

AUTISM SPECTRUM NEWS™

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INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

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Exploring Educational Challenges and Opportunities

Evidence-Based Interventions for Students on the Autism Spectrum

By Lynda Geller, PhD
Founder
Spectrum Services

The Individuals with Disabilities Act (IDEA) and No Child Left Behind (NCLB) legislation both demand that schools utilize scientifically supported, evidence based methods. Yet, outside of applied behavior analysis there are few well-designed studies supporting interventions for our students on the autism spectrum. This is particularly true for those who are in mainstream educational placements. In scientific research, the gold standard is the randomized, double-blind study, yet in so many aspects of educational practice for students on the spectrum such research does not exist. Factors such as a reluctance to place children in a potential no-treatment group, the presence of complex, comorbid conditions eliminating many potential subjects from studies, and the fact that more mildly affected (and more likely to be mainstreamed) students may



not be diagnosed or included in such research all contribute to the difficulty of conducting specific treatment research on interventions for students on the autism

spectrum, particularly those with more typical academic abilities.

In reviewing the literature on interventions for students on the spectrum, it is

clear that it may be more productive to address a deficit a student has rather than a diagnosis that may have been given. Then a wide array of evidence-based interventions would become available to utilize, rather than only those that have been specifically tested on groups of students on the spectrum. For example, executive function (EF) problems affect individuals with ADHD, Asperger Syndrome, Nonverbal Learning Disability, and others with no diagnosis at all. We can confidently utilize proven organizational strategies for a student on the spectrum who struggles with that aspect of EF if we have determined that that individual has the deficit that the intervention was designed to address, without being concerned that it has not been double-blind tested on students with an ASD. Thus, to be answering the mandate for more scientifically proven educational techniques, we must come to recognize that autism spectrum conditions are highly variable and that students on the spectrum need to

see Interventions on page 12

Improving the Written Expression of Children with ASD

By Kristie Asaro-Saddler, PhD
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University at Albany

Writing has become an increasingly important element across curricular areas. However, many young children, including children with autism spectrum disorders (ASD), struggle with this key literacy skill. While it has been well-documented that many children with ASD have handwriting deficits, difficulties in the writing process, including planning, content generation, and revising text, are also pervasive. Therefore, it is essential to examine the writing of children with ASD, determine how their characteristics impact their writing ability, and discuss how parents and teachers may foster improvement in writing outcomes.

Writing is a foundational skill that can support and extend student learning across the curriculum. It allows the sharing of opinions, the demonstration of critical thinking skills, and the display of content knowledge. Writing is critical for school success, as it is the primary means by which students demonstrate their knowledge in school, and the major instrument that teachers use to evaluate academic performance (Graham & Harris, 2005). Beyond school, students need to be able to write well to succeed in society and to obtain and maintain employment.

Writing presents a unique challenge, as it requires putting thoughts on paper in such a way as to transmit a message to another person who may not have knowledge of what you are writing. While developing these thoughts, writers must coordinate the processes of planning, text production, and revision, while also self-

monitoring their work. In addition, they must consider the conventions of the language, and the constraints of the topic and the genre, along with the audience needs and perspectives.

Why Writing is Difficult For Children with ASD

Deficits in writing have been well-documented in ASD research. In one study (Mayes & Calhoun, 2008), for example, 63% of students diagnosed with ASD also exhibited a writing disability. It can be difficult for these students to think of ideas, organize their writing, and physically write their ideas. So what is it that makes writing so difficult for children with ASD?

Children with ASD characteristically exhibit a range of impairments that make written expression difficult. Among these characteristics are:

- An inability to use imagination, engage in abstract thinking, consider perspectives of others, and imagine future events or possible scenarios (Harbinson & Alexander, 2009; Myles, 2005; Myles & Simpson, 2001). These characteristics can lead to a literal interpretation of a writing task and an inability to comprehend or use metaphors, idioms, or rhetorical questions, and may hinder the exploration of counter-arguments and various perspectives.
- Deficits in theory of mind, or the ability to take another's perspective or believe that others think differently from you (McCoy, 2011), which makes it difficult for students with ASD to recognize that their work will be read by someone else with different

see Written Expression on page 40

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Autism Spectrum News 2013 Theme and Deadline Calendar

Spring 2013 Issue:
"Maintaining Skills During Summer Vacation"
Deadline: March 5, 2013

Summer 2013 Issue:
"Supportive Housing for Adults with Autism"
Deadline: June 5, 2013

Fall 2013 Issue:
"Managing the Financial Needs of Autism"
Deadline: September 5, 2013

Winter 2014 Issue:
"Integrating Assistive Technology"
Deadline: December 5, 2013

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AUTISM SPECTRUM NEWS DESK

Rise in New Jersey Autism Prevalence Documented in New Study *Results in Line with Trends Elsewhere in the Country*

Staff Writer
Autism Spectrum News

Newly published research led by Walter Zahorodny, PhD, of the University of Medicine and Dentistry of New Jersey (UMDNJ), shows that over a four year period in the past decade, the documented prevalence of autism spectrum disorder (ASD) rose substantially in a sampling of four New Jersey counties. The new study uses 2006 data compiled in 58 communities across Essex, Hudson, Ocean and Union Counties, and shows a prevalence during that year of 17.4 children per one thousand. That compares to a prevalence in 2002 of 10.6 per thousand in those same communities, which had been found in an earlier study. The new research, which mirrored the methods of the previous study in order to make as accurate a comparison as possible of the two years, has been published online in the journal *Autism*.

The study finds that ASD prevalence rose over the four year period both for boys (from 17.0 to 28.7 per thousand) and for girls (from 4.1 to 5.9 per thousand). ASD prevalence also varied by ethnicity,



Walter Zahorodny, PhD

with white non-Hispanic children showing the highest levels of ASD, 20.4 per thousand in 2006 compared with 15.0 per thousand for black, non-Hispanic; 14.7

per thousand for Hispanic; and 14.0 per thousand among Asian children.

Zahorodny, who is an assistant professor of pediatrics and psychiatry at UMDNJ-New Jersey Medical School (www.njms.umdnj.edu), says the rises in ASD prevalence that the new study documents fall in line with those measured when similar methodology has been applied in other states. That, in turn, indicates that children in New Jersey do not appear more at risk for ASD than others, as some had earlier feared. "New Jersey has long been a leading indicator of general ASD prevalence, because our state was out front early in its ability to recognize and symptoms in schools and health care settings," says Zahorodny. "As diagnostic skills become more sophisticated in other states, we are finding that they, too, are seeing higher numbers."

They are numbers that exceed experts' earlier expectations. "In various parts of the United States, overall ASD prevalence is approaching two percent," Zahorodny says. "In the past, scientists predicted the prevalence rates would ultimately level off around one percent." Zahorodny says further research is needed to determine what factors have contributed to rises in

documented cases of ASD, and also whether documented ASD prevalence will now plateau at approximately two percent or continue to rise when later years are thoroughly analyzed.

About UMDNJ

The University of Medicine and Dentistry of New Jersey (UMDNJ) is New Jersey's only health sciences university with more than 6,000 students on five campuses attending three medical schools, the State's only dental school, a graduate school of biomedical sciences, a school of health related professions, a school of nursing and New Jersey's only school of public health. UMDNJ operates University Hospital, a Level I Trauma Center in Newark, and University Behavioral HealthCare, which provides a continuum of healthcare services with multiple locations throughout the State.

This article was originally printed on the UMDNJ website and has been reprinted with permission. The original press release can be viewed at www.umdnj.edu/cgi-bin/cgiwrap/hpappweb/newsroom.cgi?month=12&day=17&year=12&headline=Rise+in+New+Jersey+Autism+Prevalence+Is+Documented+in+New+Study.

Highlights From the Seaver Autism Center's 16th Annual Advances in Autism Conference

Staff Writer
Autism Spectrum News

The Seaver Autism Center's sixteenth annual Advances in Autism Conference was held this past fall at Mount Sinai School of Medicine (MSSM) and included several scientific presentations, as well as breakout workshops presented in conjunction with our community partners. Participants included psychiatrists and several other health care professionals, educators, family members, and advocates. They learned about current model systems of autism; advances in understanding the causes of autism and novel treatment possibilities; and current pharmacological, behavioral, educational, and group treatments of autism. "It was a wonderful conference, and I intend on attending next year as well. The speakers were excellent, and the information was cutting edge," said one conference participant.

"We were happy to welcome an increased number of participants, and we enjoyed the opportunity to discuss the field of autism spectrum disorders with researchers, advocates, and family members," said Dr. Joseph Buxbaum, Director of the Seaver Autism Center.



Joseph D. Buxbaum, PhD

The morning included three scientific presentations by Drs. Joseph Buxbaum, Timothy Roberts, and Walter Kaufmann, as well as a personal presentation by Jamie Rosenblum. The afternoon featured a

keynote presentation by Dr. Simon Baron-Cohen and three breakout workshops focusing on treatments and services for individuals with autism spectrum disorders (ASD).

Scientific Presentations

"Getting to Novel Treatment Approaches in Autism Spectrum Disorders," Joseph Buxbaum, PhD (Seaver Autism Center, MSSM) - After providing a brief overview of ASD, Dr. Buxbaum presented recent findings on the genetics of ASD and explained the importance of moving forward in gene discovery. He noted the genes that have been discovered to date, and he identified barriers to gene discovery. Importantly, he proposed a path forward and discussed the Autism Sequencing Consortium, an international group of researchers involved in high-throughput sequencing in autism.

"Targeted Treatments in Rett Syndrome: Implications for Autism Spectrum Disorders," Walter E. Kaufmann, MD (Boston Children's Hospital, Harvard Medical School) - Dr. Kaufman provided a thorough overview of Rett Syndrome and explained that it is a clinical diagnosis characterized by impaired synaptic development. Dr. Kaufmann also shared preliminary results of his study testing the effects of insulin-like growth factor-1 in

see *Seaver Center* on page 24

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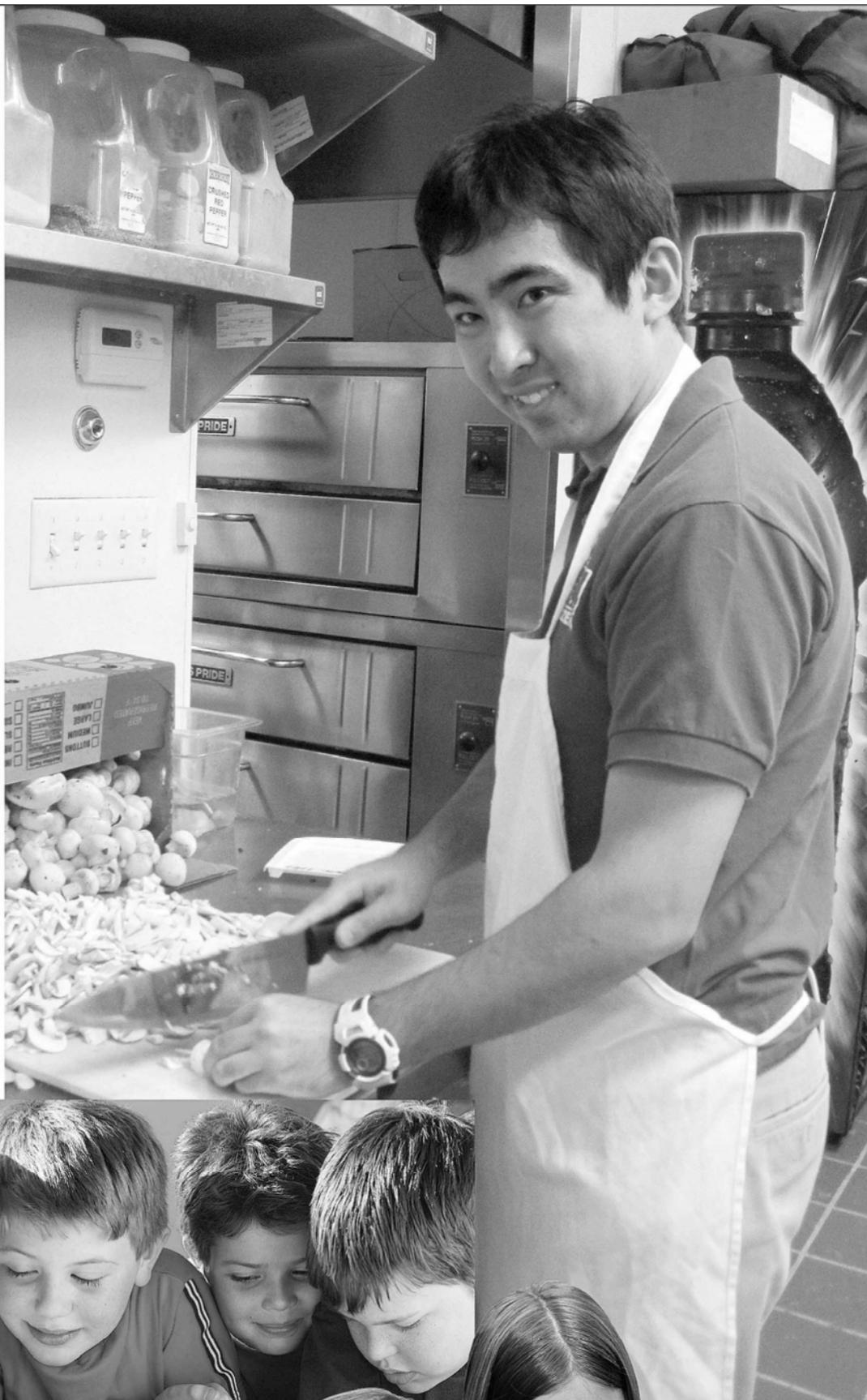
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Supporting Students on the Autism Spectrum in Higher Education

By Mitchell Nagler, MA, LMHC
and Stephen M. Shore, EdD
Bridges to Adelphi Program
Adelphi University

The continuing rise in prevalence of autism, now at 1 in 88 (Center for Disease Control, 2012), has engendered greater awareness of the condition, followed by increased research, and improved interventions and strategies for individuals with Asperger Syndrome (AS) and High Functioning Autism (HFA). A part of the autism spectrum, persons diagnosed with AS and HFA experience significant challenges in communication, social interaction, repetitive motions, and restricted interests (APA, 2000). Yet, as suggested by the number of resources written on the subject, these individuals have the cognitive ability to process college level academics, and to attend institutions of higher education (Brown, Wolf, King, & Bork, 2012; Palmer, 2005; Freedman, 2010; Wolf, Brown, & Bork, 2009; Martin, 2010; Zager, Alpern, McKeon, & Mulvey, 2012; Shore & Rastelli, 2006).

