York. Nine years ago, Dr. Greiner developed this program as an offshoot of a program serving students with psychological disabilities already in place



**Diane Slonim, PhD**

on campus. Dr. Greiner worked earnestly for the need for more specialized services for students with ASD. To this end, she continued the college's collaboration with a private funding organization (The FAR Fund) to support her efforts. Beginning with 12 students, Lauren now serves more than 50 students on the campus. This program is now funded by both SUNY Pur-

chase and the FAR Fund. To understand what makes this program so successful, one needs to look at both "qualitative" and "quantitative evidence."

Dr. Greiner has been running the program at SUNY Purchase for almost a decade; the program currently serving approximately 50 students. She estimates (based on faculty and student reports) that there are another 100 students on the campus who do not want to identify themselves with any sort of "disability," and this is one of her greatest challenges. Dr. Greiner's program is highly comprehensive. It provides academic and transition support (especially to those entering as freshmen), a social network, education of staff regarding the nature of her student's issues, internship development, and career development. Dr. Greiner is assisted by graduate interns in psychology and a large group of peer mentors. This enables the program to provide individual case management. What is particularly striking is Dr. Greiner's attention to building community for her students. Many students entering college with ASD are fearful of attending social events secondary to social anxiety. Speaking of one student in her program, Dr. Greiner commented, "I don't think he ever had a friend before entering the program." Dr. Greiner runs weekly social groups for students and maintains a closed Facebook page so that students can easily connect with one another. Dr. Greiner encourages the students

to invite their friends to events sponsored by the program. This, in turn, integrates the students with the student body at large.

From 2008 to 2011, the program was exclusively funded by the FAR Fund. Beginning in 2012, SUNY Purchase contributed to the expenses of the program. Approximately 30% of the operating budget is contributed by the college. The program runs largely on a three-year renewable grant. Continued funding is an ever present source of concern.

Statistically, what are the results? Students in this program have an average of a 3.21 GPA, higher than the school at large. Data to date, based on tracking of one incoming freshman class, show that close to 80% graduate in 8 semesters and 20% of the students graduate in 9 semesters. Importantly, some students in this freshman class either withdrew or transferred. As the data indicate, academics for Dr. Greiner's students are usually not the problem. As Dr. Greiner says, "It has to be a community" with social events, and game nights. Students consider themselves beyond "social skills training." Therefore teaching has to be done "organically, in real-world situations." Dr. Greiner also reports that students who don't come for help early don't do as well as students as others. Some students participate in her program for two years, and some for all four years.

*see Supports on page 27*

## Hospitals from page 12

not at all." Pediatric intensive care protocol and routine procedures are about to careen into the equally gridiron world of autism. Despite all the drugs, Billy fights to wake up and take charge of his body. The staff do not understand his larger-than-life tenacity. Our immediate task is to keep Billy calm so that he will lie still for hours as the pellet passes through his lower intestinal tract. Despite my instructions, the nurses adjust his bed, reconnect the IV, and move back and forth through the flapping curtain. They act as Billy's wake-up call. No matter what potency, type, or variation of sedative administered, adrenaline surges through Billy's body.

Billy knows. His senses are not dulled but sharpened by the noise, the lights, and the pressure of the mounds of tape on his arm and chest. This is not going as planned. With every passing hour, different doctors, different specialists peer in, concerned and perplexed by what they observe. Matt and the nurse stand on one side of the hospital bed and I stand on the other side. Our hands are placed on Billy's chest and arms. We are not there to comfort Billy. We are there to restrain him while every 20 seconds his upper body struggles to rise and break our tackle.

We are his silent tormentors. Intimidation by force is the real sedative. Alert, Billy resists this assault continuously for 4 hours. With almost supernatural concentration, Billy waits to make his move. If the

nurse leaves to update the chart or turns around to answer the anesthesiologist's question, Billy surges forward. If I leave for a restroom break or if Matt momentarily relaxes his hold on Billy's arm, Billy struggles to make a break. It is relentless. Into the third hour, my lower back aches and my feet are leaden; I just want to get the reading. This cannot fail. The cost is too high and we need answers. We need information.

But I am angry. Sedation was supposed to avoid this emotional catastrophe. A concerned doctor starts to order another sedative to add to the existing cocktail and I yell out, "No more!" I will not subject Billy to any more attempts to lure him into twilight sedation. The damage is done.

In the fourth hour, they complete the readings. The mission is complete. No longer a hostage, Billy sits up and with speed and dexterity removes all the tape, pads, and wires, as well as the needle from his vein. Blood pulses out, and Billy refuses the nurse's attempt to place a gauze pad on his vein. Billy's blood colors the white sheets and his T-shirt. Infuriated and betrayed, Billy looks at Matt and hits him on the head. Power, remorse, humiliation, and an incendiary rage blanket his face. Matt holds Billy back and gently says "no." We feel obliged to reassure the nurse that all is well, and Matt and I thank her for her exceptional help. She tells us to take our time. Billy can stay as long as he needs.

We are alone. It is dusk. The light softens outside the large square glass window.

Billy sits on a built-in alcove vinyl seat that nearly spans the length of the wall. I give Billy a pillow and our green afghan. We encourage him to rest, but he will not. Instead, he rails against what he doesn't understand. His wails are loud and deep. Matt and I silently ache. But Billy does not seek retribution. He seeks closure, and understanding. Sitting up on the bench, facing us but intently focused on his communication device, Billy replays his hospital experience over and over and over. He presses "hospital," "colonoscopy," and then he stops, cries and quivers, and begins the dirge again. Matt and I stand in a hospital room next to a bed of blood-spattered, tangled sheets and a grieving son, but we know we are blessed.

Billy does not avert his penetrating focus from the breach of trust that happened in this hospital room. No one ever told him what would take place after the colonoscopy. We had been assured that Billy would remain sedated and thus relaxed as the pellet passed through his lower intestine and the x-rays were taken. By all accounts, this medical process would be seamless. That was the plan. It didn't happen that way. Sitting on the bench, Billy faces the truth as he reviews the information on his device and evaluates the information he never received. As dusk becomes night, we cannot comprehend wholly what had occurred for Billy, for us, and for our family's humanity.

Several hours pass, and it is now evening. The doctors and nurses have gone home or are attending to other patients. We

are alone. Billy stands up from the bench. We are all ready to go home. In a line of three, Billy, Matt, and I walk around the interior corridor of the pediatric intensive care unit. With his communication device strapped around his neck, Billy is composed and resolute as he walks straight ahead. As we exit, I turn my head, nod, and smile briefly at the doctors who watch our dignified procession move out the sliding doors. Billy is a class act.

*Eve Megargel is an educator and speaker about effective communication initiatives for individuals on the autism spectrum. She is the creator of the Voice Colors Communication Resource Model and the mother of a 22 year old with autism and ongoing medical needs.*

*Sarabeth Broder-Fingert, M.D. is a fellow in the Harvard Pediatric Health Services Research Program and works at the Center for Child and Adolescent Health Research and Policy at the MassGeneral Hospital for Children.*

*Address correspondence to Sarabeth Broder-Fingert, MD, Center for Child and Adolescent Health Research and Policy, MassGeneral Hospital for Children, 100 Cambridge St, 15th Fl, Boston, MA 02114 (e-mail: sbroderfingert@gmail.com).*

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# Igniting Passion - Actualizing Potential

By Molly K. Rearick, EdD  
Founder & Director  
Reid's Gift, Inc.

**P**icture an ember – a small glowing spark that with proper care and attention will grow into a warm, radiating fire. Now picture your spark – what gets you up in the morning, what motivates you to keep going, and how do you nurture that spark?

For many of us that spark is our work, and it is nurtured by feelings of fulfillment and purpose. For many diagnosed with Autism, fulfilling, purposeful work is but a dream (Scheiner, 2011).

David's spark is painting. He is an artist whose brightly colored, uniquely designed pieces hang in homes and businesses throughout his community and beyond. David is an adult diagnosed with Autism who, after aging out of public education, chose to pursue his passion. This option is not available for many adults with Autism or other developmental disabilities, so how do they find their sparks? Thankfully, though many issues are at play in the number of adults with Autism who are unemployed, alternatives to traditional work options are becoming more abundant (Carley, 2016).

David works at an art studio that is specifically designed for individuals in his position – adults with developmental dis-



**David painting at Kindling Studios**

abilities whose passion is art – and that is run by a collaborative team of professionals and family members. Kindling Studios opened in Camarillo, CA in 2015 and currently supports ten artists with Autism and other special needs.

Though not everyone is skilled in, or even interested in art (the author included), each person has inside him or her a spark that needs kindling. By learning about each individual's strengths, skills, and

needs, and by exploring new activities it is possible to create meaningful work that employs natural supports and community partners. In the case of Kindling Studios, a number of families with creative proclivities came together to create a working studio for their adult children with Autism. With a similar model it is possible for others to create programs based on music, theatre, computer programming, accounting, or any other field.

## *Volunteerism from page 13*

participate in competitive employment opportunities without support on a consistent basis. Other individuals may require job training and support on a consistent basis, which may also require more than one individual working at that site.

Through volunteering, we have been able to bridge the gap for our individuals who are interested in eventual competitive employment, but who do not yet possess the skill set necessary for community employment. Slowly, these placements can be shaped into experiences that parallel paid employment. In the interim, it provides a flexible, safe, and individualized context in which employment skills can be honed, either individually or in small work enclaves of two or three individuals.

It is essential to find employment or volunteer placements for individuals with ASD that match their interests and skills. Individuals with ASD also need to secure opportunities that match their distinct needs (Gal, Landes, & Katz 2015). To match the individual to the best environment for them, an assessment must be done. The individual's skills, strengths, behavioral challenges, social skills, and unique characteristics must be considered in this process. In addition, preferred activities, settings, and tasks should be considered when placing individuals in potential employment environments. This process is challenging for individuals with disabilities, as they may not be able to communicate their opinions, preferences, and wishes. Furthermore, some individuals may not yet be ready for employment; more skills

training and adjustment may be required before viable employment is possible in the community.

Although the opportunity to work is very important for all individuals, there are a plethora of volunteer opportunities that may provide individuals with an entry-level introduction to various job skills and potential employment opportunities. It has been demonstrated that volunteer opportunities provide individuals with training that cannot be replicated in a day program by virtue of the environmental restrictions. There are tools and social encounters that can only be trained in real time in the natural environment. Additionally, volunteer opportunities may help the typically developing individuals in those environments to be more accepting and amenable to individuals with disabilities and ASD (Nieto, Murillo, Belinchón, Giménez-de la Peña, Saldana, Martínez & Frontera (2015)). This paves the way for more individuals with ASD being afforded opportunities in those settings in the future.

Individuals with ASD are capable of participating in a variety of volunteer opportunities. These may include areas such as sales, cleaning, organizing, pet care, service to others and greeting guests. There are several businesses and agencies like the Red Cross, Homeless shelters, food banks, libraries, animal shelters, Meals on Wheels, and other organizations that are eager to have reliable and supportive volunteers. The training provided at these jobs is easily transferable to other employment sites both in terms of the skill set and social interactions that the individuals may have while delivering, organizing, stocking, and

providing animal care. Furthermore, the development of these important socialization skills may then generalize to other social opportunities.

Many individuals with autism rely on routines, thrive on structure, and have a high level of attention to detail. These are valuable traits for any individual in a competitive employment setting. These traits may also be readily displayed during volunteer activities and assignments. Additionally, there is a great sense of self-satisfaction that can be gained by helping others. We have volunteered at homeless shelters, museums, organizations for the elderly, and organizations that support animals. The reward of helping other people is an integral part of volunteering and important for individuals with ASD to experience - as a helper vs. as a recipient of help.

Volunteers with ASD are reliable and steady, and become integral parts of the organizations that they support. This can increase the confidence and skill sets of individuals with disabilities as they move into employment opportunities. The ability to volunteer provides opportunities to build the resumes of individuals with ASD to help them secure employment in the general and competitive workforce. Many volunteer placements turn into employment situations for our learners. Even when they do not, supervisors at these settings might serve as employment references. And in all cases, the volunteer opportunity serves as a step in the move from sheltered employment with familiar staff and settings to independent employment in the community. This bridge can help build skills in a role that is not associated with pay, and which

When creating a passion-based program, a working partnership between families, professionals, and community members is paramount. Most importantly, individuals with Autism must be involved in the creation of programs and services meant to support their strengths and needs (Hagner, May, Kurtz, & Cloutier, 2014).

Kindling Studios incorporates instruction in both art and entrepreneurial skills, and is advised by its artists and their families as to goals, art mediums, and other programmatic components. Paid professionals include an art therapist, professional photographer, professional musician, and special education expert. Volunteer instructions include weavers, ceramicists, sewers, quilters, painters, and other artists. Artists work in an art collective that houses a number of other community members, most without diagnosed special needs. This integrated setting allows artists with Autism to practice not only art and entrepreneurial skills, but also to engage in real life social interactions, problem solving, and collaboration.

Kindling Studios is not unique in its approach to teaching and supporting artists with Autism, and its creators are inspired by other similar programs across the United States including MAKE STUDIO, Imagine That!, Arts & Services for Disabled, Inc., and Pure Vision Arts.

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therefore can be more flexible, individualized, and stress-free.

A comprehensive approach to work experience is needed to prepare learners with ASD for ultimate employment. Volunteering creates a novel way to build work relevant skills in a context that is lower in stress and in expectations. At the same time, it provides an unfamiliar environment outside of the therapeutic setting in which skills can be generalized and further refined. Individuals with lower stamina, challenging behaviors, or emerging skills may have more success in these experiences, as it may allow them to take the necessary time to develop the skills that could help secure later employment. In addition, such experiences sometimes provide social support, social skills opportunities, and increased community involvement for individuals with ASD. It may also enhance the understanding of ASD in these environments and among the employees in that setting, through building relationships with the individual(s) and employees. Such connections advance the dissemination of accurate information about people with ASD. As we consider creative models to equip learners with ASD with skills for adult living, volunteering options should be considered.