These conditions have set the stage for increasing numbers of individuals with AS and HFA to enroll in institutions of higher education. However, challenges in social interaction, executive functioning and sensory issues create barriers to their success in academics, relationships, employment, and involvement in the community.



Mitchell Nagler, MA, LMHC

Different Strokes for Different Folks:
External and Internal Models

In response to these challenges a growing number of programs have been created specifically geared towards supporting individuals on the autism spectrum. These programs can roughly be divided into two categories; external to, and internal to, an institute of higher education.



Stephen M. Shore, EdD

The External Model - External programs are not associated with universities; and have minimal contact with administration, faculty, and staff. They provide varying degrees of support and education in interdependent living for individuals on the autism spectrum who are already enrolled in, or planning to enroll in, higher education. Examples include the College Internship Program (CIP) and the College Living Experience (CLE);

both which have a number of branches around the United States.

The external model often involves individuals with autism sharing a house or apartment off campus with one or more roommates who also are on the autism spectrum. These programs provide support by educating these individuals on strategies to successfully navigate the challenges of living "on one's own" in conjunction with attending a college or university. Some areas of focus include schedule and financial management, maintaining proper nutrition, addressing use of leisure time, and involvement in the community. Another important area of focus is promoting a deeper understanding of what having autism means in terms of the students' success in education, and life in general.

Because these programs are external to colleges and universities, there is a substantial fee beyond what is paid for college tuition. This fee can reach upwards of \$60,000 a year, whereas costs for the internal model are significantly less.

The Internal Model - In contrast, internal models are housed within institutions of higher education with services being provided on campus, save for off-campus excursions organized by the program. Examples of internal programs include the Bridges to Adelphi Program, at

see *Supporting on page 30*

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Education, Training, and Job Trends

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

There is no time greater than during a recession to consider the truth behind the phrase “education matters.” This is especially important for people with autism and other disabilities that, even in a “good economy,” have a difficult time finding employment. Why does post-secondary education and training matter?

Post-secondary education and training matter for three reasons. First, it protects an individual against unemployment in general. According to the U.S. Department of Labor, the unemployment rate for all workers in 2011 was about 8%. However, as shown in Table 1: Unemployment Rate in Percentages (2011), the reader can see a direct relationship between education and unemployment. As one’s level of education and training increases, one’s rate of unemployment decreases. For individuals with less than a high school diploma the unemployment rate reached almost 14% in 2011. Individuals who earn a high school diploma reduce the risk of unemployment by over 40%. Even taking a single college course or two reduces the odds of unemployment. If a person is capable of earning an associate degree, he or she reduces her unemployment risk by



Ernst O. VanBergeijk, PhD, MSW

25% over a person who merely completes a high school degree and cuts the risk of unemployment by half over someone who has not completed high school.

Second, post-secondary education and training used to have a second protective factor. Not only did education protect from unemployment in general, but it also affected the length of time one was unemployed. The more education and training a person had, the less time he or she would



Paul K. Cavanagh, PhD, MSW

remain unemployed. Recent data suggest, however, that once one is unemployed for a considerable length of time, then level of educational attainment no longer offers a protective factor (Aliprantis, & Zenker, 2011, p.12). This recent phenomena underscores the importance of receiving postsecondary education and training to prevent unemployment.

Third, the amount of education and training one has also affects his or her life-

time earnings. According to Julian (2012) a person who drops out of school by the 8th grade can expect to make a little over \$900,000 between the ages of 25-65 (known as synthetic work life, which assumes continuous employment between those ages), (See Table 2: Education and Lifetime Earnings). The individual doubles his or her lifetime earnings by earning an associate degree and earns approximately \$1.8 million over the course of a lifetime. As the educational level increases, so do the lifetime earnings. A person who achieves a doctoral or professional degree earns 4 times more money as a person who drops out of school early (See Table 2: Education and Lifetime Earnings).

According to the U.S. Department of Labor, Bureau of Labor Statistics (2011), the projected job growth by training and educational level will vary from 2008-2018. Jobs requiring short, medium and long term training will grow by about 8%. The same rate of growth will hold true for work experience in a job related field and those jobs that require a bachelor degree plus some work experience. Jobs requiring a Post-secondary Vocational Certificate Award will experience an approximately 13% growth by 2018. The education and jobs “sweet spot” is for those individuals who are able to earn an associate degree. Jobs requiring an associate degree will experience the largest amount

see Trends on page 35

Do you need support for a child, teen or adult on the autism spectrum?



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Education and Social Support for Adolescents and Young Adults



Employing Evidence-Based Practices in High School to Enhance Accessibility to Learning and to Build Executive Competence

By **Dianne Zager, PhD**
Michael C. Koffler Professor in Autism
Pace University
 and **Samantha Feinman, MEd, TSSH**
Director for Student Support Services
New Frontiers in Learning

Educators have made great strides in integrating students with autism spectrum disorders (ASD) into general education over the past several decades; however, at the secondary school level, these students still often experience serious difficulties. A major obstacle to success for adolescents on the spectrum is executive dysfunction. There is a growing awareness of the importance of executive competence for all aspects of academic and social life, and for navigating the complicated maze of everyday life. For high school students with ASD, executive functioning is a critical area of development, especially as they prepare for the transition to postsecondary environments. It is critical to understand the significant role played by executive skills in our lives and to explore opportunities to build competence in this domain. Educators can help students to be successful in high school by presenting learning tasks in flexible ways that address individual learning styles and support access to cognitive processes. This article discusses strategies that build reciprocal teacher-student relationships, support positive behaviors for learning, and present instruction through means that enable diverse learners to engage in learning, therein reducing school-based obstacles that may lead to anxiety and executive functioning difficulties. Central to this construct is the tenet that every student has strengths upon which successes can be achieved. The model is based on ongoing personalized support through approaches that are grounded in scientific evidence and that focus on environmental modification rather than on changing students.

Executive function refers to a set of mental processes that helps connect past experience with present action; processes which people may use to perform activities such as planning, organizing, strategizing, paying attention to and remembering details, and managing time and space (National Center for Learning Disabilities, 2012). Executive dysfunction may interfere with organization of time and tasks to the extent that students become frustrated and depressed. For adolescents with ASD, the consequences of executive dysfunction can be devastating. As students progress through their high school years, executive functioning competence becomes increasingly critical to academic and social success.



Dianne Zager, PhD

While many executive functions, such as inhibitory control do begin in childhood, it is during adolescence that brain systems become more integrated. During this period, neurotypical adolescents experience maturation in executive functions, such as attention and focus, inhibitory filtering, goal-directed behavior, and organizational planning. Most students with autism spectrum disorders do not show the same level of maturation in these essential skills as do their neurotypical peers, and challenges in these areas create significant obstacles to engagement in school and community activities. These difficulties become increasingly apparent as expectations rise in multi-tiered school assignments and in forming more multidimensional friendships. Strategies and supports to facilitate success in school and out of school are critical to help adolescents with ASD engage in both the academic and social arenas.

According to Ozonoff, South, and Provençal (2005), executive functioning is a cognitive construct used to describe behaviors that are goal-directed. These behaviors involve task planning, self-regulation, flexibility, organizational skills, and working memory. Adolescents with ASD, along with their teachers and parents, face continuous challenges in secondary school that are unique to their learning and behavior repertoires. Even when mandated supports and accommodations are available for academics, difficulties in managing the complex schedules and routines of high school often continue to frustrate students who are on the spectrum. In addition, the social arena remains an enigma, without a road map to



Samantha Feinman, MEd, TSSH

help them navigate. These students need an educational environment that will foster development of nurturing relationships and full participation to enable them to be actively engaged in their school community and prepare them for successful postsecondary experiences.

In order to prepare students with learning and behavior challenges for everyday life in secondary school and beyond, high school special educators need to be able to design strategies that promote independence (Kaweski, 2012). The educational path that leads to independence in adulthood is paved with operational executive skills. These skills are central in the development of self-determination, self-advocacy, and social competence (Roberts, 2010; Wehmeyer & Patton, 2012; Zager & Alpern, 2010). To adequately prepare students with ASD for college and other postsecondary environments, school personnel should work closely with families to foster competence in organizational skills, self-determination, self-advocacy, and socialization. In short, competent executive functioning is the undergirding for success in school and adulthood.

Models to Promote Successful Engagement

High school educators can increase students' opportunities for success by presenting instruction and other school activities in flexible ways that take into account how individuals access and understand new information. By building trusting safe relationships and by providing conditions that enable all students to

participate, teachers can establish a school community in which diverse learners are empowered to be successful participants. Three scientifically validated (i.e., evidence-based) approaches that hold promise for enhancing school learning and the high school experience, therein promoting successful engagement are: (1) Universal Design for Learning (UDL), (2) Positive Behavior Supports (PBS), and (3) Developmental Individual Difference Relationship (DIR). It should be noted that while these approaches have been researched extensively, they still require further investigation to be fully endorsed as effective methods for improving executive functioning and engaging students with autism in high school.

The promise of these practices resides in their potential to yield educational programs that enable learners of differing ability to successfully access curriculum. Within these existing models of intervention and instruction lie opportunities to create learning-rich environments to support students across the age span from early childhood through adolescence and into adulthood. While at first glance it may appear that these approaches require extensive time and effort to implement, and it is true that the learning curve can be steep for those that have not been exposed or trained in utilizing these techniques, the fact is that by employing systematic school-wide supports, students will be more engaged in education and outcomes will be better.

Universal Design for Learning

One model that has been proven through research studies to be effective in increasing engagement and improving learning outcomes for students with disabilities is Universal Design for Learning (UDL). Universal Design for Learning is a broad term that refers to making learning accessible to all students. It is founded on a set of curriculum development principles that provide all individuals equal opportunities to learn, and is a derivative of environmental and architectural design that affords access for all individuals to navigate their community (e.g., ramps, accessible bathrooms). Universal Design for Learning is not targeted at accommodating persons with a particular disability but is planned to ensure that the learning environment is inclusive and meets the needs of all learners. It is both individual and systemic.

Universal Design for Learning has been shown to lead to increased engagement in academic and social environments for students with diverse learning characteristics. Instructional practices and

see Competence on page 34



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What You Need to Know Before Your Child Transitions to School

By Bernadette Murphy Bentley, MPA
Autism Resource Specialist
Tufts Medical Center

Although it is common knowledge that transitions are hard for most children with special needs, transitions can also be difficult for their parents, especially the transition from services in the home to services in the school.

Under the age of three years, children are cocooned in their own home with occupational therapists, speech language pathologists, service coordinators, and behavioral specialists coming in to provide a variety of necessary services. Parents often participate in the work being done with their child, are there to provide a snack or diaper change or a shoulder as needed, and have instant access to their child's therapists to share concerns, ask questions, and learn from their expertise. In most cases, a trusting relationship develops in which parents come to rely on these therapists as coaches - and even as a support system - because the therapists know the family so well and also understand the challenges of raising a child with special needs.

As soon as the clock strikes three years, however, just like Cinderella's beautiful ballroom gown, it all disappears and parents have to depend on the public school system to meet their child's edu-



Bernadette Murphy Bentley, MPA

cational needs. Unlike Early Intervention, which has a family-centered approach, the focus of the school is solely on the needs of the child. While special education law does allow for parent training, and parents will often develop strong relationships with their child's teachers, it is not the same as being there every single day, observing what is going

on and being able to give your input and get guidance.

So what is the best way to prepare so that YOU will be ready for the transition to school?

Educate Yourself

I hate to break the news to you, but not only do you have to be an expert on your child's disability - and his/her social, emotional, behavioral, and learning needs - but you also have to become an expert on special education law and process. This is not an easy task, but in order for you to be able to effectively advocate for your child, you have to be at least as knowledgeable (if not more so!) as everyone else at the table regarding what protections your child has and how the system works.

You also have to learn the essential skill of being persistent, while also being polite and persuasive. The fourth "P" I like to add is "powerful." Although most parents don't realize it, they are the most powerful members of the educational team. You are the expert on your child, you have the strongest commitment to getting her needs met, and you are the one who accepts or rejects the services. Without you, the educational team does not truly understand your child and without you, the educational team cannot move forward in educating your child. Changing your mindset from feeling that the teachers and therapists know more than

you, to recognizing that you are the person leading the educational team because you are the most knowledgeable about your child, will help ensure that your voice is heard, your concerns are addressed, and your child's needs are met. "Assertive, not aggressive" is your goal.

My favorite books about the special education advocacy process for parents are *The Complete IEP Guide: How to Advocate for Your Special Ed Child* by Lawrence Siegel (2011) and *Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide* by Pam Wright and Pete Wright (2006). In these pages, you will learn about the law while also discovering how to effectively advocate for your child.

I also recommend that you contact your state's Parent Training Institute (find your local PTI at www.parentcenternetwork.org/parentcenterlisting.html). These nonprofit organizations are funded by the federal government to provide information and training to parents of children with disabilities. The main PTI in Massachusetts is the Federation for Children with Special Needs (www.fcsn.org) and they provide two excellent free resources for parents of children transitioning to school services: "A Parents' Guide to Special Education in Massachusetts" and "Turning Three" workshops, teaching parents what they need to know about the transition

see *Transition on page 32*

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Government Benefits

These may change by the time your child reaches his or her 18th birthday. You'll know where your child stands by learning about certain programs, such as Medicaid and Supplemental Security Income (SSI), as well as Social Security Disability Insurance (SSDI).



Employment

Finding a job is key to financial independence. Parents can help their children assess their skills, identify employment goals and find training and educational opportunities. *Disabilityinfo.gov* is a great place to start.