*Liza Jones, MA, is Director of Adult Day Services at Melmark. Patricia A. Finney Schulman, EdS, BCBA, is Administrator of Program Services at Melmark New England. Mary Jane Weiss, PhD, BCBA-D, is Executive Director of Research at Melmark.*

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# Screening for Autism in an Adult Psychiatric Facility

By Annette L. Becklund, MSW, LCSW  
Autism Consultant  
Oglethorpe, Inc.

**T**hree years ago, the CEO of Oglethorpe, Inc., John Picciano, LCSW, sat snoozing in the back of the room while listening to a presentation at a National Association of Social Workers (NASW) Conference called, "Autism, Asperger's and the Culture of Neurodiversity." Somewhere in the middle of that presentation, John's eyes flew open as though a light bulb suddenly switched on in the back of his head. John shared, "I'll bet there are a great number of patients admitted to our psychiatric facilities who are misdiagnosed and may be on the Spectrum."

According to the CDC, the current Autism rates in children are 1:68 (Center for Disease Control, 2014). Autism rates with adults are a different story. There are no definitive numbers. A simple search on Google yields articles on the needs of adults, but estimations of the numbers based on new diagnosis are not easy to find. The adult population is in need of services and effective strength's based programming. What is the best approach to best serve the newly diagnosed adult?

The Autism Project

The Autism Project (currently pilot-



Annette Becklund, MSW, LCSW

ed through one of Oglethorpe's psychiatric hospitals, Springbrook Hospital in Brooksville, FL) seeks to screen and evaluate patients admitted to psychiatric facilities for Autism in order to provide proper treatment and referrals upon discharge. The program, currently in its infancy, has gathered raw data through the use of the Autism Research Center's AQ10 screening test (Allison, C Auyeung B, and Baron-Co-

hen S, 2012). Those who meet the criteria (scoring 6 or above on the AQ10) are then evaluated for Autism Spectrum Conditions (with informed consent) by a trained clinician utilizing the AAA Assessment (Baron-Cohen, S, Wheelwright, S, et al (2001) and (2004) Scott F., et al (2002)). During the month of January, numbers of patients warranting a more thorough evaluation (scoring 6 or above on the AQ10) were over 11%. These 11% carry labels such as Schizoaffective Disorder, Mood Disorders, Borderline Personality Disorder, ADHD, PTSD, and Substance-Related and Addictive Disorders.

Rough estimates prior to January averaged 7.3%. However, a more efficient source to gather raw data was discovered and procedures changed. Though it is still early, it is clear that more services are needed as the number of individuals admitted to Springbrook Hospital with comorbid and/or misdiagnosis is higher than the 1 in 68 (Center for Disease Control, 2014).

## Florida Resources

In the state of Florida, there is a wait list for services through the APD (Agency for Persons with Disabilities). "Waiver applicants who are in a crisis situation (homeless, danger to self or others, or caregiver unable to give care) should contact the Agency for Persons with Disabilities regional office serving their county" (<http://apd.myflorida.com/customers/application>).

## What is Needed

Research is needed to determine the precise numbers of misdiagnosis and/or comorbid conditions. Those numbers could then be reported to federal and state governments in order to hopefully increase the number of available resources for individuals who are adults and newly diagnosed.

The creation of effective programming is needed. Someday the 1:68 numbers will grow up to be adults. A more proactive, creative approach across the board (throughout the United States) is needed

*see Screening on page 30*

## Empowering from page 16

While we often reward focus and staying on task it can be confusing to our trainees when we say, "Well, usually but not always" and have them understand the exceptions and when to shift focus. Staying on task is great, but learning to shift is just as important. The shifting demand needs to come from an authority, not only self-determined.

### Motivation and Perseverance

No matter how routine a job is designed to be there are bound to be situations that need new solutions. Too often our trainees ask for assistance before they have put in the effort to find a solution on their own. They don't understand that they are responsible for their work. This behavior will undermine them in their job. No manager expects to do her employee's work (where's the value add?). We encourage our trainees to turn to a peer for support before asking the supervisor for help. And even more important is the ability to think through the situation and propose a few possible solutions so that the manager can choose between two options. That is providing value, but it requires effort. When an employee is motivated to be successful because of her interest in the work, she is more likely to persevere when called upon to take responsibility.

Many of our trainees seem to be conditioned to expect someone else to figure things out for them. This has been referred to as "learned helplessness." They are afraid to make a mistake so would rather

ask for help before trying.

On the other hand some trainees have been taught to work so independently that they do not seek advice and feedback in a collaborative way. They make some decisions that are inappropriate, but feel they must be doing the right thing because they are being "independent." Collaboration and consent are not the opposite of independence. Understanding the balance between working independently and collaborating with peers and managers is another challenge for our trainees with autism.

Where do people learn how to collaborate, be responsible, negotiate, accept feedback and push through to completion? One important opportunity to gain these skills is in group projects at school. In general education students are expected to work in teams even in elementary school. Students learn to divide up assignments, be responsible for their portion, and yet be accountable for the whole project. They share ideas, practice negotiating, receive feedback from their team mates and adjust. During my daughter's school career in inclusion programs she was never included in those week long or month long team assignments. By third grade she no longer was involved in team sports. And the Girl Scout troop would not accept her. So she never had the opportunity to develop the skill of teaming which is so necessary in the work world.

Schools need to enable our special education students to gain these critical workplace behaviors by having them work on projects with peers. Let them struggle, depend on each other and learn to persevere.

### Social Communications

Good communication skills are essential at work to accomplish assignments and assist customers. At Girl AGain we work on appropriate workplace social interactions, including the different ways we communicate with peers, managers, and customers.

Generally, women are expected to be more skilled in social behaviors than men. Women with moderate to high functioning autism often initially present as more competent than they really are in the social realm. When a woman with ASD behaves inappropriately, she is compared to a neurotypical woman and is more likely to be penalized than either a typical man or a man with ASD.

Recently a trainee was working at one of our customer workshops (Doll Hair Do's and Don'ts) and in front of all the 8 year old customers she was chatting with a peer about all her accommodations she needed at school. This would be a fine discussion over lunch with her peer, if she wanted to disclose her disability, but inappropriate not only at the work site but in front of customers. She thought she was being "social" but context is everything. In her case, I was able to call her name and shake my head and she picked up that it was time to stop the chatter.

Another trainee was conducting research on the web for a doll outfit and when frustrated she would yell out my name, demanding that I come over to her to help her. While as a manager I am friendly to her, we are not friends. She needs to learn that an employee can't treat the manager in a disrespectful way, how to more appro-

priately get the attention of the supervisor. Learning to differentiate styles of communication based on roles is a challenge for our trainees.

### Manage Emotions

People with ASD have sensory, emotional and attention regulation issues that need to be considered when choosing appropriate work place environments. Our trainees at Girl AGain boutique must develop coping mechanisms to manage their bodies and emotions on the job. This is something that each worker needs insight into and she must develop ways of coping to maximize her work productivity and minimize her emotional issues effecting her performance.

In addition, organizational and attentional weaknesses can impede her learning and productivity on the job. This can't be taught in an artificial setting. It needs to be taught in an authentic business environment where the individual has to learn to deal with realistic challenges, in an environment where all things cannot be controlled.

Many of our trainees can become overwhelmed by noises, crowds, and unpredictable movements. When three families with excited little girls show up at the store, some trainees can't cope. They know to retreat to the "cozy corner," put on their ear buds and listen to music. As long as this plan has been established in advance with the manager, it is acceptable. While we want to avoid melt downs we also want

*see Empowering on page 28*

# The Benefits of Coaching to Develop Key Skills for Independent Living

By Sheila Simchon-Steinhof, MS  
and Samantha Feinman, MSEd  
New Frontiers in Learning

**I**ndependent living skills, or life skills, are important tools that are needed in order to successfully navigate the world. In the 1990's, a surge of children were diagnosed with autism spectrum disorders (ASD) and are now approaching adulthood (VanBergeijk, E., Klin, A. & Volkmar, F. 2008). Through early diagnosis and intervention, many of these children are now able to consider moving on to living independently, pursuing post-secondary education and entering the vocational world. However, continued support and interventions may be necessary to continued success. Moving out on your own for the first time can be very daunting for anyone. There are a whole new set of skills that you will need to learn to make this transition manageable. Having the support and guidance of a coach can relieve much of the stress. Being prepared on what to expect, having a community to support you and the ability to turn to someone to resolve conflict can help to ensure greater success.

A longitudinal study examined the prevalence of young adults with ASD ever having had, and that currently have, a paid job from 21 to 25 years of age. The study analyzed the rates of full-time employment, wages earned, number of jobs held since



**Sheila Simchon-Steinhof, MS**

high school, and job types. Results showed that approximately one-half (53.4%) of young adults with ASD had ever worked for pay outside the home since leaving high school, which is the lowest rate among disability groups. Further, young adults with ASD earned an average of \$8.10 per hour, which is significantly lower than average wages for young adults in the comparison groups, and held jobs that clustered



**Samantha Feinman, MSEd**

within fewer occupational types. Odds of ever having had a paid job were higher for those who were older, from higher-income households, and with better conversational abilities or functional skills. Findings of poorer employment outcomes for young adults with ASD suggest that this population is experiencing particular difficulty in successfully transitioning into employment (Shattuck, P.T. et al., 2012).

According to Developmental Psychology, a study showed that the transition from adolescence to adulthood is a time of amplified risk for individuals with ASD (Taylor, J.L. & Mailick, M.R., 2014). The results indicated significant declines in the level of independence and engagement in vocational/educational activities over the study period, particularly for women. Greater independence in vocational activities was found for those with more independence in activities of daily living. After controlling for personal characteristics, receipt of more services was marginally related to greater improvement in vocational independence.

It is clear that those identified with ASD are at a higher risk of experiencing difficulty in independent living, job attainment and job retention. The types of supports that are linked to greater success are those that involve working closely with adults with ASD on daily living skills. In a study examining 417 adolescents with a diagnosis of autism spectrum disorder, Duncan et al. found that approximately half of the adolescents were identified as having a daily living skills deficit (Duncan, A.W. & Bishop, S.L., 2013). Autism symptomatology, intelligence quotient, maternal education, age, and sex accounted for only 10% of the variance in predicting a daily living skills deficit. Identifying factors associated with

*see Independent on page 36*

## *Partnerships from page 16*

been clearly documented as most effective and should be incorporated accordingly in teaching each of the critical skills outlined by the team (Wilczynski, Green, Ricciardi, Boyd, Hume, Ladd, & Rue, H. 2009). Most teaching plans should therefore include descriptions on how to best utilize reinforcement systems, visual supports, prompting procedures; how to arrange lessons in natural contexts using an established lesson format; how to program for generalization and maintenance; and a description of progress monitoring and evaluation systems (McNellis and Harris, 2014).

Once critical skills and intervention plans have been developed, the team must also discuss the specific settings where instruction should occur and who will provide the instruction. This issue is critical for nontraditional student instructional settings such as the home, employment and community settings. One effective approach is assigning educational staff responsibility for achieving initial skills acquisition in the school, employment, and community settings. Once skill mastery has been achieved, then the family receives support so it can assist in facilitating generalization to community settings as well as the home.

To support families in their role as "co-instructors," educators should initially share and review the lesson plan summary with family members. It is also helpful to provide the opportunity for families to see professionals teaching the skills using the strategies outlined in the lesson plan summary. While necessary, these initial

steps alone are often insufficient in helping families to implement instructional procedures consistently in home and community settings. However, when families are provided with additional in-situ coaching and feedback, they can quickly learn how to consistently implement these strategies (Harris, Peterson, Filliben, Glassberg, and Favell, 1998). Therefore, family coaching and feedback in the home and in community settings during their initial teaching attempts is important in achieving success. Eventually, support can be faded as the family becomes more fluent in using the teaching strategies.

## Conclusions

Research has conclusively shown that family involvement in each student's education leads to better outcomes as the individual transitions from school-based services to adulthood (McDonnell and Nelson, 2010). The use of person-centered futures planning to guide team education activities and shared ownership of teaching among families and professionals enhances the benefits of parent/professional partnerships and help families meet goals that result in a successful transition to adult services.

*Todd Harris, PhD, is Autism Director and National Autism Consultant, Devereux. Richard Allen, PsyD, BCBA-D, NCSP, is Clinical Director, Devereux's Community Services. Lois Trusler, BSW, is Transition and Employment Coordinator, Devereux CARES. Kate Langston, MED, BCBA, is Clinical Coordinator, and Amanda Duffy, MED, BCBA, Pro-*

*gram Director, at Devereux CAAPP.*

*For any additional information about the content of this article or about Devereux's Autism Services, please feel free to contact Dr. Todd Harris at [Todd.harris@devereux.org](mailto:Todd.harris@devereux.org) or 610-873-4930 or visit [devereux.org](http://devereux.org).*

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# Adults and Autism: Insights and Changes from a Clinical Perspective

**By Susan Cortilet-Jones, LMHC**  
**Therapist/Adult Coaching Specialist**  
**for Autism and Neurodifferences**  
**Discovering Your World, P.C.**

**I**t has been six years since I first wrote on the topic of evidence-based behavioral health treatment for adults diagnosed with autism spectrum disorder (ASD). I would like to revisit this subject to address progress in the field. Without substantive data to help guide behavioral and therapeutic treatment, the research and scientific communities are still working to develop methods for gathering evidence to help address the growing needs of adults with ASD. Thus, insight on how to help these adults remains “paper thin” (Carpenter, 2015). For the stakeholders (e.g. autistic adults, parents, educators, healthcare providers, the mental health and rehabilitation communities, etc.), we are seeing an accelerated focus on identifying the needs of autistic adults since research has been largely focused on genetics and early intervention.