Independent Living

Parents and caregivers like to know that their child will be capable of finding employment and healthcare, living at home or in a supported living facility with assistance from a worker. *Disability.gov* is a helpful resource for this information.



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Interventions from page 1

be individually assessed and supported in ways specific to their particular needs.

There is an evidence base for supporting developmental characteristics many students share. In bringing this rich research literature to bear on the diverse problems students on the spectrum present, we have a large pool of possible interventions with ample evidence to support their use for individuals who share the problem, if not the diagnosis. This philosophy is consistent with current thinking on the transdiagnostic approach to treatment, where underlying mechanisms, rather than diagnostically driven categories, are targeted for intervention.

Common issues for students on the spectrum include social isolation and bullying, social skills deficits and socially inappropriate behavior, the development of empathic skills and perspective taking, emotional dysregulation and over-reactivity, aggression, disorganization and poor executive function, rigidity and difficulty with transition, anxiety, depression and other psychiatric issues. There exists a general research literature addressing each of these issues that we can draw upon to develop an individualized education plan for our students on the autism spectrum. Let's examine each issue and posit some existing solutions.

Social Isolation and Bullying

School-based bullying programs have demonstrated only modest effectiveness. Researchers advocate that we need to concentrate more specifically on those who

**Lynda Geller, PhD**

bully and those who are victimized. There are evidence-based approaches to help children on the spectrum with these skills through the development of improved social thinking and behavioral skills.

Social Skills research tells us that interventions need to occur in authentic settings to maximize maintenance and generalization, need to be more intensive than the typical once weekly session, should use manualized programs to counterbalance skill differences in personnel, need to be individually designed and very specifically described on the IEP, and should

have an explicit plan for generalization. It is critical to remember that in the absence of additional treatment, mainstream placement has NOT been shown to increase social interaction (McConnell, 2002).

The developmental literature tells us that the negative effects of peer rejection can be ameliorated by having just one friend (Parker & Asher, 1993b). So helping a child find someone who shares interests and can be a regular interaction partner can have a significant effect on positive personality development. Making an effort to find connections outside of typical classroom friendships can be invaluable for students on the spectrum.

Social Skills Group Models

There are two manualized social skills training models that have recently published positive findings for social skills improvement. They are Children's Friendship Training (Frankel et al., 2010) and Comprehensive School-Based Intervention (CSBI) Manualized Social Treatment (Lopata et al., 2010, 2012). Children's Friendship Training addresses conversation skills, peer entry, expanding and developing friendship networks, handling teasing, practicing good sportsmanship, and good host behavior. The specific components designed to focus on these issues include instruction on simple rules of social behavior, modeling, rehearsal and performance feedback, rehearsal at home, homework assignments for practice and generalization, and coaching by parents during assigned peer play. The Comprehensive School-Based Intervention (CSBI) Manualized Social Treatment includes

manualized instruction and therapeutic activities (Skillstreaming, 2005), face-emotion recognition, cooperative activities and problem solving, a non-literal language curriculum, a behavioral system, and homework and parental participation. Although neither model was developed uniquely for students on the autism spectrum, the manualized programs could easily be set up to serve this population as the elements addressed are ones that such students often manifest. An assessment of a particular student's social profile and underlying skill deficits should be the guideline for inclusion for participation rather than a diagnosis driven selection.

Social Thinking

Social thinking is an alternate approach for improving the social cognition of students who struggle with the social aspects of life. It was developed by Michele Garcia Winner and is based on cognitive behavioral therapy (a well-supported therapeutic methodology for changing cognitions, and consequently emotions), visual cues and concepts, and pragmatic language development. The approach, and the continual enrichment by professionals of various backgrounds in the last few years, provides a wide range of possible interventions that can be applied based on an individual student's particular set of social cognition strengths and deficits. The program was developed to address needs, rather than particular diagnoses. Students learn how their own social minds work, how their behaviors affect the way

see Interventions on page 37



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The Asperger Syndrome Training & Employment Partnership (ASTEP) focuses on employer education and training, and advises employers on how to recruit and manage employees with Asperger Syndrome. www.asperger-employment.org

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

Career and Employment Options, Inc. (CEO) provides transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities. www.ceoincworks.com

The Elija Foundation provides advocacy support, educational outreach and comprehensive workshops in Applied Behavior Analysis for educators and family members. www.theelijahfoundation.org

www.spectrumservicesnyc.com for clinical services and **contact information**

www.aspergercenter.com for articles of interest for families and adults with Asperger Syndrome

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The Daniel Jordan Fiddle Foundation's Latest Signature Programs Focus on Supporting by Educating Adults Living with Autism

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

The Daniel Jordan Fiddle (DJF) Foundation has entered its second decade of developing, advocating for and funding unique and groundbreaking initiatives that benefit the lives of adults living with autism spectrum. Exciting new collaborations with the nation's leading advocacy organizations and DJF's longstanding commitment to developing programs based upon the needs expressed by individuals who live with the challenges of autism have led to the development of original programs and public service materials geared towards educating and supporting adults on the spectrum.

A Manual for Self-Advocacy and Leadership on Campus

Last year, Linda Walder Fiddle, Founder and Executive Director of DJF Foundation met with Ari Ne'eman, President of the Autistic Self Advocacy Network (ASAN) and one of the nation's leading self-advocates to discuss Ari's interest in developing a manual that every college student on the spectrum could get when they enroll that would offer advice, insights and strategies to advocate for them-



Social outings in the community are part of The Daniel Jordan Fiddle Foundation Ignition Grant Program at the JCC of Manhattan

selves on campus and beyond. In addition, the manual aspires to help foster advocacy leadership and affiliation on campus and beyond. Linda loved the idea, recognizing that 35% of people on the spectrum are now attending college or college classes as adults. Further, The Daniel Jordan Fiddle Foundation had previously funded programs on several campuses to help students including a program at Kean University and one at Camden County College.

The first draft of this exciting manual known as the *ASAN/DJF Empowering Autistic Leaders Manual* was produced in

2012. Still a work in progress, that includes first-hand writings from individuals on the spectrum about such topics as planning self-advocacy events, sustaining advocacy groups on campus and how to deal with disability discrimination on campus, the manual will be edited on 2013 and piloted on several college campuses. Ari stated at the inception of the project that it will take three years in total to develop, pilot and disseminate. "As more and more Autistic young people enter college, a new generation of Autistic leaders is emerging. ASAN and The Daniel Jordan Fiddle

Foundation believe this resource will be a critical tool towards empowering that new leadership and swinging open the doors of higher education for all."

A Pocket Guide for Everyday Travel

Another key area identified by people living with the diverse challenges of autism that was previously unaddressed, yet is vital to every aspect of community participation, is transportation. The social-entrepreneur spirit of DJF Foundation inspired by an adult who travels to and from destinations independently but gets confused and flustered if things do not go according to plan, led Linda to seek out the expertise of Dr. Mary Leary, Senior Director of Easter Seals Office of Public Affairs and leader of Easter Seals Project ACTION, the national center on Senior transportation and other transportation and mobility initiatives. Mary and Linda discussed the idea of creating a pocket-sized guide that individuals could carry in their wallet or purse that provides trouble-shooting tips when the unexpected happens when traveling using public transportation.

The purpose of the *GET Going (Guiding Everyday Travel) Pocket Guide* is to provide an easy-to-use, portable tool for travelers who may become flustered or forget the

see Signature on page 36

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Finding the Best Fit: Exploring College and Vocational Options

By Mary Riggs Cohen, PhD, Director
OASIS Program at Pace University
and Evan Oppenheimer, LMHC
JCCA Compass Project

In the last twenty years the growing awareness of autism, the reconceptualization of autism as a spectrum of characteristics, and improved diagnostic techniques have contributed to the increased demand for specialized educational programs in elementary, secondary, and post-secondary educational institutions. Many young adults have benefited from the development of the improved treatments and instructional strategies and are now enrolling in colleges in greater numbers each year. It is estimated that as many as 1 to 2% of college students may have an autism spectrum disorder (White et al., 2011). In a 2008 article, VanBergeijk, Klin, and Volkmar addressed the “surge” of ASD children approaching college age with specific recommendations for transition and support services. Universities were encouraged to “learn how to effectively intervene in the areas of communication, social and independent living skills, and executive functioning.” They concluded that college supports must be expanded “to include social skills groups, psycho-educational groups, directive counseling, vocational training and life coaching.”

The OASIS (Ongoing Academic Social Instructional Support) Program, a fully



Mary Riggs Cohen, PhD

inclusive college support program for Pace University students with ASD or other learning differences, realizes this model. Our students are matriculated in a Bachelor's degree program and many live in campus housing. Students receive the following support services: individualized advisement and supervision for course selection, academic support such as tutoring, assistance with time management and organizational skills, campus life support, career develop-



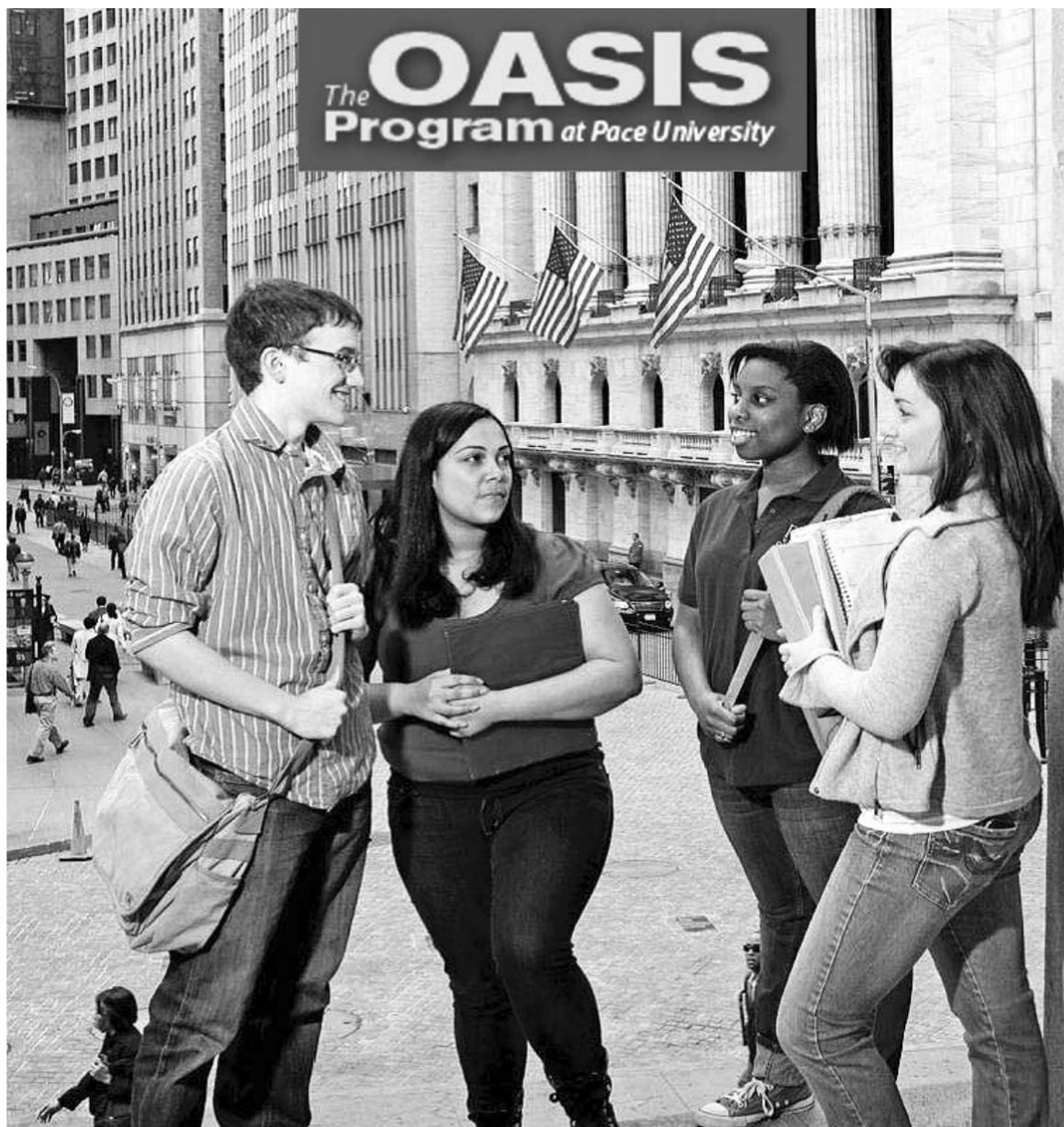
Evan Oppenheimer, LMHC

ment and internships, social/emotional support through specialized counseling, communication groups, dating/relationship groups, and social literacy classes. While all college students with disabilities receive accommodations (such as extended test time) in courses through the Americans with Disabilities Act, the work is not modified and remains at the college level. This is true of all colleges and universities which award Associates or Bachelor's degrees

and is an important consideration for any ASD student considering college. An academic coach meets with each student a minimum of four times weekly to assist and support them with assignments, organization, and management of their studies. The academic coach meets with faculty as needed to ensure communication among OASIS students, staff, and university professors. While the OASIS program provides intensive academic support, other areas of support are seen as critical to the student having a successful college experience. OASIS students receive support for social, emotional, and vocational development as essential components of college life. Students are encouraged to participate in weekly psychodynamic groups which address issues of transition to college, independent functioning and identity. Topical didactic groups are also offered in sexuality, dating and relationships, mindfulness and emotional regulation.

Even with this comprehensive level of support, a four year Liberal Arts degree is very challenging for certain students. College life is rewarding because it provides a variety of new experiences for students. However, these experiences also create social demands and difficult situations. Many ASD students are surprised to learn that they must take core curriculum courses outside their special areas of interest. They are often resistant to these requirements.

see College on page 36



Independent. Confident. Successful.

A true college experience is more than just the completion of coursework. It is a time for students to grow, make friends, and develop skills to succeed not just in the workplace, but in life. The OASIS program at Pace University is designed to do just that.

Located on Pace University's New York City Campus, OASIS is a small, inclusive program to empower academically capable students with autism, Asperger Syndrome, and other learning differences. OASIS students are matriculated in the bachelor's degree program of their choosing, and most students reside in Pace's dormitories. They attend undergraduate classes with other Pace students and engage in all facets of campus life.

“This has been the best academic year of my student's life. The OASIS program enabled her to reach a level of performance and develop the self-confidence she had been unable to develop before.”

—OASIS parent

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From Assessment to Intervention: Strategies for Identifying and Monitoring Treatment Progress in ASD

By Sam Goldstein, PhD
and Jack A. Naglieri, PhD

Evidence based treatment and the assessment of treatment effectiveness are dependent upon the collection of data during the evaluation process providing information about symptoms, impairment and abilities in children with ASD. Such an assessment allows for a seamless transition from diagnosis to effective treatment. Evaluating the effectiveness of a treatment strategy or program is important for interventions designed to address a broad range of ASD symptoms. The validity of the entire process is closely related to the tools used during the evaluation and diagnostic process. More specifically, the reliability (ability to measure the same construct accurately over time) and validity (what is actually being measured) of the tools used will be directly related to the psychometric qualities of the instrument. As in all areas of evaluation, what is learned depends upon the quality of the data generated and the manner in which the findings are interpreted. Tests and rating scales developed to provide valid and reliable information about children with ASD better informs researchers and clinicians. Tools used for diagnostic deci-



Sam Goldstein, PhD

sion making and treatment planning have a profound impact on the information obtained and the conclusions reached. The better the tools, the more valid and reliable the decisions and, most importantly, the more helpful the information gathered will be in developing a treatment plan monitoring progress and documenting treatment effectiveness.



Jack A. Naglieri, PhD

Determining the effectiveness of any treatment program for individuals with ASD should be accomplished using methods that reflect specific behaviors as well as larger conceptualizations of the condition (e.g., social, communication and atypical behavior problems). Four key questions must be addressed in this process. They are:

1. How are these behaviors identified?
2. How are these behaviors measured?
3. How do these behaviors change with intervention?
4. To what reference point or points will behavior change be calibrated?

In this article we present a way to evaluate symptoms related to ASD on both global and specific levels, identify areas for treatment and evaluate the effects of treatment. To do so we will illustrate using information from the Autism Spectrum Rating Scale (ASRS; Goldstein and Naglieri, 2009, Naglieri and Goldstein, 2013, in print). We choose to illustrate using this tool because it is nationally normed and provides several different types of global scores as well as measures of specific behaviors. In addition, the reliability of the scales is well documented and guidelines for assessing treatment change are also provided.

The ASRS is a rating scale for assessing behaviors associated with ASD in children two through eighteen years of age. The scale was developed based on a comprehensive review of both current theory and literature on the assessment of ASD and

see Assessment on page 39

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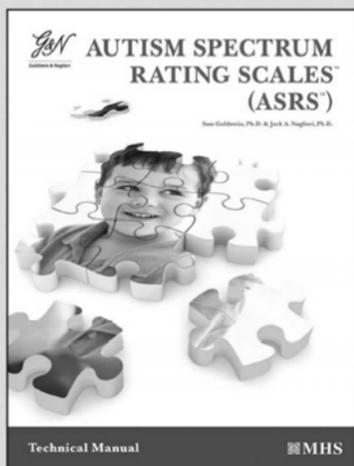
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Key Elements of Social Skills Groups in Schools

By Jennifer G. Weber, EdM, SM, MS and Natalia Appenzeller, PhD
Fay J. Lindner Center for Autism

Autism Spectrum Disorders (ASDs) are characterized by impairments in the domains of social interaction, communication and behavior. For many individuals with ASDs, especially those with Asperger's Disorder and high functioning autism, social interaction and communication difficulties can have the most profound impact on their everyday functioning. Therefore, a focus to ameliorate social deficits has branched out to the schools, where children with ASDs spend the greater part of their day and tend to have the greatest number of social interactions. Most commonly, social skills intervention in the schools takes the form of social skills groups. Although there is an evidence-base for social skills groups, there is neither standardized format nor content for these groups. Accordingly, while some groups may be tremendously beneficial, others, while not harmful, may not be of enough direct benefit to warrant pull-out from the classroom or other school activities. This article will outline the fundamental attributes of worthwhile social skills groups for children in the schools to help parents decide if the social skills group being offered to their children is right for them. Parents are encouraged



Jennifer G. Weber, EdM, SM, MS

to weigh the pros and cons of having their children join the social skills group prior to enrollment.

What skills should be taught in a social skills group? According to the National Association of School Psychologists (NASP), essential social skills can be classified into four categories:

- Survival Skills (listening, following directions, ignoring distractions)



Natalia Appenzeller, PhD

- Interpersonal Skills (sharing, asking for permission, turn-taking, joining others)
- Problem-Solving Skills (asking for help - including self-advocacy, offering an apology, decision-making)
- Conflict Resolution Skills (coping with bullying and peer pressure)

NASP suggests that any school-based social skills curriculum utilize an approach that focuses on behavior regulation and teaching appropriate social behavior. Furthermore, they recommend that the program be consistent in the language used and skills taught so that participants are more likely to reliably apply the skills in real-life social situations. In order to develop a beneficial social skills group, schools should make sure their groups include the following elements:

- Focus on facilitating desirable social behaviors as well as eliminating undesirable ones
- Emphasize the learning, performance, generalization, and maintenance of appropriate social behaviors which includes providing students with immediate feedback
- Employ primarily positive strategies to encourage participants to learn new desirable social behaviors
- Provide training and practice opportunities in a wide range of settings with different groups and individuals to facilitate generalization of new skills to multiple, real life situations

see *Social Skills* on page 38

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The Critical Importance of Advocacy and Government Relations

By **M. Christopher Tabakin, MS**
 Director of Quality Management & Advocacy
 Melmark



M. Christopher Tabakin, MS

The term “advocacy” often elicits many different thoughts. The actual word “advocacy” is defined as “the act or process of supporting a cause or proposal.” We advocate all the time, and for many different things. Most are very worthwhile causes, and others are perhaps more trivial (have you ever voted for your favorite member of Dancing with the Stars?) We regularly engage in the act of advocacy. This article will focus on ways to effectively advocate to our elected and appointed officials, the critical importance of doing so, and how to build mutually beneficial relationships.

Advocacy and lobbying to the government are not just for some well-paid, well-dressed Washington D.C. professionals. It is for everyone, and actually is a right that we all have. This right is one of special importance to those who support loved ones living with any form of disability. Advocacy is at all levels - from Washington D.C. to your local elected or appointed officials. In this case, the term “lobbying” refers to attempting to influence the government. By supporting a cause (advocating), we are also often attempting to influence decision makers to also support this cause as well (lobbying).

We just exercised an absolutely wonderful right here in the United States: we voted. We spoke out and elected or re-elected people into office with the hope that they will represent us and make decisions that benefit us and those we serve on the issues important to our field. By identifying and communicating priorities impacting our respective human service ar-

reas, we help to inform and influence the elected and appointed officials on what they can do to advance the lives of children and adults with intellectual disabilities.

Those who serve us in public office come from a variety of different backgrounds and experiences. This often makes them well versed on a number of specific topics while having general knowledge of the rest of the topics. Many of us do not consider ourselves extremely well versed on government policy or process, however we ARE experts on the individuals with disabilities we serve and the existing or proposed legislation that affects their support structure. This expertise is vital to share with those who hold office so that they gain knowledge, and even more importantly, know where to go to get answers and gather information when necessary.

When a topic comes up, elected officials should represent the many, not the few. If a particular piece of legislation is introduced that could impact students and adults with disabilities, the more people that the legislators hear from, the more they know what the priority should be and how they should act on the issue (support/oppose) to represent us. The only way they can know what the priorities are is by hearing from us!

How can we accomplish this? The first way is by being “on the radar” - be visible, be available, and be a resource. Elected officials are used to being asked

for things. But when you make yourself a resource, your communication about your cause has just become more effective. Through developing a mutually beneficial relationship, you can have a “gain-gain” scenario. When legislators hear from us, those we serve and family members, we are more likely to positively impact outcomes. In return, we become a useful source of information to legislators. When legislators are knowledgeable and supportive of important causes, this often results in their increasing popularity with constituents, and ultimately votes. A colleague uses the example of asking a friend to borrow a tool every time you see that friend. After a while any time that friend sees you, he/she will expect you only to ask for a tool, and perhaps will develop some negative feelings. But if you develop a good rapport with your friend and ask how he/she is doing and offer to help in some aspect, when you do need a tool, your friend will most likely be more than willing to share them with you and reciprocate.

Take opportunities to meet with legislators, call them, write them a hand written note, email them and thank them for the work that they do. Let them know what is important to you. Whenever possible during the “ask” and education process, be specific with a story or example. If you know of a particular vote coming up and you want an elected official to

see Government on page 34

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For more information on the Bridges to Adelphi program, contact Mitch Nagler, director, at **516.877.3665** or mnagler@adelphi.edu.



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An Interdisciplinary Treatment Program in the School: A New Model

By Eric London, MD
 Director of Autism Treatment Research
 NYS Institute for Basic Research

From our vantage point in 2012 there is nearly unanimous agreement among the scientists who study autism, that it is really many diseases, and some have suggested that we call it the "autismS." Along with the three key diagnostic signs (language and social disorder as well as a rigid adherence to sameness) are a host of medical, neurological, psychiatric and behavioral problems making the complete treatment of autism very difficult for any one practitioner. The primary care physicians have recognized this problem for autism and other diseases and have suggested what is called the "medical home" This consists of a primary care provider with the backup of all needed specialties all under one roof or more accurately under a virtual roof, which is to say that all the practitioners work closely together.

The problem is that this has rarely if ever been put together adequately for autism. Both primary care specialists as well as parents of autistic children both agree that there is little to celebrate in the current system. Even in the rare situations when all of the medical specialties work together and even if there are adequate behavioral practitioners for a given case, the question is how to integrate with the educational system. I have observed this first hand over many years. I have been repeatedly frustrated by knowing that the child needs a behaviorist but cannot access one leaving me (a psychiatrist) to use my medications to the best of my ability but overall it is a suboptimal situation. I have heard many stories from parents concerning teachers who seemed not to know how to handle a given child. If only the teacher could receive a little more help, a whole year of learning and poor behavior could at times be averted.

Physicians and psychologists and the other specialties who work together all conceive of themselves as "treatment" professionals and perhaps for that reason there is a common vocabulary and an ability to work together when that is possible. The educational personnel and the school systems do not share that outlook. They see themselves as educators. If a child has



Eric London, MD

an infectious disease or even a chronic disease (such as juvenile onset diabetes) the schools role is to educate, not to "treat." With autism as well as with the other brain-centered developmental disorders, one of the primary problems is not the most severe problem is the learning disability involved. Examining the issue practically, the school system and the teachers can realistically be said to be the most important treatment professionals for many of the cases. To improve the outcome of autism we need to improve the school's effectiveness.

Proposing a Medical Home Within the School Building

One way to improve the effectiveness of the teachers is simply to give more training and support. However, with the multiplicity of problems autistic children present with, both behaviorally and medically, this will only help up to a point. What is needed is the multi-specialty "medical home" to be working closely with the teachers. What I am proposing is that the medical home actually be housed in the school and along with this the school and the teachers become a part of the medical home.

Teachers spend five hours per day, five days a week with the students and other

than the child's parents, nobody including all of the treatment professionals has a better understanding of the child's needs and issues. In the traditional medical model, treatments are prescribed and after a period of time the outcome is evaluated. Then there is an office visit for follow up which in reality is often no more than 12-20 minutes. Most of that time is taken up with communicating the outcome of the intervention although if new problems occur, it may even push out the time for evaluating the previous interventions. Having a teacher as part of the treatment team and having the treatment team physically in the location where the student and teacher are can therefore facilitate a much greater efficiency. More in depth assessment can take place on a day-to-day basis and regular feedback becomes possible. Perhaps the greatest advantage is that those issues which are preventing or slowing down learning can be addressed by the other professionals according to their expertise. For example if a behavior problem is hampering learning, having a behaviorist and or a psychiatrist observe this first hand can lead to interventions with much more frequent adjustments and re-evaluations. If a child appears to have a medically-based problem (for example, headaches or gastro-intestinal problems), the primary care physician can have the direct feedback on the success of their treatments. Better medical and behavioral treatment by itself will lead to better learning. Psychiatric medications can help with behaviors; however, a question which is rarely studied is, "What effect do they have on learning?" There is little if any understanding of the role medications play in helping or hurting the ability to learn. Psychiatrists lack the tools to be able to measure this. Teachers however have those tools. By measuring learning acquisition rates, we can obtain powerful information to guide the use of the medications, thus improving the effectiveness of the psychiatrist.

The science of learning is a field which is in its infancy. Neuroscientists have just recently come to understand some of the basic issues of how humans pay attention, absorb, process, and retain information and are able to produce that knowledge in the context of their lives. New treatments for learning problems are possible. One of the stumbling blocks for the creation of how to evaluate the new treatment is how to measure the

success. For Alzheimer's disorder we assume a body of knowledge and test the person's ability to demonstrate that information such as knowing the date, and repeating back strings of words or numbers. For the developmental disabilities, every child has a dramatically unique level of cognitive functioning. To measure success, there will need to be sophisticated and individualized measures available. I believe this will only be possible (for the foreseeable future) through the direct measurement of learning and will need to be coordinated with the learning which is going on in the schools.

One might ask, "If the advantages of this are so clear, why aren't these school-based programs already in existence?" The answer I believe is the administrative systems which are already in place find this challenging. Putting treatment professionals in the schools system takes the educational system (as well as the medical professionals) out of a comfort zone. The schools are paid for through local taxes and run on tight budgets, altering procedures often requires time and money. Medical services are paid for by governmental or private insurers or directly out of pocket by the families. Governmental regulators of the schools and school principals have little experience in evaluating medical programs and the same is true for medical regulators. So is this idea possible?