Often by the time individuals with ASD reach adulthood, they have developed a learned distrust of healthcare professionals in response to failed treatment interventions and misdiagnoses. During the years I have worked with adults, I have come to realize that successful outcomes only occur when a trusting relationship exists between the provider and client, as each person will



**Susan Cortilet-Jones, LMHC**

often possess unique characteristics critical to understanding and implementing a treatment plan. In 2012, the Missouri Department of Mental Health recommended in a guide that evidence-based practices “include consideration of individual characteristics.” Further, it recommends that clinicians should not make treatment decisions based “solely on scientific evidence and professional expertise,” but, rather should be “made in the context of the

strengths, concerns, values, and preferences of the person with ASD and his or her support network” (Interventions, 2012).

An outcome of growing up having mostly negative experiences often results in distrust towards professionals working with autistic adults. One client when presented with multiple opportunities related to their goals, for many years patently responds with, “I don’t believe you.” This individual like many others has a lifelong history of failed interventions and limited progress in adulthood stemming from earlier experiences. Currently, in addition to understanding the basic needs of adults with autism, those of us working with this population including self-advocates, parents, policy-makers, employers and others recognize what I consider a looming public health crisis if we don’t dedicate resources to helping these individuals.

It is important to mention that not all adults with autism and their families seek or need services. There are those who have navigated their way through life without need for supports and are satisfied with their “differentness.” A family member shared a description given to them by their adult child: We are a “pragmatic tribe” (referencing Steve Silberman’s book *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*) (Silberman, 2015). This autistic individual and their family approach the strengths and challenges associated with autism not as an overarch-

ing deficit, but rather as their collective and individual identity. Additionally, the Autistic Self Advocacy Network (ASAN) co-founded by Ari Ne’eman, is advancing the self-advocacy movement by ensuring that “autistic people enjoy the same access, rights, and opportunities as all other citizens” (Autistic Self Advocacy Network (ASAN), 2016).

As a therapist and life-skills coach, the general focus in coaching or therapy is geared towards a process of growth and achievement of goals. A priority for the therapist should consistently be a therapeutic approach that is “client-centered” and focuses the individual towards internalizing skills and developing ownership towards a greater sense of independence, self-worth and dignity. Progress towards goals, which can be short or long term, is heavily dependent on improving personal insight, adapting life skills, and collaborating the needs of caretakers, the client, therapist and all supports. All parties must recognize that the intent is not to “change” the adult to fit the needs of their family, friends, etc., but rather to help clients internalize skills that secure a sense of self-worth and dignity.

Although I often direct clients and families to written material, support groups and seminars, parents are especially overwhelmed and frankly tired after years of

*see Insights on page 29*

## Wish I Knew from page 15

Those obsessive interests are a perfectly normal part of your diagnosis. You care more about a single topic (or handful of topics) than most people do about any of their hobbies. You’re awesome, and you can harness that intense focus to do a lot of good in the world. Make art, write books and inspire others.

6. You’re not lazy or unintelligent.

I struggled to hold down a job and stay

in college full-time before receiving my diagnosis. I now know that this was because of sensory overload, social exhaustion and executive functioning difficulties. In other words, I couldn’t juggle real life as well as other humans. Choose your jobs carefully, practice time management and take time to recharge at the end of the day.

7. You’re not ugly for dressing comfortably.

This one is mostly for the ladies, although it can spread across all genders.

You’re not any less feminine for dressing comfortably because of your sensory issues. I’m often perceived as lazy and not “girly” enough, when I just dress for comfort most days. You’re beautiful no matter what you wear and don’t let society pressure you into thinking otherwise.

8. You’re you. And you’re wonderful.

Like me, you might be a mess most days. You may not be friends with your diagnosis right now. However, your diagnosis is a manual to living a more suc-

cessful, fulfilling life. Use your strengths, know your weaknesses and work on the social aspects you struggle with. It’s so worth it.

*Taylor Raines is a 23-year-old writing & rhetoric major at the University of Central Florida. After receiving her diagnosis at the age of 22, she’s dedicated her professional career to studying high-functioning autism from a gendered/sociological perspective. To contact Taylor, please email taylorraines@Knights.ucf.edu.*

## Dilemma from page 29

a spider needs to rebuild her web? So far this hasn’t worked because without the spider, the web decays. People with adequate social skills innately know how to rebuild their own webs. So who is going to build and maintain hers?

Now I am beginning to think differently. I am coming to the conclusion that residential living isn’t necessarily a bad idea. Maybe we just need to tweak the model. Intentional communities with brilliant designs are beginning to pop up. At the same EASI Foundation conference mentioned earlier, Desireé Kameka, National Coordinator, Coalition for Community Choice at the Madison House Autism Foundation in Rockville, MD, showcased some exciting pilot projects. Unfortunately, most parents like myself are priced out.

In the end, I believe poverty is a significant factor. Currently, without supplemental residential funding, most adults with

autism cannot afford to live anywhere else but with their parents. Currently the potential sources of state and federal funding are focused elsewhere. What will it take to wake our elected officials up? If we are not proactive now, the epidemic numbers of autistic adults will face much more costly crisis placements into prisons, nursing homes and homeless shelters!

If our Federal and State governments share the cost of developing innovative affordable housing options with us now, and they support us now in the process of creating the necessary networks of supports, our children will win, and the self-determination movement will succeed. Help us advocate for the funding we need now to create the affordable housing models our adult children need. Help us let go. It’s the right thing to do.

*Alexandra Bricklin is a music therapist currently living with her husband in an apartment above the garage of the house*

*owned by Rebecca Bricklin’s Personal Assurance Team Inc., the corporation founded to create and protect quality of life across lifespan for their daughter Rebecca and two roommates. To learn more, visit our Facebook page, Rebecca Bricklin’s Personal Assurance Team Inc. at [www.facebook.com/CommunityforRebecca](http://www.facebook.com/CommunityforRebecca) or contact Alexandra at alexsol-re@mac.com.*

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# Defining Care for High-Functioning Adults with Autism

By Daniel Crofts, MA  
Day Habilitation Assistant  
Genesee County Chapter, NYSARC

**A** lost art in modern conversation (not surprisingly, as we are quite possibly the busiest society in world history) is the definition of one's terms. To be sure, this requires time and patience; but by clarifying all foundational points, we make the rest of the conversation much easier. Consequently, that is how I intend to begin.

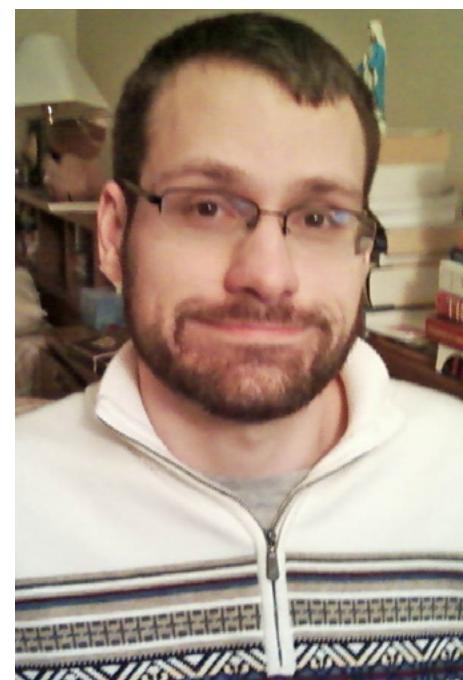
The topic of this issue is *care for adults on the autism spectrum*, and so I will begin by defining three key terms – namely, *care*, *adult*, and *autism spectrum*.

Here are some of the ways in which Webster's Dictionary defines *care*:

"A source of worry, attention, or solicitude; Caution in avoiding harm or danger; The function of watching, guarding, or overseeing; To be concerned or interested; To have a liking or attachment" (Care, 1984, p. 230).

Notice that all of these elements are broadly applicable. To name just one example, there are many ways of "watching, guarding, or overseeing" that include neither constant surveillance nor parental oversight.

Next, *adult*. Let us turn once more to Webster's Dictionary:



Daniel Crofts, MA

"One who has attained maturity or legal age; A fully grown, mature organism" (Adult, 1984, p. 80).

Here, it is the concept of maturity that covers the broadest range. Chronological maturity is universal among the adult population. Physical maturity is, of course, nearly universal (barring certain types of

disability that cause stunted development). And when it comes to psychological maturity, we find by far the greatest diversity – we might even call it a "spectrum."

And this, of course, brings us to the *autism spectrum*. This term designates a variety of conditions that share certain commonalities such as social deficits, sensory irregularities, literalistic thinking, and idiosyncratic habits/interests. At one extreme is the non-verbal individual with no functional life skills at all; at the other, you have geniuses like Bill Gates and Albert Einstein.

Okay, so we have three terms, each covering a wide span. How do they fit together?

First of all, it is important to remember that the *autism* and *maturity* spectra overlap at various points. In other words, it is possible to be both on the autism spectrum and a fully functional, *mature* adult. For convenience, I will refer to such adults as HFAAs, or "high-functioning adults with autism."

Precisely because HFAAs are not as visibly affected by their diagnosis, they tend to fall through the cracks. They are just capable enough to be deemed not in need of any help, but their disability gives them just enough trouble to prove socially and professionally prohibitive.

As you may have guessed, this brings us back to the concept of *care*. The care that HFAAs require will obviously differ from the type of care appropriate to their brethren further down the spectrum, and

probably stands in less need of various funded services. The onus, I submit, rests on family, friends, coworkers, and other close acquaintances.

What does this "onus" look like? How does one give HFAAs the help they need without being overbearing? On the other hand, how does one give them their independence without setting them up for failure?

The answer to these questions is going to depend upon the nature of one's relationship with any given HFAA, as well as upon the setting of that relationship. With that in mind, I will explore the aforementioned questions within the context of two of the most typical human relationships.

## Bosses

Professional relationships are important, as the workplace is where people spend most of their waking hours. The Webster's definition of *care* applicable here is the one involving *concern* and *interest*. All employers have a vested interest in their human resources and in the success of each employee.

For those employing people on the autism spectrum, my advice is this: Above all, be patient with the extra hurdles over which your HFAA employees, through no fault of their own, must leap. Try to respect

*see Defining Care on page 30*

## Supports from page 22

Whereas it is relatively easy to quantify GPA and graduation, it is much more difficult to qualitatively provide evidence of success, beyond anecdotal data. For example, how many students may have dropped out were it not for the supports of this program? How many students made friendships, joined clubs, and participated in other social events for the first time? Certainly these are precursors to the social skills needed to successfully navigate the work place. Moreover, they are the experiences almost all successful college students engage in.

### College Steps

College Steps, founded in 2011, is another comprehensive program that has successfully gained foothold on several community colleges campuses on the east coast. The program supports an average of 10 to 20 students on each campus. The first mission is to provide a transition from high school to college, as students move from the shelter of an IEP and family involvement to a campus setting where family involvement is far from standard. The goals of the program are as follows: academic, independent living, social development, employment training, and individualized college planning. Each program is staffed by a full time program coordinator as well as 15 to 20 mentors from the college campus. These mentors are paid and provide reportedly 25 hours weekly of direct support. The support extends to families and to assisting educators to understand the

needs/limitations of each student. The program is funded by government agencies (including Medicare) and private donors.

With regard to outcomes, College Steps documents the grades for students at the end of each semester. The average grade for all community college students is reportedly a "B." In order to measure independence, the program administers the Adaptive Behavior Assessment II to all students. Employment data is just beginning to be aggregated, as many students have not graduated from the programs in Massachusetts, Connecticut, and Virginia. For Vermont graduates, based on 26 students who have completed the program, 87% of these students are working 15 hours or more and are paid more than minimum wage.

With regard to qualitative data, Lauren Merritt, Program Director, acknowledges that it is difficult to obtain. That is, few researchers or programs have successfully measured and reported on "friendship" - that is improved social outcomes. Given the comprehensive scope of this program and funding limitations, it is easy to understand why and how this data has not been collected. Funding agencies are seeking a particular type of evidence based practice. Nonetheless, engagement on campus (participation in social events, clubs) and friendships may prove to be important predictor of successful employment (Test, R. 2015).

### New Frontiers in Learning

Finally, Daniel Koffler, Executive Director, and Samantha Feinman began New Frontiers in Learning in 2012 with less

than 10 students. The program now serves 60 students in the greater New York area (Long Island, New York City, Westchester, and Northern New Jersey). New Frontiers is a private, for-profit company whose mission is similar to the programs described above. The goals are to increase independence, self-advocacy skills, and academic learning, and to improve executive function and social interaction. Executive function includes time management, planning, and learning to break assignments into manageable segments. The program includes a two week college readiness program to ease the transition from high school to college. It is highly personalized so that each student learns about what to expect on the particular campus they are attending. Students meet 1:1 with coaches; sessions are highly geared towards academic learning and improvement of executive function. The program also offers career development services and job coaching. To further address social success and executive functions, a three week Summer in the City program is also offered. Students meet staff at Grand Central Station or Penn Station in New York City (students must plan how to get there and the time it will take) and visit a sight or engage in an activity in the morning. Students then have lunch and discussion (including skill building) at the program's New York City office.

To date, this program reports no statistical outcome measures. Success is anecdotal in the form of parent and student testimonials. The administrative team recognizes the need for this information and plans to implement a more comprehensive form of program evaluation. According to

Koffler and Feinman, what makes their program successful (continuous growth, with new offices potentially opening in White Plains and Northern New Jersey), is the relationship between coaches and students. For students who are not comfortable identifying themselves with a disability, this model offers students privacy. Importantly, these students are at a higher risk for failure, according to Dr. Greiner at Purchase College.

With so many students with ASD college bound, colleges and universities are increasingly including special support programs for these students. Several questions remain, including how these programs will document both quantitative and qualitative evidence to give parents/students a sound way to evaluate their effectiveness. Furthermore, the questions of whether these programs will be able to sustain funding is a question, particularly in New York State. Whereas public (city and state) universities and colleges in New Jersey and Connecticut can charge parents for their special programs, this is not allowed in New York. It is important, as these programs proliferate, that there be a way to compare and contrast their effectiveness, similar to the public and private data ranking colleges and universities as a whole. On a personal note, one must also consider the personal recommendations of parents and students who have (or have not) reaped the benefits of these programs.