There is a good model for this type of program. There is a program which already has the "medical home" in the schools and it is known as the School Based Health Centers. Physicians, social workers, psychologists and nurses are all present inside the schools and provide comprehensive primary care. There are about 2,000 of these programs in existence nationally. Originally conceived to tackle the issue of the lack of medical access for teenagers who were HIV positive, the program has grown in many directions and now includes mental health most commonly aimed at substance abuse by teens. While there are School Based Health Centers in Special Educational Settings, I have not seen this implemented in a comprehensive, multidisciplinary way for autism and the developmental disabilities.

If there is a School Based Health Center or school district in the NY Metropolitan area which would be interested in creating this type of program, please contact me at naarlondon@gmail.com.



Collaborators Wanted

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Sensory Scanning for Self-Advocacy

By Valerie Paradiz, PhD

Many individuals with autism, like myself, have challenges with the sensory world. Sometimes these challenges are difficult for us to identify, and quite often it's even harder for those around us to see or understand them. Our senses provide our brains with information about the environment, which in turn helps us respond to the environment and organize our actions and behavior. People with sensory differences don't adjust easily to some environments, which can make it harder for us to participate as fully as we would like to. For example, we might perceive sounds or smells that don't seem to bother others. At times, such sensory input can be so challenging that it prevents us from being able to keep up in school lessons, join in activities with our friends or families, or go to community events. Sometimes they can be deal breakers when it comes to keeping a job or performing well at work.

The good news is that when people with autism have the opportunity to learn more about their sensory systems, they can anticipate and prepare for difficult situations (by bringing supportive tools such as earplugs or sunglasses to work or other settings) or advocate for an accommodation (such as requesting to turn off the fluorescent lights). I developed the ISA Sensory Scan™ for this purpose. It is a simple tool that helps any person methodically scan an environment to identify what his/her sensory challenges are, and, more importantly, do something about it. The great thing about the Sensory Scan is that you can do it either on your own or with someone to support you. In other instances, the scan can be



Valerie Paradiz, PhD

conducted as an observation by a staff person or educator. This method not only helps the person with autism in understanding his/her sensory differences, but it also sensitizes staff to the individual's particular sensory needs and preferences in a given setting. See figure 1 on page 30 for an example of a simple Sensory Scan from the ISA® scan series.

This particular scan is designed for those who learn best with visual and communication supports. The ISA scan series includes a broad range of scan types to support different learning and processing styles for all people on the spectrum and across the life span.

see *Sensory* on page 33



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OUTREACH PROGRAM

For those learners not enrolled in the school, The ELIJA School Outreach Program provides support, education and training to parents, family members, caregivers, and professionals—as well as conducting private consultations—within and outside of the school's community. ELIJA also participates in local and national conferences to help disseminate our knowledge and share valuable treatment designs with other programs that serve and care for individuals with Autism.

THE ELIJA FOUNDATION

The ELIJA Foundation is a not-for-profit, 501c(3) organization serving parents, educators, professionals, and caregivers of children with Autism Spectrum Disorders (ASD) on Long Island, New York. Since 2002, The ELIJA Foundation has provided the community with educational opportunities that focus on improving the quality of programs and services available to children with Autism. In 2006, The ELIJA School opened its doors to extend the mission of the Foundation and start helping children with Autism. The Foundation's focus is to empower families and improve the competency levels of professionals, by providing training on the most advanced treatment and educational strategies that maximize the potential of those affected by Autism. The Foundation hosts workshops that give the community access to local and nationally recognized Autism professionals who present topics which will allow those with Autism to more fully participate in their families, communities and educational settings. The ELIJA Foundation is committed to offering the most comprehensive information that is geared toward improving the lives of persons with Autism and their families.

For more information on The ELIJA School, Foundation, Outreach Services, and Events, please visit www.ELIJA.org

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The Real Priorities in Advocacy: Keeping the Whole Child, The Whole Family and the Big Picture in Mind

By Christine Rosenow Hoff
Family Advocate, Educator & Consultant
Children's Mental Health
Coalition of WNY, Inc.

In my observation, an effective Autism Advocate is someone who is often isolated from the rest of the "typical" society because they are the parent of a child with Autism, which is a 25 hour a day job. They become consumed in caring for their child on top of their other life duties such as caring for their other children and their partners or themselves for that matter. If they are lucky enough to have a partner that is mutually engaged in the care of the rest of the family, they only have to work 24 hours a day. An Autism Advocate is selfless, caring, nurturing, and as fierce as a mother bear protecting her cub. They become negotiators (sometimes terrorist negotiators), politicians, peace keepers, lawyers and emergency service workers all in one. They are educators, anger managers, social workers and crisis counselors. They are Moms and Dads. They are probably the most knowledgeable and intelligent individuals known to mankind in dealing with an autistic person without a degree in any of those particular fields (in most cases) because they have dedicated their lives to the care of their chil-



Christine Rosenow Hoff

dren and their children's disease. They are tired, overwhelmed and almost always lonely because most people do not understand Autism and find it easier to ignore or blame on parenting skills. "They are the definition of LOVE" - Tom O'Clair, Dad of Timothy.

I am a very lucky person! I get to meet

the most interesting, smart, tenacious and wonderfully different people. They may be parents, doctors, teachers, social workers, human service professionals, politicians and most importantly people with an autism spectrum disorder.

I work part time in a residential treatment facility for children with significant mental health challenges ages 5-14. I also volunteer to advocate for families in my off hours and I run a support group for parents of ASD children. I have helped start a very successful recreation program for children who have an ASD as well. I am also an intricate part of the Children's Mental Health Coalition of WNY, Inc, a family run family support agency for families of children and youth with emotional, behavioral, social, learning, and developmental disabilities in 19 counties in Western New York. In this part of my life I provide educational workshops and consultation services for families served by and the agencies involved with the "Coalition."

What Can an Advocate Do?
Why is Advocacy Important
In the World of Autism?

An advocate can be the most valuable person on any team when dealing with helping a family function and be successful when autism has become part of their

life. We often help professionals navigate and interpret a tough situation. There are many different types of advocates and a family may need to use the services of more than one at times.

I am a family advocate, so when I work I try to keep the whole family in mind no matter what the makeup of the family is. I find that most times the family is in need of advice. Some families may need education about the specific disabilities associated with autism so they can accept their child's challenges and the different ways they may have to parent - versus how they originally thought they were going to parent. Families need to understand that there are three big systems they are going to have to navigate (State Education Department, Office of People with Developmental Disabilities and finally The office of Mental Health) and hopefully give them a sense that they are not alone. I try to help build confidence and courage that a family will need for the years to come.

Here are some typical ways that I meet and work:

- I usually get a phone call from a parent or a professional asking if I can help. Many times the issues are the same, sometimes there are extraordinary situations that I am astounded can still

see *Advocacy* on page 41

A Collaborative Education Creates a "Lifestyle" for Learners with Autism

By Marianne Clancy
Parent of Teenager with Autism and
President AutismAIMS, LLC

Education is defined by dictionary.com as: 1) The act or process of imparting or acquiring general knowledge, developing the powers of reasoning and judgment, and generally of preparing oneself or others intellectually for "mature" (complete in natural growth or development) life.

What is Education?

After nearly a decade and a half of focusing and collaborating on the education of my son with autism, I can say unequivocally the single most important purpose of education throughout the years is to deliver the knowledge and skills that generally prepare the youngster for his adult life. The challenge is for us - school teachers, behaviorists and parents, as I am my child's first and forever "teacher" - is to use learning opportunities that exist at school to specifically teach my child relevant real life skills he needs and to enable him to use these skills to his best ability in all environments: at school, home and in the community, encompassing what I like to call the 3 "I"s ©: *Interaction* (communication and socialization); *Independence* (knowing what to do and how and when to do it, accountability, self-management, self-regulation); and



Marianne Clancy

Inclusion (being able to participate in settings and events as needed and/or desired, for: activities of daily living, as well as social, leisure/recreational and vocational purposes).

Is this really that different than what I expect in the development of my "typical" children? No, it's not. However, my typically developing children will rely on their own skills as they are taught through lessons and experiences in school, home

and community; skills such as observational learning, awareness of the people and events around them, reasoning skills, and more.

My child with autism lacks those skills, and so we, his teachers and I, must deliver to him an education that includes effective instruction and supports to provide him with the knowledge and skills he lacks. We must teach that which he needs in order to learn and to function at his best. That's what's provided for through the Individuals with Disabilities Education Act (IDEA) for special education to meet the unique needs of students with disabilities to be provided in the least restrictive environment.

So it seems imperative that the purpose of educating my child with autism is to use opportunities that exist in the least-restrictive environments in which he is capable of participating in order to teach to his needs.

Where Does Education Take Place?

These learning opportunities exist in the school, home and community, and so for my son that is where "education" needs to take place.

In school, we may use the general-ed math class, or resource room, or self-contained small group, and even the lunch room and/or walking-down-the-hallway-between-classes to teach and target those many varied real life skills that help my

son "know what to do and how to do it." These may include attending to teacher, complying with authority, awareness of people and events around him, engaging and participating in a group, acting in a socially acceptable way, being organized, self-reliant and accountable for assignments and responsibilities, and many more. These skills can be broken down into small measurable objectives and taught/enabled through effective instruction and tailored supports during the many teachable moments that exist in all environments in the school. Learning the academic subject matter in the classroom (the "core curriculum" or other lesson plan) does not have to be THE goal of that classroom or setting. Developing vital relevant real life skills to one's greatest level of participation and independence can be the goal.

At home, adapting a focus on daily life that enables my son to learn to use those very same relevant real-life skills has been essential. Striving to use a proactive instructional approach in parenting (as opposed to reactive), and to provide supports (such as a to-do list, written cue card, or picture schedule) helps my son know on his own what to do and how to do it, and to provide enjoyable and rewarding (motivating) activities for his successes. This creates a home-life that promotes success and quality of life not

see *Lifestyle* on page 42

Traditional Education May Be the Biggest Barrier to a Meaningful Education

By Gloria M. Satriale, Esq, BCABA and Thomas L. Zane, PhD, BCBA-D
Preparing Adolescents and Adults for Life
 Institute for Behavioral Studies
 Endicott College

Unlike many disorders that are treatable with a pill or procedure, the most important form of treatment for an autism spectrum disorders (ASD) is education. However, the traditional special education model, notwithstanding the great advances made in public education, individualized programming and evidence-based practices, remains largely confined to the classroom (e.g., Kavale & Forness, 1999). The classroom remains the primary context in which children with autism are educated despite the fact that once graduation day comes, these ex-students will never again spend another day in a carefully organized, highly staffed, and attractively decorated classroom environment. As such, the continued utilization of the traditional classroom model may, in fact, be one of the greatest of the many barriers currently standing in the way of an education that results in meaningful outcomes for individuals with ASD.

Learners with ASD face many challenges. These include social and communication deficits along with behavioral excesses or idiosyncrasies. The complex nature of the core deficits and the diver-



Gloria M. Satriale, Esq, BCABA

sity that is the autism spectrum can be an overwhelming challenge for educators. Individualizing programming to meet the unique needs of each student is, in itself, often an overwhelming endeavor for the educator. Add to that the variability in resources both between and within states, and mandated adherence to state curriculum standards and the complications multiply exponentially. In the face of all of these challenges (and there are many,



Thomas L. Zane, PhD, BCBA-D

many others not noted), it may be time for school systems to consider simplifying the process and embrace an environment that allows for the easiest and fastest acquisition of skills under circumstances that maximally promote generalization and maintenance of these skills in a manner that has the greatest potential to teach important skills and decrease unwanted behavior. These circumstances are found in the community at large.

Let's start with this simple maxim - generalization and maintenance of skills over time is a significant challenge to individuals living with ASD. A primary consideration in promoting generalization of skills is that instruction needs to be provided where the behavior is most likely to be displayed. There is ample documentation (e.g., Simpson & Otten, 2005) that individuals with ASD are not proficient at generalizing skills to new environments or maintaining skills across time. Given that for transition-age students the classroom will shortly cease to be their primary environment, effective instruction must emphasize skills necessary for success in the environments where they will spend the rest of their lives (i.e., their neighborhoods, communities of faith, home, jobs, etc.). For example, teaching purchasing or money concepts in the isolated context of a classroom may have little, if any, impact on an individual's ability to use money in exchange for desired goods at the supermarket. Being able to differentiate coins by value, while a potentially usable skill, is a significantly different skill from using money to purchase a candy bar. As individuals begin to age out of the educational entitlements, specific attention needs to be given to context of instruction whether that is

see *Barrier* on page 39

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Make Inclusion Work! Reducing Behavioral Challenges In the Classroom for Children with an Autism Spectrum Disorder

By Jill Krata, PhD
Manager of Clinical Services
YAI Autism Center

Autism presents itself differently in every child. And while there is no one-size fits-all strategy to help these children, as some are more severely affected than others, it's clear that evidence-based practices can work for all of them. The following article details some effective strategies which can be fine-tuned for the higher-functioning child with an autism spectrum disorder (ASD) in a mainstream school setting, or used for lower-functioning children on the spectrum in an inclusionary classroom. The key is using methods which are proven effective and can help increase desired behaviors and outcomes.

In recent years, there has been an increased emphasis on including students with disabilities in the general education classroom. Over the years, Public Law 94-142 (Education for All Handicapped Children Act, 1975), which was most recently revised in 2004 under the Individuals with Disabilities Education Improvement Act (IDEIA, 2004), legally mandates that students with disabilities be provided educational services in the least restrictive environment. Specifically, what this means is that children with disabilities, including



Jill Krata, PhD

children in public or private institutions, are to be educated with children in the general education classroom (IDEIA, 2004, p. 118). The legal push for inclusion applies to all students categorized as having any disability, including those with ASD.

ASDs display deficits in three core areas of functioning: social interaction skills, communication skills, and restricted or repetitive interests (von der Embse, Brown & Fortain, 2011). There is tremendous variability to the extent in which these impairments manifest themselves, as does the severity of associated characteristics, such as cognitive impairment. While social and communication deficits are the most common areas of research, students with ASD often display a host of other behaviors that can make learning in the classroom more challenging. For example, resistance to transitions, sensory issues, hyperactivity, short attention span, impulsivity, aggression and self-injurious behaviors (von der Embse, Brown & Fortain, 2011) are often the primary barrier to inclusion and social integration into the general education classroom (Harrower & Dunlap, 2001). Therefore, behavioral interventions to help facilitate inclusion for children with disabilities into the general education classroom are vital for students with ASD.

Educators must consider interventions that are most effective in reducing challenging behaviors typically associated with ASD in order to promote effective inclusion. Research has demonstrated positive social benefits of inclusion through Circle of Friends (Kalyva & Avramidis, 2005) and interactions with

typically developing peers also promote positive social behaviors (Odom & Strain, 1984). However, despite these positive effects, students with ASD have historically been separated from their general education peers (Stainback & Stainback, 1996).

Given the rising rates of ASD and the emphasis placed on inclusion, it is necessary to take a deeper look into best practices to reduce challenging behaviors in the classroom, thus, promoting inclusion of students with ASD in general education settings.

A literature review on inclusion that was conducted by von der Embse et al. (2011) within the past 10 years indicated that despite the lack of evidence-based practices that measure inclusion as an outcome, there were however several themes that emerged that can be used as a starting point toward the identification of effective practices to reduce challenging behaviors for students with an ASD and meet the federal requirements of inclusion into general education classrooms.

Functional behavioral assessments, social skills training and behavioral approaches, such as discrete trial training (DTT) were all found to be effective methods to help reduce problem behaviors for students with ASD in the general

see Behavioral on page 40

Do you have a child with an Autism Spectrum Disorder and noncompliant behavior or hyperactivity?

Yale Child Study Center is conducting a research study comparing parent training and parent education for young children with ASD.

Eligible children are **between 3 and 6 years with ASD** accompanied by **irritability and noncompliant behavior**.

CONTACT: 203-785-5805. Yale IRB # 0411027217.



Yale Child Study Center is also conducting a research study to test the effectiveness of a **non-stimulant medication**, extended-release guanfacine (Intuniv®), for children with PDD and hyperactivity. Eligible children are **at least 5 but younger than 14 years old**, with **autism, Asperger's, or PDD-NOS**, and clinically significant **hyperactivity**, currently medication-free or on ineffective medication. **CONTACT: 203-737-5317. Yale IRB # 1001006172.**

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children with Rett Syndrome. In the last segment of his presentation, he demonstrated how new knowledge of Rett Syndrome and Fragile X Syndrome can be effective in learning about ASD.

"Electrophysiologic Signatures of Language Impairment in ASD," Timothy Roberts, PhD (The Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania) - Dr. Roberts provided a thorough and exciting overview of electrophysiological technologies used in his laboratory, and he shared how he measures the brain electrical activity of study participants. Because the techniques used by Dr. Roberts measure language impairment, they have a strong application to autism research and therefore may lead to novel treatments and interventions in the future.

Keynote Presentation

"The Fetal Androgen Theory of Autism," Simon Baron-Cohen (Cambridge Univer-

sity) - Dr. Baron-Cohen's keynote presentation focused on the question of, "Why the male bias?" He discussed differences in brain structure between males and females, and he demonstrated that there is a biological basis for the unequal gender distribution in autism. More specifically, Dr. Baron-Cohen presented evidence that fetal testosterone levels are correlated with autistic traits and influence sex differences in brain structure.

Afternoon Workshops

"Psychosocial Interventions in Autism Spectrum Disorders: From Research to the Community," Danielle Halpern, PsyD (Seaver Autism Center, MSSM); Kari Y. Philips, LCSW (Westchester Jewish Community Services); Ting Wang, PhD (Seaver Autism Center, MSSM) - In this workshop, the presenters discussed social impairments in autism, the evidence-based social skills intervention research that was conducted in a groundbreaking study at the Seaver Autism Center, the preliminary results of this study, and how this research can be brought into the community.

"Current Trends in the Pharmacological Treatment of Autism: A Panel of Experts," Peter Della Bella, MD (YAI); Charles Cartwright, MD (YAI); David Grodberg, MD (Seaver Autism Center, MSSM); Alex Kolevzon, MD (Seaver Autism Center, MSSM) - This workshop summarized current autism treatments, such as n-acetylcysteine, riluzole, memantine, and oxytocin, and the panel of experts offered an extensive amount of time for questions from both parents and health care providers.

"Transitioning Across the Spectrum: A Focus on Education, Residential Opportunities, and Day Programming," Michelle Gorenstein-Holtzman, PsyD (Seaver Autism Center, MSSM); Kathleen Kingston (NYS Office for People with Developmental Disabilities); Harry Nussbaum (F·E·G·S); Dianne Zager, PhD (Pace University) - Moderated by Dr. Gorenstein-Holtzman, this panel covered services during the transitional period from adolescence to adulthood for young people with autism, focusing on three main areas. The presenters' brief presentations allowed for much-

wanted question-and-answer time for workshop participants.

In addition to these presentations, Jamie Rosenblum, sibling of an adult with autism, gave a moving and heartfelt presentation on her experience growing up with a brother who has autism. Mr. Hirschell Levine and Mr. John Cohen, Co-Trustees of the Seaver Foundation, presented welcoming remarks during the morning and afternoon sessions. Alexandra Roth-Kahn (Caring Commission of UJA-Federation of New York) and Lee Rambeau (F·E·G·S) also gave introductory remarks, and we were joined by several exhibitors, such as the Autism Science Foundation and *Autism Spectrum News*. We would like to offer our sincere gratitude to all speakers, exhibitors, supporters, attendees, and to the Seaver Foundation for helping to make the annual Advances in Autism Conference possible.

If you would like to be notified about the 2013 conference, or if you could not attend and are interested in obtaining the materials, please email annualconference@seaverautismcenter.org.

Setting the Stage for School: A Guide for Parents

By Debra Reicher, PhD
and Carolyn Waldecker, PsyD
The Hagedorn Little Village School
Jack Joel Center for Special Children

It is an extraordinary milestone when any child enters school for the first time. This event is often marked with excitement, anxiety, ambivalence and tears of fear and joy for both the child and his or her family. Entrusting the care of your child into the hands of another can be anxiety provoking. This may be exacerbated by the fact that children with ASD often have significant difficulties communicating their needs. There are several steps parents can take to ease this transition. Most children with ASD are visual learners, so creating a social story with photographs of your child, a school bus, the school your child will attend and even the teacher can help prepare a child for the new environment. You can read this story repeatedly as the first day of school approaches. Taking your child to visit the school and the playground will develop a sense of familiarity with the new environment. You can also take your child school supply shopping so that he or she can pick out items of preference. If your child does not like shopping, pick out a lunch box or folder with his or her favorite character on it. Taking advantage of any orientation program your child's school offers is also important, as many schools



Debra Reicher, PhD

will provide a chance to come in and meet the teacher before the school year begins. Children with ASD often have difficulty with transitions so plan ahead. It is a good idea to start an earlier bedtime and waking time midsummer rather than waiting until the first day of school.

As children with ASD are often diagnosed during toddlerhood, a center based program may be recommended and your



Carolyn Waldecker, PsyD

child may begin school sooner than you intended. Many children with ASD begin attending early intervention school programs around the age of two years. You may be concerned about sending baby who is non-verbal, may not self-feed, still naps and is not toilet trained to school. Feelings of guilt and ambivalence are common as you try to explain to other family members that your toddler will be

attending school. Remember your reasons for deciding to enroll your child in school are sound, as you are taking advantage of the brain's neuroplasticity or brain's "moldability" at early ages. Also keep in mind that the staff working with your child is specially trained in early childhood development and special needs children. They will therefore be skilled at reading cues in young children, even non-verbally, in an effort to decipher what your child needs. All activities should be developmentally appropriate for the needs of your child. You should inquire as to the staff to student ratio is to ensure adequate supervision and safety. If your younger child is attending a full day program, there may be a scheduled nap time during school hours. There may also be a psychologist at your child's school to help with the transition, so do not hesitate to call him or her for information and support.

Close communication between classroom staff, therapists and parents is the key to a successful experience. Inform the school staff of any changes at home that may impact your child's functioning and ask what you can do at home to reinforce learning that is occurring at school. Communication can be via phone, e-mail if the school permits, and most commonly through a notebook you send back and forth daily to give and receive messages between yourself and the classroom staff

see Guide on page 27

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*I'm so deeply grateful for this book. . .
 I just finished reading 'Making Sense of Autistic Spectrum Disorders' and had to take a moment to thank you. The information in the book was easy to understand, comprehensive, and helped me calm down and focus on the steps I need to take to help my son.*

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ROBIN'S VOICE ~ A Resilient Mom's Commentary on Autism

By Robin H. Morris, Freelance Writer

Autism Then and Now: A Family's Perspective

It is a good time in the world to have autism. Times were very different in 1987 when our son Paul was born. A diagnosis of "atypical developmental disorder" was vague and mysterious. We have been living with this disorder for over 25 years and I can assure you that being labeled as pioneers was neither inspiring nor hopeful. However, at the time, we did the best we could with every challenge and searched for opportunities to help our boy. Given my indefatigable tenacity, the words "I don't know" were not in my vocabulary. Autism was facing its match, and equipped with fervent support and glass half full mentality from my husband, we forged ahead.

Back in the day, when Paul was non-verbal and made garbled noises while looking at his hands, a speech therapist at our local elementary school commented, "Maybe he's like Italians, they talk with their hands." I mentally noted that I should have asked her if that was her professional opinion. It was no man's land and we were on our own.

Thus began the hunt and peck method, we approached autism with a trial and error process. What we did learn was that



Alison Singer, President of the Autism Science Foundation, Paul Morris, and Andres Martin, Professor of Psychiatry at Yale, at the Autism Science Foundation's Science & Sandwiches Event

data taking was vital and whatever school or program that our child experienced was equipped with a notebook, with detailed information about his progress. Perhaps this effort has not changed and as parents

approach their annual meetings, the proof is in the data: an "educated consumer, is the best customer."

One challenge is the ego factor. My mother always warned me that in life, no

one wants to be told they are doing the wrong thing. This was sage advice, for when parents attend their child's PPT (Parent Professional Team) if often poses sides that are fit for battle. The teacher does not want to be blamed for a curriculum that doesn't work, and the parents want progress. It is a challenge for all parties. Nevertheless, it is to be cautioned that the child has the most to lose when meetings become adversarial.

Now it is time to shift roles in this article. I defer to our son Paul, who has met his challenges with great zeal. Learning to live with being "different" is and will always be a struggle. During adolescence, he fought compliance. Nevertheless, he approached adulthood demanding to be noticed; and that he has. Recently, he contacted Alison Singer, President of the Autism Science Foundation. Unbeknownst to his parents, he suggested to Alison that he create a speaker series and ask Dr. Andres Martin, Professor of Psychiatry at Yale to be his first guest. Imagine our surprise when we received an invitation to this event. Paul wrote an introduction that he read to the group. His words resonate about challenges and opportunities. They speak for Paul and how living with autism has shaped his life. The following report was written for the ASF website:

see *Perspective* on page 38

Career Training at Its Best: Roses for Autism

By Linda H. Rammler, MEd, PhD
Director of Technical Assistance
UCONN Center for Excellence in
Developmental Disabilities

National Labor Statistics as well as a recent National Longitudinal Study (see analysis at www.communityinclusion.org/article.php?article_id=341) show disappointing employment outcomes for individuals with autism. For example, less than half were employed at the time of the study compared to over 90% of the general population. Those who were still employed tended to be low-paid and received few benefits such as paid sick or vacation leave, or retirement benefits. Individuals with autism who do get hired are more likely to get fired because, by definition, they possess many of the traits (e.g., not getting along with co-workers or supervisors) rated as among the top reasons anyone might lose a job.

Research also points to the conclusions that, without work, individuals with autism experience the same loneliness and poor life outcomes (e.g., poverty, poor physical and mental health) as neurotypical people do. Yet we know that, when an individual's skills are matched to an employer's needs, and employers and co-workers understand and accept what may appear to be a "trade-off" between a high "degree of individuality" and exceptional



Linda H. Rammler, MEd, PhD

technical skills, everyone benefits (Jordan, 2008, *Supporting Individuals with Autism Spectrum Disorders: Quality Employment Practices*, Institute for Community Inclusion Issues Brief #25).

Although school districts are responsible for assuring a smooth transition from "school days" to "pay days" (Individuals with Disabilities Education Act Amendments 1983, 1990 and 1997), many are unable to do so because of other issues

(e.g., emphasis on academic achievement or liability concerns about providing transportation to off-site work experience situations). As such, many need outside help from programs such as the Roses for Autism (RFA) Career Training Program (CTP) located in Guilford, CT.

When the concept of RFA evolved in 2009, it had the added benefit of keeping the 4th generation Pinchbeck Rose Farm operating. But the concept primarily met a critical service need by combining RFA's agricultural purpose with an evidence-based, inclusive CTP for transition-aged and young adults with autism. As a real business, varied opportunities to find and build on individual strengths in an existing competitive environment are coupled with professional instruction using evidence-based practices so that each individual can reach his/her Career Training Plan goals and objectives seamlessly. And, although its original focus was agricultural, in practice there are numerous career tracks available to participants related to RFA operations. These include production, e-marketing, retail, and delivery among niche opportunities expanded to meet individual interests.

At RFA, we hold the following vision for all teenagers and young adults:

- Autistic students complete their academic programs at the same time as their chronological peers. Prior to graduation, they may hold part-time

jobs. Those who are going directly into the workforce have the supports they need to succeed.

- Autistic students who require additional career training are evaluated in real-life employment settings by experts who can help them identify career goals and objectives consistent with their strengths, interests and needs. Post-evaluation, these individuals have a portfolio of what jobs they can perform and what supports and accommodations they might need. This portfolio may focus for some on components of jobs known in the field as "job carving." Those who need more work experience in real job settings have the time they need to get it. Others go directly into existing job vacancies. All become successfully employed eventually. Additionally, individuals who seek continued education get the support they need to be successful returning students for personal growth and development or for career changes.