For more information on programs cited, please contact: Lauren Greiner, SUNY Purchase, [lauren.greiner@purchase.edu](mailto:lauren.greiner@purchase.edu);

*see Supports on page 34*

***Direct Care from page 9*****The Direct Care Collaborative**

To provide a more complete perspective of the opportunities that exist to improve the quality of life of both of these marginalized groups, The Direct Care Collaborative was established. The collaborative proposes a cost benefit analysis comparing the impact of investments in training, a living wage, performance-based compensation and opportunities for professional growth to cost savings to the care provider, the broader community and society at large. This work is significant and may provide the required evidence that supporting these populations, in addition to being the right thing to do, may also be the smart thing to do. Our goal is to become a national model in the training of staff to improve their lives and the lives of those they care for.

**Collaborators****Service Provider: Bancroft**

Bancroft has been a service-provider in New Jersey, Pennsylvania and Delaware for 130 years. Annually Bancroft serves 1,500 individuals with autism, other intellectual or developmental disabilities and those in need of neurological rehabilitation. Their methodology is evidenced based and all programs have a clinical presence.

This Collaborative will begin by creating a demonstration site at the Lakeside Campus. Lakeside is a campus-based setting that serves 48 individuals with severe autism, including, complex and challenging behaviors. Many of the individuals do not have natural language and have been unsuccessful in traditional group homes. The pilot will include two homes and eight individuals.

**College/University Partners: NJ Community Colleges and Universities**

The Collaborative will include a(n) Educational Partner(s) that will incorporate the Bancroft competency curriculum. The goal is the development of a skills based certificate program. The certificate will be available as a stand-alone program and as a prerequisite for an Associate or Bachelor's Degree and/or credits and supervised hours towards becoming a Registered Behavior Technician (RBT) or Board Certified Assistant Behavior Analyst (BCABA).

**Research Design:** Dr. Laurie Sperry (see bio at end of article)**Project Management:** Dr. Cyndy Hayes (see bio at end of article)**Proposed Project**

Our project is comprised of four cor-

nerstones aimed at addressing the needs of the direct care worker and the person with ASD:

**Professional Development** - Our mission is to professionalize and incentivize training for direct service workers. To accomplish this goal we will develop competency based, video training modules leveraging the expertise of Bancroft clinicians and other autism experts. The training will incorporate the videos and hands on practice and feedback sessions to reinforce competencies and reflect the principles of adult learning. Staff will provide modeling, coaching and feedback to the direct care staff. As adults are accustomed to being autonomous and self-directed they will have opportunities to share their expectations and training needs that must be met. These sessions will be filmed and edited and become a major component of subsequent training initiatives and support the sustainability and scalability of the work.

Adults want information that is timely and topical. Theory is not helpful to the adult learner without pairing it with practical, relevant solutions. They need to focus on current and real life issues, rather than material that may be useful in the distant future (Satterfield, 2013). To that end, Bancroft managers will provide additional coaching within the direct care staff's work settings. Workers will be asked to apply information to current work situations as research has demonstrated that a new skill that is not used within 30 days of its acquisition is often lost (Knowles, Holton, & Swanson, 2014).

**Career Ladders** - To retain and motivate individuals in the direct care field, there must be a clear path for advancement. A career ladder will be developed that will include levels of skill and experience leading to supervision, managerial or clinical positions. Each of these will require different competencies and will include salaries commensurate with those competencies. Performance reviews will focus on performance and career goals. Direct care workers will not have to leave a position to advance. Even if they choose to stay in the direct care position, salary steps will acknowledge their knowledge, experience and skills.

**Metrics** - Measurable outcomes are particularly significant in this initiative. In addition to proof of concept, metrics may provide the tool necessary to change public policy regarding how people with autism are served as well as create a living wage for the millions who serve them.

- **Individuals Served** - Data will be collected on Individual behaviors and skill acquisition throughout the pilot

for comparison to baseline.

- **Care Provider Metrics - Dashboard** will measure costs including turnover, overtime, staff medical costs and legal fees
- **Related Costs** - Other related costs will include the cost to insurers for hospitalizations, ER visits, complications, medications, and re-hospitalizations.
- **Other CMS** - Cost of public assistance to direct care staff by ensuring a living wage.

**Community Building** - Community building is imperative to enhance the ability of the individuals served to participate within their community in a safe and meaningful way. Community building will begin with a large stakeholder workout session including parents and guardians, staff and management, members of the board and leadership team, support agencies, local businesses and the community at large. This diverse group of stakeholders will co-create the future at its best for the individuals served. This shared vision will drive the strategy and guide the action planning.

**Concluding Thoughts**

This initiative will provide four urgently needed outcomes:

1. Opportunities for two million direct care workers to advance their training and education and thereby earn a living wage and reduce this population's reliance on public assistance.
2. Reduce the employee turnover and thereby create a stable employee base allowing administrators to focus on the individuals they serve rather than dealing with constant staff replacement, reducing the high costs associated with turnover and overtime.
3. Provide the stable training, direction and relationships that are critical to improving the lives of individuals with autism and other related disorders.
4. Reduce the disruption that staffing changes cause, residential and day programs will become stronger and more effective.

*For additional information, please contact Dr. Hayes at [cyndyhayes@gmail.com](mailto:cyndyhayes@gmail.com).*

*Dr. Cyndy Hayes, DBA, is an international lecturer in leadership and organizational development, and has led major organizations in strategic change and cultural transformation. She continues to use her organizational skills in her advocacy of individuals with autism. She has*

accommodate our candidates and even reconsider how a job is defined in an organization.

One way for a person to add value to the business is to perform a portion of a job so efficiently that it makes sense for the business to carve out that part of the job across the organization and bundle it to make a new position, then freeing up the employees who had that task as their responsibility to now perform other mission critical tasks.

There are many organizations and family

*led several non-profit organizations that provide support to individuals with autism and their families. She is currently President of Aging with Autism. Dr. Hayes co-founded Advancing Futures for Adults with Autism, a National Collaborative that many credit with starting the national dialogue on the needs and challenges of adults with autism. She is also founder of the iAssist Company, a social enterprise dedicated to providing technology and support to teens and adults with severe autism. She is a parent of a 25 year-old son with severe autism.*

*Dr. Laurie Sperry, PhD, BCBA-D, participated in global outreach in Australia, Saudi Arabia, Qatar, Jordan, Africa, Saipan, Singapore and developed a school for children with ASD in Bangalore, India. She served as a Principal Investigator on OSEP grants and IES grants. From 2004-2007 Dr. Sperry served as a director of the OSEP funded Professional Development in Autism (PDA) Grant, working with US school districts to build 33 model ASD classrooms. During her tenure as director, Dr. Sperry and her staff worked collaboratively with districts to build 33 model sites across the nation. In 2010 she worked at Griffith University in the Department of Arts, Education and Law, Australia. While in Australia, Dr. Sperry worked to build model sites in rural and remote parts of the country. Starting with the development of one model site, she worked with state and local agencies to develop 4 additional sites across the country.*

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***Empowering from page 24***

to help the trainee to build up tolerance and resilience to their stressors.

Managers in conventional businesses will need to be taught how to get the most productivity from an employee with autism, and in appreciating the value the employee can bring to the job be willing to accept unconventional behaviors and coping strategies of autistic employees.

Business managers do not want to increase expenses by hiring employees unless that incremental investment has a positive return. So the employee needs to add value. Employees need to be self-sufficient, take work load off of the manager or other employees, solve problems, and create more opportunities for revenue.

We want employers to see the value that our ASD candidates can bring to the business but we also want the employer to ac-

commodate our candidates and even reconsider how a job is defined in an organization.

One way for a person to add value to the business is to perform a portion of a job so efficiently that it makes sense for the business to carve out that part of the job across the organization and bundle it to make a new position, then freeing up the employees who had that task as their responsibility to now perform other mission critical tasks.

There are many organizations and family

initiatives that are now focused on helping young adults with autism enter the workforce. Yes She Can is seeking to collaborate with other organizations to improve employment outcomes.

*For more information, contact Marjorie Madfis, President of Yes She Can Inc. at [Marjorie@YesSheCanInc.org](mailto:Marjorie@YesSheCanInc.org) or visit [www.YesSheCanInc.org](http://www.YesSheCanInc.org). Yes She Can Inc. - Women with Autism. We work. With you.*

# The Dilemma of Aging Parents of Adults with Autism Still Living at Home

**By Alexandra Bricklin, MA, MT-BC  
Parent and NSEAI Certified  
Special Education Advocate**

In a summary of key findings from the 2015 National Autism Indicators Report, we parents now have confirmation: "Young adults with autism had the lowest rate of independent living (19%) compared to their peers with other disabilities."<sup>21</sup> The 2015 State of the State in Developmental Disability reported: "71% of people with developmental disabilities live at home with a family caregiver... [and] over 41,000 individuals with I/DD are living with caregivers over the age of 60 in Pennsylvania."<sup>22</sup>

PA Deputy Secretary Nancy Thaler's opening statement at the 1/16/16 EASI Foundation's conference on Creating Communities for Adults with Special Needs was: "We should not lose sight of the fact that, in this country it's a poverty issue, it's not just a disability issue. Housing in this country is a crisis!"<sup>23</sup>

Too many adults with autism and their parents are resource poor and are competing with single moms on welfare, people with mental illness, people with developmental disabilities, people with physical limitations and the elderly for affordable housing in a scarce market. In addition, residential funding is on the decline while the numbers of autistic adults are on the rise.



**Alexandra with her daughter  
Rebecca (above)**

The quality of life for too many our adult children hangs on our ability to continue living with them. This, of course, is impossible indefinitely because we are not

engineered to outlast them. Planning and implementing successful outcomes for our children's future without us in it is not just emotionally overwhelming, it is virtually impossible for us to accomplish without more support!

Those of us who are providing direct care for our dependent adult children are often struggling financially, coping with aging and health issues and like me, are feeling burnt-out. Michelle Diament, a writer for the Disability Scoop website, addressed this concern in a 2009 article: "Researchers followed a group of moms of adolescents and adults with autism for eight days in a row. Moms were interviewed at the end of each day about their experiences and on four of the days researchers measured the moms' hormone levels to assess their stress. They found that a hormone associated with stress was extremely low, consistent with people experiencing chronic stress such as soldiers in combat, the researchers report in one of two studies published in the Journal of Autism and Developmental Disorders. This is the physiological residue of daily stress, says Marsha Mailick Seltzer, a researcher at the University of Wisconsin-Madison who authored the studies."<sup>25</sup>

Out of situational necessity, many of us still revolve too much of our life around our adult child. This is not our preference, but we cannot find any alternatives. Statistically, "4 out of every 10 adults with

autism are disconnected from both work and-secondary education,"<sup>24</sup> meaning they have nothing to do and nowhere to go. It's not just that our children cannot afford to live on their own, they often have no life of their own outside of what we create and maintain for them.

In Pennsylvania, many families are receiving day supports called "waivers." Initially, waivers were designed as alternatives to institutional care. Our children had a choice to "waive" their right to institutional care in lieu of community-based supports. In today's culture of self-determination, institutional care is not readily available.

My daughter receives 5 hours of support, 7 days a week. She has an Individualized Service Plan (ISP). She does have opportunities to go places and do things without me. This is good for both of us, but she is still one of those 4 out of 10 individuals not working and not in school. So, what does she do all day? She spends our money.

I am determined to succeed at the endeavor most parents take for granted, securing for my daughter a life of her own. In the process, I am going to take my life back. Initially, my strategy was to build a web of formal and informal supports, replacing myself with a team. I have encountered something I call the spider web phenomenon. Did you know that every day

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advocating for their children in school with doctors, therapists, psychiatrists and many others. The lack of understanding and the changing definitions of autism (i.e. Pervasive Developmental Disorder (PDD), Asperger, Autism Spectrum Disorder (ASD)) adds to the confusion of understanding what autism means for adults. Some clients embrace their differences and the diagnosis while others resent labels. One client whose interests and strengths are in the arts, refers to their diagnosis as "Spinart." Adults associated within the growing self-advocacy community use terms such as autism spectrum disorders, autism and neurodiversity interchangeably.

Inevitably, the first call I receive from a referral source (most often the parent) is one in which they feel that efforts have been exhausted with prior treatments. They emphasize that their child is "high functioning" and "so smart" followed with frustration that their child can't get employment, that their son or daughter lacks "motivation," or that they spend all of their time on the computer or in the bedroom. Clearly, technology is an essential tool for all of us (in many cases, tools developed by individuals with autism), but for many adults with autism, it has contributed to their delay in social interaction and personal development. Frequently, there is frustration and confusion since the adult with ASD has completed high school or has an associates, bachelor's or advanced degree in college. The parents and child relay the feeling that their previous interaction with "experts" (i.e. Vocational reha-

bilitation, psychiatrists, pediatricians and academic personnel) has contributed to a lower sense of self-worth, anger, frustration and increased social isolation. Finally, professionals driven by privacy laws often focus their attention squarely on the client without consideration of loved ones, even when both agree that the family system needs help.

A significant number of clients received an autism diagnosis in adolescence or later (a few into their 50's). Early in therapy a pattern emerges with descriptions such as: "Joey has no friends;" "Alice paces back and forth in her room and talks to herself;" "Frankie is mentally challenged;" "Sarah doesn't interact with anyone and is SO BRIGHT;" and "I'm upset because Joy hides in her room and doesn't interact with the family." Years ago, I was invited to a home with a young adult who experienced multiple diagnosis throughout their life. This individual presented as withdrawn and was described as socially isolated. Even during the intake, doubt was presented about the accuracy of an autism diagnosis. The meeting started with a parent describing me as their "Annie Sullivan." Many intakes include variations of this message with the underlying message that their adult child needs to be "fixed;" that what they understand of autism is that it is an illness or defect. Partnering with the client and family, we focus on changing this mindset.

Another often destructive myth is the notion that the individual is lazy and lacks motivation. Poor motivation has its own stigma and I often see this being confused with "inability to take initiative." Difficulty with taking initiative correlates with

difficulty in everyday transitions that most people take for granted. For example, initiating conversation, interacting with people, calling to set up an interview, and constant changes in settings throughout the day are difficult. Without understanding concepts like initiative and transitions, many adults experience resistance to change and a sense of failure. Distinguishing between initiative and motivation, adults with autism are inspired by the fact that the difficulties associated with initiative change their sense of worth away from negative labels like lazy and unmotivated. With increased insight, the client learns cognitive tools and strategies to improve their ability to be independent in their goals and decision-making.

One common misperception of autism is that it manifests as one broad issue. Not everyone with autism experiences the same challenges associated with socialization, obsessive thinking, anxiety, etc. For example, many people think that difficulty with social interaction equates with social isolation. On the contrary, many adults with autism enjoy socialization but have difficulty interacting within societal norms. Sometimes resistance to social interaction is not rejection of social interaction; rather it is the result of environmental and sensory experiences (lights, sound, voices, crowds, being touched, etc.).

A unique and specific example associated with sensory difficulty is that of an adult who experiences a painful reaction to words and phrases. Words to this individual have texture but the experience results in pain, self-loathing and self-injury. Causing a sort of paralysis, this individual describes

their experience as preventing them from taking initiative outside of their comfort zone: "I am the only person" that suffers from this "horrible thing" and "that's why I can't get a job." Negative, painful and uncomfortable sensory experiences can result in extreme stress.

Obsessive and perseverative thinking varies widely in presentation and is another disabling experience for many individuals with autism. Over the years, I have come up with a visual of these thought patterns and refer to a video of a hamster running on a wheel. The hamster wheel represents repeatedly becoming stuck on a thought (e.g., "I will never have a girlfriend;" "I don't believe you...why should I believe you?", "It's not nice to look at a pretty girl...I'll go to jail"). In spite of strategies designed to help with obsessive and perseverative thinking, it is extremely difficult and challenging to help an individual extinguish, channel and/or eliminate these thoughts.

While many people will read my insights with sympathy, I want to emphasize that my impressions for the reader should not leave one with the idea that individuals with autism should or want to be pitied. After years of working with adults, I believe that without a better understanding, we are denying adults with autism and ourselves the incredible potential they have to offer. One of the biggest changes is the growing number of adults with autism leading the way to greater inclusion and empowerment by promoting the valuable contributions they have to offer society. It is a moral imperative that we continue to learn and

*see Insights on page 30*

### **Screening from page 24**

to help individuals with Autism Spectrum Conditions lead productive lives with a good quality of life. The need is evident now, with those who are adults finding out they are on the Autism Spectrum. Support groups, social opportunities, psychoeducation, life skills support, and training on issues such as healthy sexuality are only a few areas where there is "opportunity for improvement."

Trained, compassionate therapists are needed to understand and treat conditions within the context of Autism Spectrum Conditions. For example, a study quoted by the National Institutes of Health regarding children with Autism from ages 10-14 years old reports that, "Seventy percent of participants had at least one comorbid disorder and 41% had two or more. The most common diagnoses were social anxiety disorder (29.2%)..., attention-deficit/hyperactivity disorder (28.2%)..., and oppositional defiant disorder 28.1%.... Of those with attention-deficit/hyperactivity disorder, 84% received a second comorbid diagnosis" (Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., m Baird, G., 2008). One therapist called looking to make a referral because he informed the writer, "I am not qualified." The writer asked, "Do you treat anxiety?" The answer was affirmative. "Do you treat individuals from diverse cul-

tures?" The answer was affirmative. "Then how about treating anxiety within the context of an Autism Culture?"

Training mental health technicians, doctors and nurses, teachers and related educational professionals, police officers, crisis workers, grandparents, parents, aunts, uncles, etc. etc. etc. to recognize signs of distress without presuming someone is "just being difficult" or "just needs discipline" is also advisable. Speaking to sensory differences and awareness of the impact of sensory overload is necessary. A hospital or school environment is sometimes loud, may echo, and may be a reason for an individual with Autism to melt down due to sensory integration difficulties. Perhaps creating a more sensory friendly environment for everyone would be an easy remedy. Everyone would benefit from a gentler environment. Lower the lights, speak quietly, and "say what you mean; mean what you say."

### **Conclusion**

Those of us who have worked with children with Autism are now watching those same children grow into adulthood. As the needs of the adult population outweigh the available services, more research is needed that speaks to the possibility that there are undiagnosed adults who are isolating because it is easier than navigating through the social environment. Some of these

adults are being admitted to psychiatric facilities such as Springbrook because of suicidal ideation or difficulties with emotional regulation (melt downs). More research is needed in identifying and assisting newly diagnosed adults who were without the services afforded children (such as social skills groups, occupational therapy, feeding therapy, etc.).

The main purpose of this article is to inform, but also it is a call to action for research, program development, and action on a larger scale with our colleagues with Autism charting the course.

*Annette L. Becklund, MSW, LCSW, NBCCH, is an Autism Consultant with Oglethorpe Inc. She also has a private practice in Neptune, NJ, and Brooksville, Florida. For more information, please call (732) 292-2929, email [AnnetteLBecklund@gmail.com](mailto:AnnetteLBecklund@gmail.com) or visit [www.AnnetteLBecklund.com](http://www.AnnetteLBecklund.com).*

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### **Defining Care from page 27**

the fact that for them, certain capacities that may be taken for granted in most people require a much wider learning curve and far more conscious and concentrated effort.

For that reason, it is imperative that you acknowledge your HFAA employee's incremental achievements. Do not approach the matter with the following attitude: "He should not be proud of himself for achieving something he should have been able to do in the first place, and neither should I. He is doing only what he is obliged to do, and that fairly late in the game. What is more, the fact that he is still not measuring up in other areas is inexcusable."

It is tempting for busy and overworked employers to take this stance, but the attitude is ultimately counterproductive. It will only serve to discourage people already sorely tempted to discouragement by their struggles.

This does not, however, mean sitting back and allowing your HFAA employee's difficulties to negatively impact your business. One of the traits of truly effective bosses is that they know their employees. They know their unique personalities, talents, strengths and weaknesses, and how these can fit into the overall schema of the workplace. By assigning to their employees roles in which they will likely thrive, they help set them up for success.

For employees on the autism spectrum, who bring unique and invaluable talents to the table, this is indispensable. As they progress, always be ready to commend them on what they are doing well. In addressing areas of weakness, present them as opportunities for growth. In this way, you will be exercising "boss-ly care" at its best.

### **Guardians**

I am using this term to refer broadly to parents, siblings, unofficial mentors, and anyone else to whom the other Webster's definitions of *care* might apply. The definition I wish to emphasize, however, is "(c) action in avoiding harm or danger" (Care, 1984, p. 230).

Good intentions by themselves are seldom enough, and even the best of intentions in the best of people can well suit the bricklayers of hell's proverbial highway. It is natural that you should worry about your HFAA children, siblings, etc. It is proper that you should pay attention to where they need guidance, and to patiently and prudently provide that guidance. It is, furthermore, responsible of you to encourage their ambitions while also keeping in view a realistic assessment of the obstacles an autism spectrum disorder will place in the way. But whatever you do, don't let care turn into limitation of their horizons.

Example: Johnny says he dreams of go-

ing to Europe on vacation. Your first reaction is to say something like this: "Oh no, Johnny. You have Asperger Syndrome. You have trouble finding your way around new places. You're also very innocent, and could easily be taken advantage of. A trip to Europe isn't for you."

You must resist the urge to respond in this fashion – especially if you want to maintain high expectations for the individual under your care. This may seem to be an arbitrary connection, but think about it: If you discourage your HFAA loved ones' passion-filled ambitions, this can only serve to weaken motivation and cripple initiative. Hence, while your intention is to care in the sense of steering away from danger or hurt, you may in fact be indirectly endangering two of their most valuable human assets: Freedom and (by extension) responsibility.

A better response might resemble the following: "That's an excellent goal, Johnny, and I would love to see you achieve it. Now there are just a couple of practical matters to consider. You do have a little trouble finding your way around in unfamiliar places. Also, you can be a little too trusting sometimes. So before you commit to taking a trip to Europe, we should maybe work on these things a little bit. [If you or Johnny have acquaintances who have gone to Europe, perhaps you could arrange for him to speak with them about these mat-

ters]. But if this is what you really want, we can get you there."

Notice that this response is both realistic and encouraging. Both are essential elements of care.

Needless to say, I have merely scratched the surface of this crucial topic. But as an HFAA myself, I have tried to offer some heartfelt insights that will hopefully be of help.

*Daniel Crofts is a 31-year-old man with Asperger Syndrome. He has an MA in English/Literature from the State University of New York College at Brockport and experience in the fields of freelance journalism, substance abuse prevention, online higher education, and service to people with developmental disabilities. In addition to working at Genesee County Chapter NYS-ARC, he periodically writes articles for The Batavian (a local online newspaper) and Lee Publications. He may be contacted at [danielcrofts31@yahoo.com](mailto:danielcrofts31@yahoo.com).*

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### **Insights from page 29**

understand the challenges that individuals with autism experience, but also recognize the growing role of self-advocacy. We have a responsibility as a society to support opportunity in the workplace, educational communities and society at large.

For more information, please contact Susan at [susan.cortlet@gmail.com](mailto:susan.cortlet@gmail.com), (845)

406-8730 or visit [www.discoveringyourworld.com](http://www.discoveringyourworld.com).

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# Howard A. Savin, PhD, Joins Autism Spectrum News Editorial Board

By Staff Writer  
Autism Spectrum News

**M**ental Health News Education, Inc. (MHNE), publisher of *Autism Spectrum News* (ASN), is proud to announce that Howard A. Savin, PhD, Senior Vice President of Autism Quality and Outcomes at Beacon Health Options has become the newest member of the ASN Editorial Board.

Howard Savin, PhD, is a clinical psychologist and senior behavior health care executive. His accomplishments include the development of a multi-site group mental health practice in suburban Philadelphia, which evolved into a national managed behavioral health care company, AGCA. He is the founder and CEO of Autism Services Group (ASG), the first independent autism insurance benefits management company, which became a division of Beacon Health Strategies, LLC. Following Beacon's merger with Value Options in December 2014, Dr. Savin transitioned to his present role as Senior Vice President, Autism Programs.

Upon his appointment, Dr. Savin stated, "I am committed to continuing and promoting the philosophy and ideals of



**Howard A. Savin, PhD**

Mental Health News Education, Inc. and *Autism Spectrum News*, which foster the dissemination of scientific research-based practices with the potential to improve services and quality of life. I look forward to being an active member of the ASN Editorial Board to provide guidance on content and uphold the mission of providing the

autism community with a trusted resource of safe and proven effective information that is based in science."

From July 1, 1995 through June 30, 2004, Howard Savin served as Senior Vice President and Chief Clinical Officer of the Devereux Foundation - a nationwide, non-profit network of treatment programs for individuals with emotional, behavioral and developmental needs. He also directed Devereux's Institute of Clinical Training and Research (ICTR). He is an experienced senior manager and practitioner with more than 35 years of accomplishment in the fields of organized behavioral health care, child and adolescent and medical psychology, and he was a pioneer in the managed behavioral healthcare arena. Dr. Savin co-founded a multi-site group practice in suburban Philadelphia that evolved to become Achievement and Guidance Centers of America (AGCA). Through several mergers and acquisitions, this entity became a part of Merck, then, Merit Behavioral Healthcare Corporation, and, subsequently, Magellan Behavioral Health. He has written and presented in the areas of managed behavioral healthcare, quality and accountability, and clinical psychology. Savin previously served as a Board Member of The College of Behavioral Health

Leadership and was a Population Health Associate at Thomas Jefferson University.

MHNE's Board Chairman, Jorge Petit, MD, stated, "We are delighted to welcome Dr. Savin to the ASN Editorial Board. He has been a leader in addressing the care and insurance needs of the autism community and brings a wealth of experience with him that I believe will be an enormous benefit to *Autism Spectrum News'* educational mission."

David Minot, Associate Director of MHNE and Publisher of *Autism Spectrum News* stated, "I too am delighted that Dr. Savin has joined the esteemed ASN Editorial Board. Navigating the healthcare system is difficult but necessary for families with young and adult children on the autism spectrum, and I look forward to working with Dr. Savin to enhance the content of *Autism Spectrum News* to address these issues and provide hope through education. I know I speak on behalf of the entire Board at MHNE in praising his work and welcoming him to the ASN Editorial Board."

To see the full listing of the esteemed *Autism Spectrum News* Editorial Board, please visit [www.mhnews-autism.org/editorial\\_board.htm](http://www.mhnews-autism.org/editorial_board.htm).

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those areas. The result is that such education is only made available to students with intellectual disabilities. There is also a common prejudice that people with academic ability (these are known as "twice exceptional") or unusual talents (which are very common among individuals with autism) should have no significant difficulty learning these things, generally considered much easier than the areas where they excel, with at most an occasional short-term setback. Individuals with autism as a whole are very poorly served by these misconceptions, and usually need just such instruction in precisely those areas – sometimes throughout the lifespan. These erroneous ideas need to be discredited once and for all.

Not being diagnosed until age 44, I lived most of my life not understanding the nature of my challenges, and had very few of the supports that would have helped me so much. One thing that inadvertently did help me on the path to independence was the experience of living on a college campus. Usually seen mainly as a convenience provided to students, this in fact served as a transitional assisted living arrangement which greatly eased my subsequent move into an apartment after I graduated and started working. Individuals with autism who have the ability and opportunity to attend a residential college should take as much advantage of this as possible. Nowadays, more institutions provide special services for students with autism as well.

There is no doubt that many undiagnosed adults with autism, like myself, made the transitions and attained the skills to live independently even in the face of remaining challenges. Still, to this day I consider my own basic daily living skills to be little more than rudimentary.