- Employers and employees (those with ASD and their co-workers) get ongoing support when required so that employment is successful. Corporate consulting services are also available to build future employment opportunities and to assure that employees

see *Career* on page 28

Teaching the Teachers: Creating New Opportunities and Outcomes in Educating Students with Special Needs

By Cathleen M. George, LCSW
Clinical Director
Newmark Schools

Educating students with special needs is an inherently challenging task due to the individualized and shifting needs of each student. Different schools of thought emerge when contemplating this issue: inclusion, a variety of special education services, modifications/accommodations, community based instruction, life skills training, technology use in training, and behavioral interventions – just to name a few. When parents and educators attempt to sift through the range of approaches it can become difficult to create a consistent, individualized educational program that takes into account the academic, social, and emotional needs of the student.

The Newmark Schools are state-approved, private schools for children with learning disabilities and mental health disorders such as ADHD, Anxiety, Asperger's Syndrome and other Autism Spectrum Disorders, Bipolar Disorder and other Mood Disorders, Obsessive-Compulsive Disorder, Oppositional Defiant Disorder, and Sensory Integration Disorder. The Newmark model incorporates school-wide behavior modification systems, which includes extensive data



Cathleen M. George, LCSW

collection, and social skills curriculums, combined with a strong use of technology to deliver differentiated academic instruction by highly trained educators – including counselors, occupational therapists and speech and language clinicians.

One of the keys to Newmark's success is the investment it makes in training its teaching staff regarding mental health, and

specifically, how learning about mental health disorders manifest in the classroom. The goal of this training is to help teachers understand the underlying issues that are driving behavioral acting out in the classroom, how to systematically assess what they are experiencing, and to develop individualized interventions to support, challenge and foster success in our academically capable students. Many Newmark students were unable to fulfill their potential in traditional public and private schools settings because of their particular needs – but also because their previous teachers may not have received the specialized training necessary to fully understand and address their unique needs.

In an ongoing effort to fill the needs of special needs students, Newmark Schools is creating a Teacher Training Institute that will contribute to a new model in education. The Teacher Training Institute will not only provide all levels of educators, including teachers, paraprofessionals, specialists, and administrators, with the opportunity to learn the extremely successful teaching methods used at Newmark, but will also afford them the ability to observe our highly skilled teaching professionals in K-12 classrooms.

The goal is to impact educators throughout the country and to train them in the innovative methods Newmark uses to serve our student population. These

methods will be useful with "typical" students in regular education as well.

Another component to this education model includes creating a community center, housed in the school facility, to provide support services and community events that will include students with special needs. So often, our students are excluded from social events and opportunities to socialize with typically functioning peers as a result of the behaviors consistent with their mental health and learning struggles. For example, we constantly hear from our families about how they are unable to bring our students to events for fear of their behavior, and how it may impact others (quite often siblings). Although it is understandable and more practical to find alternate care for our students during these types of gatherings, our students lose out on the valuable practice and experience these events provide.

One service we often provide to our families is to host celebratory event such as birthday parties and Bar/Bat Mitzvahs. Our teaching staff runs and works the parties, and sees these as significant opportunities to train our students how to socialize appropriately. As the community center is open to the public, our students are afforded the chance to coexist with peers in a structured setting that is geared toward their success, and staffed with highly trained educators

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and therapists. Let your child's teacher know about who your child; for example, write a letter to the teacher explaining how your child communicates, what your child enjoys, what your child finds stressful and how your child calms down when he or she is upset. If your child uses a pacifier, bottle, blanket or other item to self sooth, be sure to let the teacher know this information and they will let you know about the classroom policy regarding such items. You may be allowed to pack these at the beginning of the year and as your child adjusts to the school setting, he or she may no longer need them. Some classrooms may also allow a young child to gradually increase the amount of time spent in school if s/he is having difficulty adjusting to the school setting.

Many ASD children will have their first experience riding a bus as they begin school. As children with ASD often have sensory issues, they may find stimuli such as noise, smell and lights overwhelming. A school bus may place a child with ASD on sensory overload without preparation. For some children,

being able to hold a small toy or preferred item, if it is allowed by the bus company, may be comforting and soothing during the bus ride. For other children, if approved by the bus company, headphones or an iPod may serve to block out unwanted noise and have a soothing effect. Social stories can also be useful in preparing a child with ASD to ride the bus for the first time.

The transition from early intervention and preschool to school age can be difficult for many parents and children. As many services through early intervention are done within the home, once your child transitions to the Committee for Preschool Special Education (CPSE), some of these services are likely to be done in the school setting. While your child may have received speech and language therapy, occupational therapy, and/or physical therapy at home, the frequency and location of these services may change and in certain circumstances, your child may not qualify for a service for which he or she previously qualified. Do not be afraid to ask the committee to explain the rationale for discontinuing a service. The educational classification system changes when a child transitions

from preschool to kindergarten. All preschoolers receiving special education services, regardless of the type, frequency or number of services, receive an educational classification of "Preschooler with a Disability." Once a child begins kindergarten, it is a federal regulation under the Individuals with Disabilities Education Act (IDEA) that they receive one of 13 educational classifications if they are determined to be eligible to receive special education services. One of these educational classifications is Autism, but others include Speech or Language Impairment, Learning Disabled, or Other Health Impaired (OHI). If your child is going to need an Individualized Educational Plan (IEP), one of these classifications will be assigned to your child at the committee meeting. If your child is entering a mainstream classroom, inquire about the teacher's previous experience and the approach taken with ASD children.

The first few weeks of school can be stressful for both children and parents in light of the challenges an Autism Spectrum Diagnosis presents. Aside from the difficulty with transitions and change in routine, your ASD child may not communicate with you about his or her day at

school. You may wonder what he or she did during the day, if he or she was happy, and how he or she is adjusting. A temporary increase of self-stimulatory or other maladaptive behaviors may occur during this transition but will likely dissipate as your child adjusts to the routine of attending school. Attempting to keep your own anxiety under control is also essential, as children pick up on your tone and affect and will react accordingly. Research whether or not your child's school offers a parent support group or other forum such as Special Education Parent Teacher Association (SEPTA) where you can meet other families of special needs children. Remember that children with ASD tend to thrive on routine, so once school becomes part of his or her new routine (and yours), everything will fall into place.

Debra Reicher, PhD is the Director of Psychological Services and Carolyn Waldecker, PsyD is a Neuropsychologist at The Hagedorn Little Village School, Jack Joel Center for Special Children in Seaforth, NY. For more information, please contact Carolyn Waldecker at Carolyn.Waldecker@littlevillage.org or visit www.littlevillage.org.

Accommodations at School

By Yvona Fast, MLS
Support Groups Manager
GRASP

Individuals on the spectrum often need special accommodations at school. There are many lists of possible accommodations for students on the autism spectrum. So much depends on how challenged the individual is, and in what areas the challenges present themselves. Ask, what are the barriers to your child's fulfilling his or her potential? Then work with the school to provide the modification or accommodation that addresses that barrier.

There are lists of accommodations online and many books are available. Both Pam Tanguay's *Nonverbal Learning Disabilities at School: Educating Students with NLD, Asperger Syndrome and Related Conditions* and Kathryn Stewart's *Helping a Child with Nonverbal Learning Disorder or Asperger's Syndrome: A Parent's Guide* have lists of helpful accommodations.

No single child will need all of the accommodations, but as you read through them, you will probably find some that fit your son or daughter. Bring lists of possible accommodations to your child's IEP Team meeting to discuss with the teachers and professionals who are working with your child at school. Most teachers will appreciate suggestions for what you think might work well for your child.



Yvona Fast, MLS

For all children on the spectrum, one key to success is an accepting, non-competitive, supportive environment.

All teachers should have a written document explaining a little about how the child works best, and outlining agreed upon accommodations.

Parents should obtain a copy of all the school's policies - usually there is some kind of handbook. Many schools have strict policies on certain things - like making up exams - on which they won't bend, even for a child

receiving accommodations. If you are familiar with the policies you can be proactive.

Preferential Seating - This means sitting in a spot that will reduce distractions. Some students work best in their own cubicle. For others, a good spot is in the front of the room. For others still, the ideal spot might be along the perimeters of the room with an empty seat next to him. This may also apply to taking tests in a smaller, quieter setting.

Social Skills Training - This is a special class in relating to others, often taught by a Speech Language Pathologist trained in pragmatics. This can help students express their thoughts clearly and learn skills like participating in a group discussion or conversation. One problem many spectrum folk have is knowing how to "jump in" to a conversation. They either jump in inappropriately and thus are perceived as rude, or say little and are then seen as being shy and quiet.

Study Skills/Organizational Skills Training - This special class can help individuals with executive function issues learn different ways to study, to be organized, how to keep an agenda up-to-date with assignments, made sure the student understood the assigned homework, etc. It can help the student discover what works organizationally, and will be invaluable for things like term papers and research projects.

Assistive Technology - Use of computers, tablets, and smartphones can be invaluable assets for organization, being able to read one's notes, etc. Many applications

can be co-opted to help students with autism to thrive at school. Even the clock and to-do list functions that come standard with most smart phones can be an invaluable tool. For example, they can be used to help a student remember the steps needed for a project or task. For example, Apple's iPod Touch can be programmed by an occupational therapist to guide a student through the day, providing specific instructions that can be referenced when he or she forgets what to do or how to do something. It can also help with switching to different tasks for people who tend to perseverate on one thing.

Here are some examples of how assistive technology can be used:

- Smart phone or palm pilot and software to coordinate with a laptop.
- Digital recorder with zoom microphone to record lectures and the software for a computer to transcribe them.
- Talk-to-type voice recognition software.
- Inspiration or a similar program to help with the organization of papers.
- Franklin lexigraphic tool for university/grad level vocabulary

Taking Notes - Keyboarding instead of handwriting can be a simple but important for individuals on the spectrum with motor

see Accommodations on page 29

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with autism are valued members of each work setting by applying autism specific strategies and an inclusionary ambiance in the work place.

- State of the art Assistive Technology or other innovations are available to increase independence and improve peoples' lives as needed. Everybody has the right to communicate using, if necessary, augmentative communication and, if behavioral challenges occur, individuals receive highly trained and sensitive positive behavior supports reflecting their neurological differences, health, and communication needs.
- When people are employed their quality of life improves particularly with respect to meaningful social connections with others in their communities including coworkers, neighbors, and friends. These connections extend beyond the work day to include community recreational opportunities, leisure activities based on interests, and faith communities. Natural relationships are built and supported so each individual is surrounded by a loving and supportive circle of friends, relatives, and colleagues so that, long term, lives are satisfying to each autistic individual and have meaning. Family members are supported in developing new relationships with their adult family members with autism that facilitate optimal independence balanced with safety.

- Individuals have the skills and/or supports they need to make quality informed choices that are beneficial to them in the short and long term. All supports are culturally sensitive and respectful of individual rights and privileges.

RFA strives to enable participants to realize this career-oriented vision by providing career training and *in vivo* social opportunities to participants, including part-time enrollment for students not yet done with their academic program). We use a person-centered framework that, in addition to MAPS or PATH or other similar strategies (c.f. CT's Department of Developmental Services *Individual and Family Fact Sheet*, <http://www.ct.gov/ddscwp/view.asp?a=2050&q=382266>), recognizes the unique neurological differences each participant experiences in terms of movement, anxiety, communication, and sensory differences (i.e., the "MACS" approach).

"MACS" is based on the current understanding of autism as a complex neurological condition (Rammler, 2009) and emerging outcome evidence that supporting autism from this perspective helps streamline the selection of which evidence-based practices work best for any one individual and which are likely to work for many. For example, visual supports outlining components of the business operations facilitate motor planning for complex, competitive technical tasks - as well as alleviate anxiety. Opportunities for a wide range of communicative skills (from social chit-chat to asking questions) abound. We can identify potential sensory trouble spots, teach actual skills (e.g., getting proprioceptive input

during breaks), teach compensatory strategies (e.g., apologizing for limited eye contact) to overcome these when possible, and/or identify needed but reasonable accommodations (such as natural lighting or more frequent movement breaks) that future employers will need to provide if they value the other assets that an employee with ASD can bring to their business.

Although some individuals who went through the first round of RFA's CTP were so good at their jobs that they were hired on as employees with the added edge of prior experience at RFA, the intent is for RFA to provide "one stop shopping" services leading to competitive or supported competitive employment elsewhere for each individual. RFA does not function at all as a "sheltered workshop" day program model.

Admission to the RFA CTP is voluntary but primarily on a first-come, first-served basis so that individuals with various manifestations of their autism are not turned down because of neurological complexities. The CTP and farm staff: participant ratios preserve realistic ratios of neurotypical employees to autistic participants as much as possible. This assures an ongoing feedback loop between the operations RFA staff and the qualified and experienced CTP staff. CTP staff provides (or coaches operations personnel to provide) evidence-based instruction in the acquisition of technical skills. Technical skills range from operating a state-of-the-art cash register to developing/managing e-marketing systems to agricultural tasks needed to grow and produce high-quality roses (as well as other flowers). The Hidden Curriculum is taught as needed, and

generalized and reinforced immediately.

The goal of the initial evaluation at RFA is to develop a individual career training plan incorporating what the individual's strengths, interest and learning styles are; how autism affects his/her ability to be employed in a real job setting; what kinds of individualized and reasonable accommodations s/he will need when employed elsewhere; and what technical and "soft skills" the individual will need in the specific type of environment s/he envisions working in once completed with the CTP. On-going evaluation during work experience, job training, community job shadowing, internships, etc., allows the individual to "tweak" his/her career plan - just like neurotypical individuals in this same age group do all the time!

CTP staff also assists participants in developing employment portfolios and may devise alternative interview formats for participants needing these. As stated in our vision, CTP staff prepares employers and co-workers to work and have meaningful relationships with any co-worker with autism. An overarching goal of RFA is to keep the floral business going while applying autism-specific expertise in an inclusive setting so that real transition can occur from "school days" to "pay days." Stay tuned for progress updates as we replicate our strategies to the many other settings in which neurotypical teenagers and young adults would find themselves!

Linda H. Rammler, MEd, PhD, is Director of Technical Assistance at the UCONN Center for Excellence in Developmental Disabilities. For more information, please visit www.uconnuccedd.org.