Individuals with autism also have difficulties finding and keeping employment. Having a dependable source of income is prerequisite to living independently, so this needs to be treated as a high priority. Once again, young people on the spectrum need to be advised on realistic career options. This should be based on areas of specialized ability and interest considered jointly with skills that are currently in demand and expected to be in the future. I strongly believe that our unusual talents and highly-focused interests offer the best hope of successful employment for adults on the spectrum. In practice, this means that appropriate vocational or career training at either the secondary or post-secondary level may be preferable to the popular ideal of a four-year liberal arts college. For a young individual on the spectrum with circumscribed interests and restricted areas of ability, such an education may be of limited effectiveness – especially at that age. They would be better served by preparing for occupations which they might succeed at and find gainful employment in. For those who genuinely wish and are able to pursue higher education, future employment prospects must be an important consideration during their student careers. I attribute my own employment success to having pursued autistic perseverations (not known as such at the time) with anything electrical or mechanical, through later interests in physics and mathematics, then attending an engineering college, and becoming an electronics engineer.

For adults on the spectrum who were never identified, these needs must be addressed by other means. One of the best things that can be done for adult individuals with autism is to provide them with diagnoses, along with as much information about autism and its effects on their lives as they can possibly absorb. Although this

ideally is a formal diagnosis, such is often not realistic or even possible. Evaluating an adult on the autism spectrum is among the most difficult diagnostic procedures. It is very expensive – unaffordable for many – and there are long waiting lists as well. Fortunately, there are readily available means of informal or self-diagnosis. The Autism Spectrum Quotient, a self-assessment developed by psychologist Simon Baron-Cohen, is accessible online, as are other resources ([http://www.autismresearchcentre.com/arc\\_tests](http://www.autismresearchcentre.com/arc_tests)). These need to be widely publicized so that anyone who suspects they might be on the spectrum, or who is suspected by a family member or friend, can gain valuable insights and find measures they might take to improve their situation. Because I was diagnosed at a late age, this knowledge was nothing less than life-changing. I thought about the countless experiences that had long perplexed and baffled me, and was able to make some sense of them. Also, I now knew what the challenges I faced were and was better able to address them.

For those who had no instruction in daily living and social skills, much more needs to be done as well. Educational aids of any kind are of great utility. Books, videos, and other resources that address these issues at various levels are marketed by various autism publishers. What would be of truly great benefit, however, are widely-distributed materials that provide explicit instruction in all areas of daily living and socialization. These should be at a level accessible to anyone regardless of ability, and made available to everyone who can benefit from them – especially newly-identified adult individuals with autism. The educational films and pamphlets used in public schools through the 1950s and 60s, while too dated to be useful, may serve as a model for more contemporary aids that can

be developed and disseminated as a public service. Nowadays, they could also be made available online. Once again, the cost of such a measure is negligible compared to the benefits and reduced costs to society that it would provide.

Appropriate continuing education should also be made more available to adults on the spectrum, especially vocational training for those with employment challenges. Learning for personal growth can also be of great value to adults; this can take the form of traditional classes, recorded video lectures, or online courses. It can serve both to pursue specialized interests and to broaden one's horizons later in life, which in turn can help with socialization. I have actually done this, as have a number of other adults that I know. Social and support groups for adults are also essential to our community and, though steadily increasing in number, many more will be needed. I have both attended and facilitated such groups for many years. In the work environment, the supports most needed are for navigating the "hidden curriculum" and social aspects of the workplace.

Because we develop so many coping mechanisms over the course of our lives, not to mention the knowledge and skills that we acquire over the years, autism is usually not a degenerative condition. If anything, many on the spectrum are able to deal with our challenges more effectively as we get older, and some of our impairments become less severe with age. This offers great hope for the many adult individuals with autism in our society who are becoming a larger and larger population. We need to stand up and be counted to get the supports we need to be as much a part of our communities as we can.

For more information, Karl may be contacted at [kwittig@earthlink.net](mailto:kwittig@earthlink.net).

### **Project CASY from page 8**

behaviors. Some felt awkward, out of place, misplaced and in the worst cases, stigmatized. The root of these concerns appeared to center be around poor fit and lack of adequate matching of group participants. Therefore, the group experience was quite aversive to this significant minority of adults living with autism. Most importantly, these groups not only created negative feelings at the time of attendance, but also long after they were over so they refused to attend any future groups. Therefore, if there were potentially helpful groups available, individuals who had a past negative experience would likely refuse these interventions altogether or they would negatively bias any new group experiences.

These and other factors create new challenges in creating helpful group interventions for adults living with autism. Because every adult has the right to choose and refuse, the group needs to be intrinsically rewarding in some way so participants want to attend and are willing to volunteer their time and effort. There are also logistical concerns for those who do not live at home and live on a college or other training campus. Easy access to appropriate transportation is also a formidable challenge. Since many adult attendees come to the group alone, group leaders must arrange for ad-

ditional facilitators if they judge that they need additional support to carry of the group's objectives. Some individuals may be working during the day, making their best available times in the evenings or outside regular business day hours. Generally speaking, any group would be competing for the potential attendees "free time" which is usually at their discretion to use as they wish. This highlights the importance that attendees must have of sufficient interest from the start. This must be sufficiently robust throughout to ensure the group program's completion. Consequently, a group may need to put more weight on recreation, making the instructional components subtler. This is a departure from group interventions involving children who are often given little choice since their caregivers often make these decisions and they are more willing to comply.

Project CASY groups take into consideration the aforementioned challenges and are constantly evolving to improve the group experience for adults living with autism. Great care is taken because negative experiences could lead to indefinite participant withdrawal. One of the biggest challenges in the successful execution of a group is making sure participants are adequately matched. The process relies on having a large pool of participants which can be divided into smaller groups and

matched on various characteristics such as age, verbal capabilities, interest, motivation and more. The Project CASY social networking website (<http://www.meetup.com/ProjectCASY/>) is instrumental in building a large online community. The primary function is to remove geographical and financial (there is no cost to join) borders which allows for a much larger community, thus greater number of potential participants. This increases the likelihood that participants will find compatible people since the population from which to choose is much larger. All are welcome to attend a monthly event entitled Social Gathering for Adults Living with Autism (Social GALA). This event is highly structured and focused on recreation. It provides a controlled and stress-free means for members to become acquainted with one another. The next step is selecting from these participants to form matched "hangout" groups. The idea behind CASY Hangout is to bring together a small number of attendees from the much large Social GALA. This small group (about 5-6 total) is chosen based on member feedback to organizers as well as organizers' observations. Therefore, participants of a single CASY Hangout are matched on a variety of characteristics such as age, verbal capabilities, interest, and motivation. Given the size of Social GALA, many different

groupings are possible. Activities of CASY Hangout are highly variable, but range from casually dining out to structured therapeutic games.

From this rough sketch of a group intervention for adults living with autism, it is clear that lots of time and effort is involved from the clinical team/organizers prior to forming functional social groups. Importantly, none of this is possible without the tireless support of parents and caretakers who are often the driving force of a participant's consistent participation in group intervention. Thus, the process is highly collaborative and uses multiple modalities all in the spirit of promoting effectiveness. However, it is too early to comment whether this approach is truly effective because the project is also going through its own experiential learning process. Over time, a protocol will be developed and trials will be conducted possibly including novel outcome measures as discussed previously. For updates and more information, please visit <http://www.meetup.com/ProjectCASY/>.

*Roger Jou, MD, PhD, is Assistant Clinical Professor at the Yale Child Study Center and specializes in autism spectrum disorders across the lifespan. In addition, Dr. Jou is Medical Director at the Center for Translational Developmental Neuroscience at the Yale School of Medicine.*

### **Accommodating from page 14**

hanging around with such an idiot? Remember that people you work with often have a hidden agenda. So if you don't know their motives and don't understand their relationships, be cautious.

- Small talk is not about content. It's about sharing a smile and a quick laugh. Listen to others' small talk and try to figure out what's appropriate. Stay informed about news and weather, so you can comment on these when they come up.
- If everyone is laughing, laugh with them, even if you didn't understand the joke.
- Listen carefully.
- Learn active listening skills - this will help you with the subtleties of interpersonal communication.
- Learn to talk about others' interests, and keep quiet about yours.
- Keep tabs on conversations, making sure not to monopolize the discussion.
- If you've been speaking for a few minutes, it's probably time to stop and give someone else a turn to talk.

- If the other person doesn't make any comments pertaining to what you're saying, or if he changes the subject, that may indicate that he/she is either bored or uncomfortable with that topic. This is a clue to change the subject and move on.
- A look to the side may also indicate disinterest, and folded arms may indicate boredom.
- When responding, relate the reply to what the other person said. To change the subject, say something like, "what you said reminded me of..."
- Practice making eye contact during conversations.
- When the other person is talking, look interested. Look at them, but don't stare. Make short comments, say, "umm, aha," and nod once in a while.
- When with a group, try to look at each person who's speaking. Also try to look around and notice others' reactions. Note facial expressions, hands, and the rest of their body. Is he or she showing interest by nodding his head, looking at you, and responding to what you say? Doing this will help you to be aware of how people respond to your reactions.
- Think twice before speaking to avoid inappropriate comments.
- Learn to decipher the meanings of idioms and figurative speech through rote memory and context. Some have found keeping a notebook of common idioms helpful.

Interpreting body language is very important to interpersonal communication. Learning to read body language is a skill that can be taught. Here are some tips that might help you learn to understand body language:

- To get help in breaking down body language like facial expressions and gestures, enlist your family or close friends for help. Gather a bunch of pictures from magazines having a range of facial expressions with body language (e.g. happy, disappointed, fearful, joyful, annoyed, angry, depressed...). Try to identify the still life. *The Artist's Complete Guide to Facial Expression* by Gary Faigin is an excellent book resource for this ([www.amazon.com/Artists-Complete-Guide-Facial-Expression/dp/0823004325](http://www.amazon.com/Artists-Complete-Guide-Facial-Expression/dp/0823004325)).
- Next try the same idea with a video. Turn off the sound and watch the body language. Try to identify different emotions.
- Try your own body language. Practice

making faces and looking happy, fearful, or angry.

- Use your voice intonations for different emotions. Learn how to communicate subtle meanings through changes in tone of voice and facial muscles. Ask a friend what emotion he thinks you are trying to communicate by using the same sentence and repeating it with different emotions.
- Watch actors in movies exchange meaningful glances. Notice how they use their eyes. Try to interpret from the context of the situation the meaning of those glances.
- Classes in interpersonal communication sometimes teach body language.
- Acting lessons often teach voice modulation and facial expressions.

Hopefully, you can use at least some of these ideas and techniques to become a better communicator.

*Yvona Fast is the author of "Employment for Individuals with Asperger Syndrome or Nonverbal Learning Disability" and 2 other books. She has spoken about these issues at conferences in the US, Poland and Canada. For more information, check out [www.wordsaremyworld.com](http://www.wordsaremyworld.com).*

### **Opportunities from page 18**

Laurie Sperry, PhD, BCBA-D, is Assistant Clinical Professor at Yale University. Bill Morris is Founder and CEO and Leigh Schilling is Recycling Technician at Blue Star Recyclers.

Your Help is Needed! Please visit [www.bluestarrecyclers.org](http://www.bluestarrecyclers.org) to find out how you can support this organization and the employment of people with ASD.

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### **Family Home from page 4**

an in-depth discussion of the benefits and considerations of the array of home options, please see the video presentations on the Autism Housing Network ([www.autismhousingnetwork.org](http://www.autismhousingnetwork.org)).

#### Systemic Issues

Thirty-five years of data collection tell us that we are in the midst of a housing crisis. Baby boomer parents are reaching the age when they can no longer support their loved one on the spectrum, and, as the image below depicts, access to residential supports for those with I/DD is glaringly insufficient.

The challenges are not limited to the scarcity of publicly funded supports. Direct support staff is one of the cornerstones of quality of life for adults with autism, and yet, turnover in the direct support industry is extremely high. With a median income of less than \$21,000 annually (Bureau of Labor Statistics, 2015), many qualified individuals simply cannot afford to work in this field. Adequate compensation is imperative to developing and maintaining a stable, high-caliber workforce.

Additionally, the prevalence of abuse is staggering. According to the Disability & Abuse Project, 67% of individuals on the autism spectrum are victims of financial, emotional, or sexual abuse (Baladerian, Coleman, Stream, 2012). Twenty-five percent are socially isolated, meaning they never saw or spoke with friends or were invited to a social activity in the past year (Roux et al., 2015). According to the 2014 National Core Indicator study, 40% of individuals with I/DD report "sometimes" or "often" feeling lonely. An individual could live in the most luxurious penthouse overlooking Central Park, but if that individual is being abused or suffering from social isolation, the beautiful home does not matter.

The final challenge is securing affordable housing in a fluctuating rental market. Fifty-eight percent of young adults on the spectrum are employed at an average rate of about \$9 per hour (Roux et al., 2015). According to the National Low Income Housing Coalition, the average adult with autism must work 68 hours per week to afford a one-bedroom apartment without spending more than 30% of his or her income on rent (2015). Therefore, access to subsidized rent through housing choice vouchers or low-income housing units is essential for most individuals on the autism spectrum. Unfortunately, there are wait lists. Contact your local public housing authority to understand affordable housing options in your area and/or to join a wait list (even if you do not plan to move for another five years): <http://portal.hud.gov>.

#### Creating a Better Future

With the lack of support services and affordable housing options, increased reports of loneliness and isolation, and high rates of abuse, individuals on the spectrum and parents are developing lo-

cal solutions. I have sat at dinner tables and worked side-by-side with hundreds of citizens nationally whose communities are embracing the challenge of creating a better future for adults on the autism spectrum.

Some of the emerging models include:

**Post-secondary Transitional Programs:** A temporary residential program that aims to teach the life skills needed to live independently after 2-5 years of program participation.

**Micro Homes/Accessory Dwellings:** A smaller home on the property of one's family home that provides privacy with a natural support system nearby. The family home could be leased in the future as a source of income for the individual on the spectrum and to maintain an immediate support system.

**Neurodiverse Cohousing:** A neighborhood or intentional community built from the ground up by whomever decides to be part of the development (i.e., neurotypical couples, families with a special needs child, a couple on the autism spectrum, etc.). Each home is owned or rented by residents. A common house hosts community dinners as desired, has amenities chosen by the residents, and is the meeting place for planned, voluntary neighborhood activities.

**Multi-family, Neurodiverse Supportive Housing:** An apartment building or neighborhood where housing is designed with the support needs of individuals on the spectrum in mind. These housing developments are consumer-owned and controlled. They often use assistive technology, attract neurotypical residents who want to provide natural supports, and/or have an on-site staff included in rent to assist with immediate needs or challenges. This neurodiverse housing model provides amenities and neighborly support for those who may not qualify for a waiver.

#### The Autism Housing Network

In 2009, the first comprehensive report on the autism housing crisis, *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders*, was produced by Southwest Autism Research & Resource Center (SAARC) and Urban Land Institute (ULI) Arizona. One of the recommendations of the study was to create an interactive housing database. After years of research, Madison House Autism Foundation is launching the Autism Housing Network ([www.autismhousingnetwork.org](http://www.autismhousingnetwork.org)) in April, 2016. Denise D. Resnik, the co-founder of SAARC and editor of the study recently stated that the Autism Housing Network "has extraordinary potential to share successes and be a catalyst for advocates and parents eager to work together on solutions."

#### A Next Step Checklist

Even if creating a local housing oppor-

tunity is not your immediate priority, here is a checklist of essential next steps that you can begin working on to ensure you or your loved one on the spectrum has an array of housing choices:

1. Begin assembling your team, and set a date to develop a person-centered plan with the individual on the spectrum leading this process as much as possible.
2. Review and shape one's IEP for acquiring life skills such as cooking, taking public transportation, exploring assistive technology, functional math, etc.
3. Apply for waiver funding and/or affordable housing.
4. Meet with a special needs lawyer and financial planner to write a *Letter of Intent* in case a sudden life event occurs, and begin financial planning for housing goals.
5. Intentionally foster relationships with those who may be a future accountability system and friendship circle.
6. Be an advocate when you see calls to action for affordable housing funding or vouchers, ABLE accounts, SNAP or nutritional assistance, HCBS waiver funding, etc.

Please join me on the Autism Housing Network by visiting [www.autismhousingnetwork.org](http://www.autismhousingnetwork.org). Together, we can create a better future for adults with autism.

For more information, please email [info@madisonhouseautism.org](mailto:info@madisonhouseautism.org) or call 240-246-7140.

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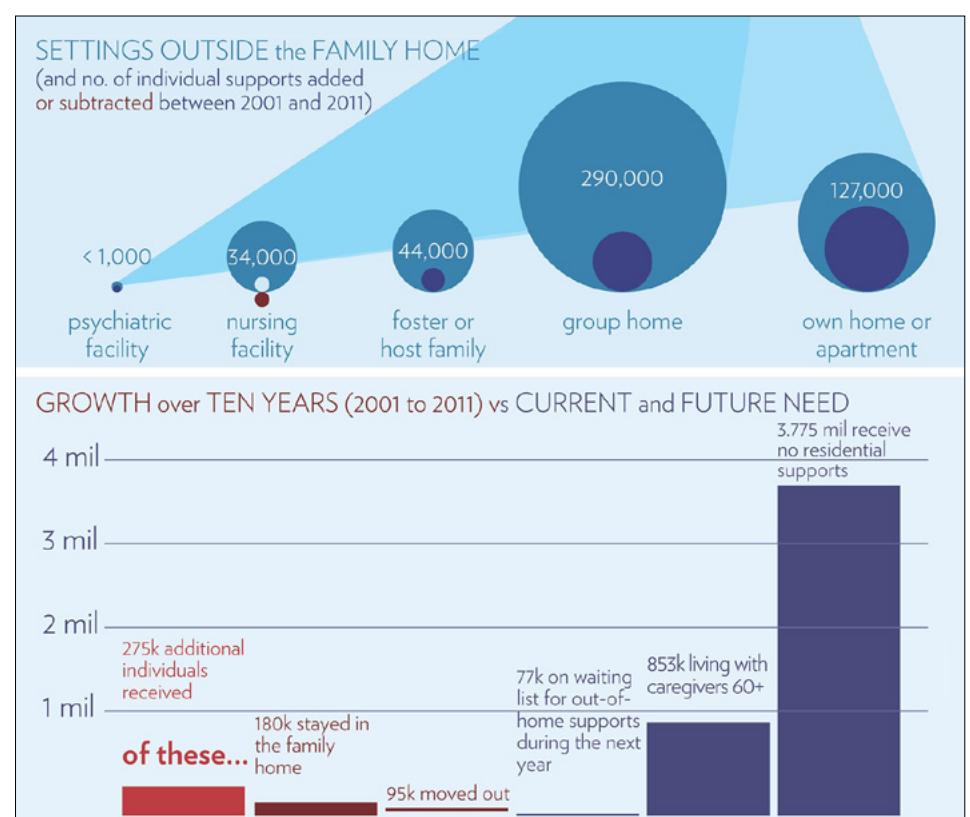
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**Job Seekers from page 10**

constituents. Eligibility criteria include motivation to work, a functional form of communication, participation in the entire week-long program, and transportation to and from the various locations. Participants completed an Interview/Resume Builder which helped participants think about their past experiences, strengths, difficulties, and future plans. This informed the facilitators who assisted the participants in creating tailored resumes and interview responses that matched their unique strengths and qualities.

The program runs out of two sites, the University of Miami (UM) and Nova Southeastern University (NSU). In addition to workshops, a key feature of the program is its ability to take advantage of the unique resources available through each location. CareerSource one-stop centers provide workshops and resources at both locations covering resume development and online job-searching. In addition, each year Nova Southeastern University has graciously allowed the group to use their shuttle system, the Shark Shuttle, to transport participants and facilitators to community locations throughout the week. This allows for greater outreach into the community, enabling the adults to connect with community employment resources which they can continue to access when the program is complete. Additionally, during the lesson on wellness a professor of physical therapy, Dr. Melissa Tovin talks about the importance of taking care of one's health and her graduate students pair with participants to create individualized work out plans. Adults in the program are also able to access the Alvin Sherman Library on campus and learn how to use the job search resources available to the public.

At the University of Miami there are also numerous resources available. After some instruction on safety in the community from Coral Gables Police Department representative, Lt. Bart Barta, and travel training from clinical staff, the group uses the Metrorail system to navigate the local

community. The lack of transportation poses a significant challenge to employment so learning how to use public transit and be safe doing so are valuable skills. They also have the opportunity for hands-on learning at campus locations such as the Bank United Center and the Patti and Allan Herbert Wellness Center, where they experience some of the types of jobs that are available.

A variety of topics are covered over the course of the week. Personal hygiene, self-care, and the importance of work-appropriate dress are discussed. During one activity the group goes to the local mall and works in pairs to complete a scavenger hunt. They are asked to identify work appropriate attire for different settings while staying within budget and a prize is awarded. Many of the participants have never shopped for their own clothes so learning how to budget and look for sales was a challenge for some. Workshops about money management and motivation for job seeking also helped participants make a clear connection between motivations and goals.

One of the most important aspects of the program is the focus on resume development and practicing interview skills. During an interview workshop direct instruction and video modeling are used to teach adults how to prepare for an interview and then develop responses to several commonly asked interview questions. It also includes a discussion on considerations for disclosing one's disability. Interviewing is a difficult skill to master since interviews can be unpredictable and include a heavy reliance on social skills, a common deficit among individuals with autism. Individualized answers to common interview questions are developed, followed by role plays and mock interviews. The participants receive feedback based on a rubric which highlights strengths as well as opportunities to improve. This information can be used to inform continued practice. Most adults in the program have never participated in practice interviews and the experience makes them aware of how much preparation they may need for actual interviews.

On the final day the group participates in a discussion about social skills at work. They learn about the art of small talk, accepting feedback, asking for help, and coping with stress at work. The week typically ends with a celebration at a site in the community where the group not only uses the social skills they learned, but also have fun in a less structured environment. During this time they have the opportunity to exchange contact information so friendships that were started can continue beyond the group.

Program facilitators have seen great improvements from the participants in their level of confidence, understanding of the job search process, and an increase in prosocial behaviors. However, once participants completed the program, there was a need to consistently track progress and provide follow-up support. A Job Club was formed to support adults who completed the program. This new group allows participants to share job search strategies, learn about networking, continue to work on resumes, practice interviewing skills, set career goals, and maintain a positive outlook.

Through the Project EAARN Employment Boot Camp and Job Club, The Daniel Jordan Fiddle Foundation Transition and Adult Programs at UM-NSU CARD are working to address some of the issues related to employment for adults with autism. Employment preparation that extends beyond the hard skills necessary to do work tasks is becoming a greater priority for anyone invested in better outcomes for adults. The autism community continues to increase employment opportunities for adults with autism. Programs such as these provide a learning experience while connecting participants to local resources, bringing more awareness, and creating community ambassadors for the cause.

*Deborah Chin, MA, is a Manager and Alexis Bitting, MSEd, is a Case Manager at The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the Uni-*

*versity of Miami Center for Autism and Related Disabilities. For more information, contact The Daniel Jordan Fiddle Foundation Transition and Adult Programs at UM-NSU CARD at: 1-800-9-AUTISM ext. 1 or visit [www.umcard.org](http://www.umcard.org).*

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*Jack, I know but you have to have an aide in school.*

Now I know. I know that one of the hardest things in the whole big entire world isn't having child who doesn't live independently because of a disability. It's hearing this child talk and wish and hope—a child who longs for California and a four-wheel drive Toyota Sequoia and a house and a wife and a son of his own—and knowing I must somehow help him build a castle out of sand.

In the meantime, all I can do is teach him how to swim, even when the water is icy cold and the undertow is dangerous and the waves are crashing down all around us.

*"What Color Is Monday?" is available on [Amazon.com](http://Amazon.com) and [BarnesandNoble.com](http://BarnesandNoble.com). You can also follow Carrie on her weekly blog: [www.CarrieCariello.com](http://www.CarrieCariello.com) and [Facebook.com/WhatColorIsMonday](http://Facebook.com/WhatColorIsMonday).*

**His Own from page 17**

molecule of my being has been dedicated to making this boy independent. Every waking hour, we work on his social skills and his muscle tone and his expressive language and his regulation so he may one day be liberated from an aide school, from the confines of the spectrum disorder, from us.

Some days, I start to get comfortable.

*Look at him! He's making waffles! He's totally going to live on his own one day.*

*Did you see? He looked the waiter right in the eye when he ordered his chicken fingers!*

*He hasn't said the f-word in three days, things are totally getting better!*

Then we travel somewhere, and I watch, two paces behind, as he tries to get through security at the airport; both he and the TSA

personnel frustrated and confused.

*Please, just step forward. No, not all the way forward, back a little. Please, back a little.*

Or as he waits in line for the water slide, impatient and abrupt when the little kid ahead of him takes a few minutes to muster up the courage to slide down into the pool.

*It is time for you. TO GO DOWN NOW.*

Or he throws an epic tantrum at school, and he cleans out his locker and insists he's never going back and the next morning he refuses to get on the bus even though I know—I know—he's desperate to graduate from high school like his older brother Joey and talks about going to college and wants to be a record producer in California.

His future self changes from time to time—for a while he wanted to be a chef,

then the owner of a fast-food restaurant, and now, a record producer. I'm pretty sure all of these require he finishes at least sixth grade.

*He wants to, but he may not be able to.*

I think about all the little nuances to an independent life for which there is no social story, no preparation.

Scraping ice off of a windshield.

Longer-than usual lines at the post office.

A girl scout selling cookies on a Sunday afternoon.

For the past ten years, I have been trying to adjust his dreams to suit his reality, the way salt water washes over rocks on the shore until they are nothing more than tiny grains of sand.

*No, only Joey is going to the birthday party, come on, I'll take you for ice cream instead.*

*Please, I need you to hold my hand and stay with me in the store.*

**Supports from page 27**

Lauren Merritt, College Steps, [lauren@collegesteps.org](mailto:lauren@collegesteps.org); Samantha Feinman, New Frontiers in Learning, [sfeinman@nfil.net](mailto:sfeinman@nfil.net).

Diane Slonim, PhD, is a speech/language pathologist in private practice spe-

cializing in ASD, from preschool through the college years. She taught writing to students with ASD transitioning to college. She works individually and in groups with students with ASD. If you have any questions, feel free to contact Dr. Slonim through her website at [www.dianeslonim.com](http://www.dianeslonim.com) or call 914-767-0488.

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***Extraordinary from page 21***

powerfully impactful Applied Behavior Analysis (ABA) theories and practice to the metropolitan New York area at time when autism was often still being treated as a psychological disorder.

A long standing partnership with the Devereux Foundation led to the establishment of the ABA-based Devereux Millwood Learning Center and as the population aged, the program was expanded to serve the need for vocational and community inclusion programming. A day habilitation program was the next project which became the Devereux Adult Program. When it became abundantly clear that area day habilitation programs needed help in finding new and expanded volunteer and potential employment sites for adults, FECA established the Opportunity Network for Employers and Employees (ONEE) and began the painstaking process of knocking on doors throughout Westchester.

Though ONEE has proven successful, it also reinforced the understanding that turning volunteer tasks into job opportunities was a daunting challenge for a local job market that lacked the ability and often the will to fit the proverbial square peg into a round hole. Even the most sympathetic employers are simply not equipped to provide the requisite work-related training and support necessary for adults on the spectrum.

The FECA board was intrigued with the EV model precisely because the individual skills required within each business match the inherent and eminently trainable talents and interests of individuals with autism. Delighted to be chosen as a replication site, FECA provided the start up funding for the creation of a nonprofit corporation which last year became Extraordinary Ventures New York (EVNY, [www.evny.org](http://www.evny.org)).

The task of hiring our first social entrepreneur was a challenging one and as the months passed, the EVNY board looked to the Nike logo of "Just Do It" for inspiration. A free basement, a ping pong table

and a starter kit led to the creation of festively decorated and seasonally inspired candles packaged by a production crew who took to the task with surprising agility and enthusiasm. The experiment, which required relatively little initial financial outlay, further emphasized a critical piece of the EV model: test to ensure that this is something our potential employees CAN and WANT to do!

Rather than anonymously selling the candles online or convincing a local store to sell the product, EVNY decided to take the candles out into the community at local craft and gift fairs. That decision led to the creation of a team of charming salespeople thus expanding the repertoire of job opportunities to match the extensive range of skills and talents inherent to adults on the spectrum. Several craft venues later and EVNY's first business was launched.

Our first entrepreneur recently joined the team in February along with a part time sales development manager with extensive experience working with adults on the

spectrum. The mentorship of the skilled and now extensively experienced team of entrepreneurs at EVNC is an enormous asset of support and counsel as EVNY looks to expand our first business and new ideas lead to the creation of additional ventures.

As adults, work inevitably defines us. It's a statement to the world of what we, as individuals, are capable of, where we fit in society and how we are recognized and valued. The Extraordinary Ventures model provides the opportunity to explore and experiment with a range of skills within a supportive environment that provides training towards future independence; all, while valuing time and effort with the simple but profoundly important earning of a paycheck.

*Gregg Ireland is the Founder of Extraordinary Ventures, Chapel Hill, North Carolina. Melanie Schaffran is co-founder and President of the Foundation for Empowering Citizens with Autism and Extraordinary Ventures New York.*

***Community from page 20***

the New Horizons Club (<http://www.newhorizonsclub.org/>), which has been in operation for 11 years in the Philadelphia metropolitan area. New Horizons is a social support group with an emphasis on community integration. In addition to scheduled social activities, members engage in volunteer service such as feeding the homeless on MLK Day of Service, providing meals to shut-ins through Project Hope, local walks for Downs Syndrome and Alzheimer's, assisting NAMI, and supporting canine friends at the Bucks County Canine Club. The club has a "mentor-in-chief" who organizes activities and provides real world mentoring. Activities are member-driven and are selected at a monthly meeting. New Horizons also provides opportunities for older members to mentor new members and driving members offer ride sharing to events. The activities include a fall camp out and a 5 day beach trip.

Each of these programs contains elements that appear essential to providing successful social experiences for adults with ASD: 1) acceptance, 2) emotional and physical safety, and 3) mentoring. Adults with ASD must feel that they are accepted as individuals and valued for their uniqueness. Many have experienced stigma and exclusion in a variety of settings and need to feel free to be themselves without being judged. They must also have a sense of safety in order for them to take social risks. They need to know that the environment does not tolerate bullying or sexual harassment. They must know that they can seek the support of mentors and other group members when feeling socially uncomfortable. Adults with ASD may have a history of trauma in relation to social situations and they may need a 1 to 1 mentor initially until their social anxiety lessens. It is important to allow each individual to socialize at their own pace and avoid expectations for participation from the outset. In

addition, these models allow for age-appropriate adult activities such as a New Year's Eve party or attending concerts or film festivals. The members suggest and plan activities that interest them.

As the adult ASD population continues to increase it is critical that these adults be given the necessary social supports in their communities. The benefits provided by these social supports will expand the social repertoire of adults and empower them to develop friendships, reduce feelings of isolation and increase their sense of societal acceptance and inclusion.

*Mary Riggs Cohen, PhD, is a licensed psychologist specializing in Autism Spectrum Disorders and is the Director of Autism Spectrum Diagnostics & Consulting. Brittny Lyman, PsyD, is a licensed psychologist specializing in Autism Spectrum Disorders. Drs. Cohen and Lyman can be contacted at [info@autismdiagnostics.com](mailto:info@autismdiagnostics.com) or visit their website [www.autismdiagnostics.com](http://www.autismdiagnostics.com).*

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

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

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### **Women from page 21**

Outside of these structured social support and skill groups, a leading expert on women with ASD, Liane Holliday Willey Ed.D., suggests that women identify a trusted “go-to” person (e.g., family member, friend, or mentor) who understands the woman’s strengths and challenges. This person can be used as an additional resource to check in with when one feels unsure or confused about a friendship or potential romantic partner. This “go-to” person can provide feedback to allow one to further develop and generalize perspective taking skills learned in support groups to evaluate another person’s intentions (e.g., “Are they taking advantage of me? How will I know?”; “Is he being genuine?”; Willey, 2012).

Finally, what about the group of women with ASD who decide that their values are not aligned with traditional feminine gender norms? While somewhat controversial, recent research in the Netherlands showed that 8 percent of a sample of children and adolescents admitted into a gender identity clinic were also diagnosed with ASD (de Vries et al., 2010). Additionally, Jones and colleagues (2012) found that female-to-male transgender individuals had higher rates of autistic symptoms compared to male-to-female transgender individuals. While this perceived linkage between gender identity and ASD still requires investigation, the need to support individuals with ASD who do not conform to traditional

gender role norms is clear. It is equally important that these individuals receive similar opportunities to gain support and skill instruction to attain their personal goals and values in society.

In summary, there has been much recent attention paid to gender differences in the manifestation of ASD across the lifespan. In light of these new insights, it has been made abundantly clear that gender-specific interventions are needed to support the social and general well-being of both men and women across the lifespan. Due to the increased pressure for interpersonal relationship investment and success for women, specific supports and interventions for women who choose their values (and for those who do not) are essential to supporting the overall and continued mental health and well-being for this population across the lifespan and particularly during adulthood.

*Dr. Alyssa Milot is a licensed psychologist at Massachusetts General Hospital's Lurie Center and Aspire. For more information, email [amilot@mgh.harvard.edu](mailto:amilot@mgh.harvard.edu).*

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### **Independent from page 25**

better or worse daily living skills may help shed light on the variability in adult outcome in individuals with autism spectrum disorder with average intelligence.

According to the Autism Research Institute, Temple Grandin, a woman who struggled with ASD, identified key skills to successful independent living, employment and a good social life for individuals diagnosed with Autism and Asperger's. She expressed the importance of managing tantrums or outbursts caused by sensory overload and controlling aggression and anger. To build on social relationships, it is important to learn manners, have adequate grooming, learn to turn take and share. Working with others, like coaches or mentors, can help to develop good work skills. Socializing is important, and doing so through shared interests, trying new things and knowing the difference between social relatedness and learning social skills are helpful.

Through working extensively with professionals in the field as well as guidance from individuals with ASD and their families, New Frontiers in Learning (NFiL) has identified 3 main areas of development that can improve successful outcomes in transitioning into independent living. With the individualized support of a coach, it is highly likely that a positive and smooth transition can be possible.

### 1) Daily Living Skills

Assistance with roommate matching as applicable to the individual can be essential and includes connecting potential roommate candidates and facilitating introductory meetings. Coaches can guide in the establishment of individualized goals focused around executive functioning and independence offering availability for individuals via phone and email communication. Support in essential daily skills can include: Scheduling and follow through of weekly responsibilities and standing appointments, making and following through with other appointments (i.e., doctor), budgeting and bill paying, cleaning and meal preparation, navigating interpersonal/roommate relationships, assistance in planning, organizing, and scheduling individual or small group social/recreational activities, and hygiene and self-care.

### 2) Social Community Supports

Assistance with social planning meetings in order to coordinate weekly social events can be beneficial as well. Small group supports can focus on developing and utilizing the executive functioning skills necessary to initiate, plan, and implement social activities, as well as teamwork, delegation of responsibilities, respect for another's home, community development, etc. Coaches can assist in organizing so-

cial events with agendas that support skills like time management, interpersonal skills, budgeting, and teamwork.

### 3) Job Coaching/Management

Coaches can have individual sessions and small group seminars that focus on the skill development necessary to find and sustain meaningful employment. Having a liaison between employers and individuals can be useful in initiating this process. Specific job coaching skills can focus on cover letter and resume building and revising, interview preparation and follow-up for internships and jobs, identification of employment and volunteer opportunities, job readiness skill development, job etiquette and navigating the social piece of working, and employment transition and retention.

*Sheila Simchon-Steinhof, MS, is a Learning Specialist, and Samantha Feinman, MSEd, is Director at New Frontiers in Learning. For more information, please email Samantha at [sfeinman@nfil.net](mailto:sfeinman@nfil.net) or visit [www.nfil.net](http://www.nfil.net).*

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### **Volunteerism from page 23**

The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. With service divisions in Berwyn, Pennsylvania and Andover, Massachusetts, we

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***Transition from page 19***

twenty-one years old, there is no longer an entitlement to services. Adult services are eligibility driven, and it is possible to be eligible for services and not receive them due to a lack of funds (Certo et al., 2008). After young adults leave high school, students with disabilities and their parents must become their own advocates for service and supports (Austin, 2000; Everson & Moon, 1987; Henninger & Taylor, 2014).

#### Transition Planning: Tips for Future Success

An ideal transition plan has no gaps in services between school and adult services. For students transitioning out of the school system, the day after graduation should look no different than the day before (Certo et al., 2008). The key in preventing gaps in services is being proactive and organized in transition planning. The following recommendations can be used to facilitate imperative conversations and discussions that are at the forefront of successful, organized, and attainable transition plans. With the support and collaboration of key personnel, an individual's post-secondary plan should be one that allows for new growth, opportunity, and a rich quality of life.

#### 1. Identify the Individual's Strengths and Interests

In a recent study on transition planning for children with disabilities (Ankeny, Wilkins, & Spain, 2009), mothers who were interviewed shared their hope for their child to be independent, successful, and happy in their adult lives. Identifying the cognitive, communicative, social, behavioral, and physical strengths of the child in addition to considering his/her interests is essential to devising an effective plan for the future. A good reference point for identifying the child's strengths is on the present levels of performance section of the child's most current Individualized Education Program (IEP). Schools are required to assess every student with a disability with a transition assessment from when the child is fourteen years old and each year thereafter if the child continues to have an IEP (IDEA, 35 years). The results of these transition assessments can and should be taken into consideration to further identify and integrate the student's strengths, preferences, and interests.

#### 2. Consider Level of Support

The intensity of support that students with severe disabilities may need varies greatly from person to person. It is important for transition teams to identify the current frequency and intensity of support that a student needs in addition to considering the frequency and intensity of support the student will need after high school. In reflecting upon which post-secondary options are a good fit for the individual, it is imperative that serious consideration is given to the level of support and the type of support that is necessary for success. It is not uncommon for specific adult service options to have rigid staff ratios, such as one direct support staff worker for every five participants. Identifying the amount of support the individual may need is key to selecting viable post-secondary options.

#### 3. Understand the Options

Each state in the United States is responsible for offering service options and funding for individuals with severe disabilities. Many states offer a range of options that simulate a continuum of services for individuals with disabilities while other states have very limited options available. Some of the adult service options that are typically available are day habilitation programs and self-directed services. It is important for practitioners to be mindful of the options that are available to individuals with disabilities in their state after they transition from the school system. Becoming knowledgeable about post-secondary options for students with severe disabilities will help professionals see the big picture and how their specialized work assists the individual in attaining his or her future goals.

#### 4. Schedule

The easiest way to ensure that the last day of high school looks to be just as fulfilling as the day after graduation (Certo et al., 2008) is to plan out what a typical day or week may look like. This is particularly important for individuals who choose self-directed plans because of the nature of that plan. The schedule should be flexible but structured. It is important to think about the types of activities the individual will begin or continue to participate in rather than the specific times and days at this point in the transition planning phase.

#### 5. Identify Next Steps and Assign Responsibilities

Schools typically help parents of students with disabilities gain access to adult services. Transition coordinators can maintain open communication with the adult service representative that is assigned to the individual's family and keep the team informed of potential day habilitation programs that former graduates have had success at. Special education teachers can offer assistance by conveying job sites that the student has had success at, as the individual may want to continue to work at that business after high school. School personnel and family members alike must pitch in to help this great vision come to fruition.

#### Looking to the Future

We live in an exciting time where there is promising news in the field of secondary transition. Research has begun to show us that high school experiences effect transitional outcomes of individuals with severe disabilities. Test, Mazzotti, & Mustain (2009) found that taking vocational education classes, participating in paid job experiences, and receiving transition programming lead to better student post-school employment outcomes. As school professionals, we must continue to do all that we can to help students with severe disabilities develop the skills that will be essential to their post-secondary plans. With a strong transition planning framework and the collaboration of key personnel, students with severe disabilities should have a high-quality transition plan that will enable them to access services and learn from new and unprecedented opportunities.

*Lauren Andersen is a high school special education teacher on Long Island. She obtained her BA in elementary and special education from Providence College and her MA in multiple and severe disabilities at Teachers College, Columbia University. She is currently working towards her doctorate at Teachers College, Columbia University in the field of Intellectual Disability and Autism. For additional inquiries, she may be contacted via e-mail at lea2123@tc.columbia.edu.*

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***Passion from page 23***

In an average month David earns \$400 by selling his paintings on commission and at local events. While \$400 a month does not come close to paying rent in Southern California, David's accompanying pride, confidence, and feelings of self-efficacy are worth much more. These and similar sentiments experienced by David and other artists contribute to improved quality of life, the benefits of which measure far beyond simple employment (Rearick, 2015).

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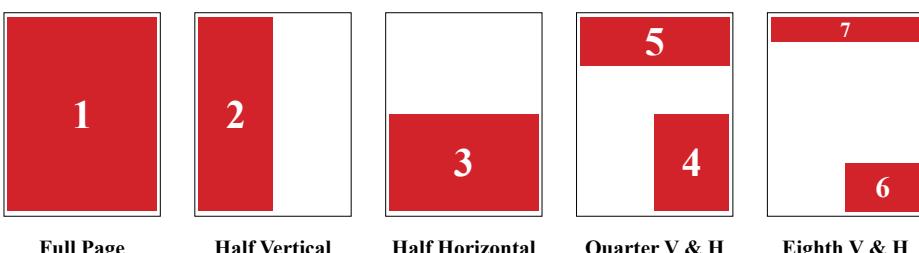
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