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

By Carrie Cariello

Dear President

Dear Mr. President,

My name is Jack and I am eight years old. I love cars, license plates, and radios. My mother says I'm *obsessed* with these things. All I know is I like to ask every single person I meet what kind of car they drive and how many radios they have.

I hear my mother and father and doctors and teachers talk about things called *cognitive flexibility* and *social skills* and *speech delay*. I hear them say the word *autism*.

But I really don't understand what any of these words mean. I just know that when there are too many people around, I feel weird and scared because I don't know how to talk to them. That's why I ask questions like, "When is your birthday?" and, "Do you like Toyotas?" These subjects make me feel safe.

I remember every single thing I read and hear and see. I can tell you what the capital of the Philippines is and how last Monday I saw a California license plate on a blue Dodge Dakota. But I can't figure out if my mom is angry or happy.

The feeling of yogurt on my tongue makes me crazy. It's way too slimy. If my mother even asks me if I want yogurt, I clap my hands over my ears and start



This is Me

screaming. I *scream* until I know that she understands me, that she'll get me something else to eat.

I clap my hands over my ears a lot because certain sounds bother me, sounds like airplanes in the sky and static on the radio. When we're in the car and the radio gets static on it, I put my hands over my ears and chant, "Turn it static turn it static

turn it static." My mom or dad usually changes it right away for me.

Sometimes I get very, very angry and I lose my good words. I say terrible things like, "I hate everyone here." and, "I want to kill my friends." But deep inside, where my heart is beat-beat-beating fast, I'm saying, "I am so sad and I feel very alone." When I feel so mad my mother tells me I've hit the *red zone* and I have to use my breathing to stay calm. I try.

I live in New Hampshire. I think people like you - people in politics - call our state the *swing state*. Whenever I hear that, I picture our state swinging like I do on the playground and I laugh out loud. I like New Hampshire, but I really, really want to see Wyoming. I talk about it all the time, how when I'm a grown-up I'm going to Wyoming. I plan how long it will take me to drive there. But unless my parents take me, I'll probably never go. I hear people say I may never be *independent*.

The world looks and sounds and feels so very differently to me than it does for most people. Maybe you could take a minute and try to see it through my eyes and hear it through my ears.

Imagine a world where the sights and sounds and smells don't make any sense to you. Where people look at you with their different faces but you still can't tell if they're happy or mad or frustrated.

Where watching their eyeballs flicker back and forth gives you a headache, but all day long people tell you, "Look in my eyes Jack, look in my eyes. Look at me!"

Picture a world where the days of the week look like colors in your mind. When someone says, "Spelling is on Friday," I think of an orange so bright it's like the sun setting in the summer sky. And Thursday is a dark purple like an eggplant.

Imagine the feeling of a thousand ants crawling up and down your body, all over your legs and your arms and your tummy. I have that feeling many times a day, and I have to jump and bounce to make it go away. I think this is called *self-stimulation*. But in my family we call it my *zoomies*.

I tried to watch the debate between you and Mr. Romney but it was very confusing—you both talked too fast and you were smiling, even though your voices sounded mad. So I was hoping you could answer a few of my questions in this letter.

Sometimes I get very, very nervous. I can't sleep and things like the wind chill factor and blue water in the toilet scare me. The doctor says I'm *anxious*. I take one tiny white pill at night to help me with being *anxious*, medicine my parents pay for with insurance. How will we pay for my medicine if healthcare changes? I really need it.

see Dear President on page 32

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coordination issues. Other possibilities are getting notes from another student or getting outlines or notes from the teacher.

Instructions should be direct and explicit, with the information broken down into smaller segments. This is because many spectrum students are very literal and may not follow metaphors and similes. Repeat, rephrase and clarify directions and information to ensure understanding. Encourage the student to restate instructions to check for understanding.

An extra set of textbooks kept at home can be invaluable for students with organizational issues who often forget to bring work home.

Large projects can be daunting for some students. A student who is stuck and unable to start a project may need help in breaking the complex task down into its individual parts. Write these steps down for next time. It helps to have the directions written down and spelled out to refer to. Help students think of one thing to begin a large task. Don't worry whether it should be the first step, middle step, or last step.

Monitoring - In the lunchroom and at recess, spectrum students need unobtrusive monitoring to make sure they aren't bullied. Students on the spectrum are often easy targets for bullies, because of differences in perception, odd behavior, taking things too literally, and gullibility.

Many people worry that accommodations in school will not prepare the child for an independent life as an adult. But this should not be a problem if we consider the following when choosing accommodations for the student: Will this skill

be important in adult life? Will it adversely affect adult functioning? Is it limited to the educational environment? For example, cursive writing is not really necessary in our computer age, and people with fine motor coordination issues can have problems with this all their lives.

If the skill that is being accommodated is something that will be needed in the future, does the student need special instruction in this area? For example, many individuals on the spectrum need training in social skills, reading body language, or having a conversation - things that neurotypical kids pick up intuitively. If this is a temporary, short-term accommodation while the student masters a more functional strategy, a periodic review is needed to determine whether he still needs the accommodation, or whether it is time to modify or drop it.

Many autistic spectrum kids will eventually develop skills needed to function independently in the adult world. But some children may never be able to live completely independently, and may need to live with family, in a group home or have outside supports. Others will be pretty functional, but still need a family member or other "designated person" to give advice and lend a helping hand from time to time.

Yvona Fast is the author of a career guide for individuals with ASD. *Employment for Individuals with Asperger Syndrome or Non-verbal Learning Disability* was published by Jessica Kingsley Publishers in 2004. Her website, www.wordsaremyworld.com, has more information. She also works as Support Groups Manager for GRASP (the Global Regional Asperger Syndrome Partnership).

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Adelphi University in New York (www.students.adelphi.edu/sa/bridges), and the College Program for Students with Asperger's Syndrome at Marshall University in West Virginia (www.marshall.edu/atc/content/college-program.php).

Generally, internal programs offer their students services in the areas of academics, social interaction, executive functioning, and vocational support services, as well as providing training for university faculty and staff. Another interesting aspect of the internal program model is the use of peer mentors to provide social role modeling. Some of the peer mentors are individuals on the autism spectrum who are at various stages of the program themselves.

The Bridges to Adelphi Program

The Bridges to Adelphi Program is an internal program that offers multifaceted, comprehensive, academic, social, independent living, and vocational support services to students who self-disclose with nonverbal and neurosocial disorders such as AS and HFA. Each Bridges student is assigned to a support team that includes an academic coach, a learning strategist, and a peer mentor.

There are many challenges that must be surmounted in order to achieve success in higher education for individuals on the autism spectrum. The Bridges Program, which is fee-based, is based on social learning theory (Bandura, 1977) and cognitive behavioral principles (Beck, Rush, Shaw, & Emery, 1979) as theoretical foundations.

Using a problem solving approach, Bridges services include *Academic Coaching* to help with executive functioning dysfunction, *Learning Assistance* to help with research, writing, and test preparation; and *Peer Mentoring* to help with social skills development.

Some of the primary challenges that internal model programs face, and how the Bridges to Adelphi Program addresses them are listed below:

Gaining the Trust of the Students so That They Will Disclose When They Have a Problem, and Ask for Help - The first goals for any support program for individuals with nonverbal and neurosocial disorders such as AS and HFA should be to get the students to come in and access service, disclose their worries and problems, and accept advice. Often, illogical thinking as well as prior stigmatization and social and academic traumas (which can lead to denial, hierarchical thinking, and in extreme cases, result in Post-Traumatic Stress Disorder) can lead to reluctance or refusal to access services and/or ask for help.

"I'm not like that anymore," "I don't want to be in Special Education anymore," and "They are more disabled than me" are comments that are often heard from students. In these and similar cases, the Bridges to Adelphi Program attempts to build trust through creating non-judgmental and cooperative partnerships with students, and by creating an unconditionally positive environment which focuses on areas of strength.

Besides trying to de-stigmatize diagnoses and challenge illogical thinking, students are told that they can be helped with almost any problem that they report or disclose, but that no one can read their

minds. Unlike high school, self-report is the primary source of information, so that if they report everything is alright and that they have been doing their work and going to classes, that is what the support staff will believe.

Cognitive Dysfunctions That Often Result in Avoidance and Procrastination - Individuals with AS and HFA often struggle with negative thoughts about themselves, their world, and their future (Beck, Rush, Shaw, & Emery, 1979). These thoughts often result in false beliefs that they cannot, or will not, be successful, so why should they bother trying? If they become organized around these beliefs, they may stop doing homework and readings, working on research papers, taking exams, or even going to classes. If they do not disclose to support staff, the long term academic consequences can be quite negative.

Individuals with AS or HFA can also struggle with concrete, yet illogical, thinking styles that can result in negative consequences. As a result, these students allow themselves restricted reactions and decision options that, although illogical, limit the ways that they deal with the anxieties stemming from conflicts or confusion. Because this thinking style is designed to create order in a chaotic world, even with regular challenges from the staff, this thinking is quite difficult for the students to change, and often contributes to their inability to solve problems.

Executive functioning dysfunction (EFD) also causes problems for individuals with AS or HFA. In addition to more obvious difficulties like keeping track of assignments and due dates, which a good support program should be focusing on, EFD can also present with more difficult problems to help with such as sleep and waking management, medication management, self-care, and diet. Since freshman year may be the first time students with AS or HFA have been responsible for these issues, the academic and social consequences from EFD resulting poor self-care can be extremely negative in the first year of college.

The Bridges to Adelphi Program attempts to address these cognitive issues through challenging and monitoring negative thinking, and offering positive reinforcement for any cognitive changes, no matter how small.

Mandated Services in K-12 vs. Offered Services in College - Many students with AS and HFA currently entering college have benefitted from early identification. They have likely had Individual Education Plans (IEP's), and received mandated services in K-12. Additionally, their parents have been instrumental in the acquisition and management of those services. In college, services are no longer mandated, they are offered, and parents are no longer part of the equation. Students must access their own services and have the ability to self-advocate. This can often be a struggle for students, especially freshmen.

The Bridges to Adelphi Program addresses this issue by asking parents to encourage their children with AS and HFA to come to all scheduled meetings and access all available services. Additionally, Bridges staff monitors syllabi, create weekly assignment schedules, and encourages students to access their academic accommodations.

Communication with Faculty - Maintaining

university academic standards, while advocating for students with disabilities such as AS or HFA is a balancing act. All college students are entitled to academic accommodations if they document their disabilities. But because of cognitive disabilities, negative and illogical thinking styles, and EFD, college students with AS and HFA often need more help than the standard academic accommodations such as extra test taking time or note takers. These students benefit from having understanding faculty members who can be flexible with the different ways that they think, work, learn, and process information.

The Bridges to Adelphi Program addresses these issues by getting written consent to communicate with faculty members and then working closely with the faculty through regular contact, and by providing training and awareness sessions for faculty and staff. Faculty members are also asked for regular updates on student progress in their classes. If informed, most faculty members will provide extra time for students to complete assignments, be willing to understand time management struggles, and have regularly scheduled one on one meetings with students.

Managing Parent Expectations - Since many parents of students with AS and HFA have been heavily involved in accessing services and managing their child's academic careers, it is often understandably difficult for them to back away when their child enters college; resulting in the "steel umbilical cord" (McManmon, 2012, p. 14). However, because of the Family Educational Rights and Privacy Act (FERPA), they can no longer have the access to faculty and staff that they used to have.

The Bridges to Adelphi Program attempts to deal with this issue by getting written consent from students to have contact with parents, and by offering group and individual parent meetings. The consent to contact is used only when all problem solving attempts by staff have not been successful, and the student is in danger of failing a class. Individual parent meetings are held only with the student present at the meeting. Group parent meetings are used to provide information and updates of services that are upcoming or newly available.

Managing Staff Expectations - Helping staff understand and manage the possible stresses of working with the AS and HFA population, and accepting the limits of the program and their own work is critical. Staff must remain alert to keeping their own needs and expectations separate from the student's abilities. A college semester can be a roller coaster of emotions for students and staff. It is important for staff to present to the students as reliably available and professional.

The Bridges to Adelphi Program addresses this issue through extensive staff trainings, and weekly one on one supervision meetings.

Addressing Vocational Challenges - With the incidence of under and unemployment for people with AS and HFA being much higher than that the general population, the Bridges to Adelphi Program recognizes the importance of providing support in this area as well. Students are offered standardized vocational and personality tests. Group support meetings are available for students to address and resolve

issues related to employment they may have while in school, or for questions related to employment after graduation.

Research Into the Bridges to Adelphi Program - While there is much anecdotal evidence that the Bridges to Adelphi Program and other internal programs are very helpful to individuals on the autism spectrum, we have taken it upon ourselves to objectively measure the efficacy of the work done at Adelphi University. Initially, we are collecting data to examine how student attendance to regularly scheduled group and individual support meetings correlate with academic success. Additionally, we will be looking at changes in self-esteem upon entering the program and at regular intervals, and how they correlate to academic success as well. It is our hope that results from this research will suggest areas of efficacy for the Bridges to Adelphi Program and point to areas that may be in need of improvement. Eventually we hope to expand this research to other programs servicing students with AS and HFA.

Summary and Conclusions

Individuals with AS and HFA present with widely diverse problems and challenges that are different from neurotypical college students. Therefore, there is not one approach; be it choosing an external or internal model, or even between programs within a model that will be effective with all students. For all programs it is important to engage in an individualized, problem solving approach, focusing on identifying individual areas of strength, while acknowledging and addressing areas of weakness or challenge.

By working to the strengths of individuals on the autism spectrum in higher education while recognizing and addressing the very real challenges faced by this population, programs such as the Bridges to Adelphi Program can make a significant positive difference for people with autism achieving success in college and university life, which hopefully generalizes to life after graduation.

When making the decision on which college to attend, or what program seems to suit the student best, there are many variables to examine beyond the standard considerations of area(s) of study, geographical location, and type and size of the campus. For those with AS and HFA, the decision of choosing an internal or external program of support, dorming or commuting, four year college or community college, an honest appraisal of student readiness, as well as the cost of participation in a specialized support program should all be considered.

Mitchell Nagler, MA, LMHC is the Director of the Bridges to Adelphi Program and the Assistant Director of the Adelphi University Student Counseling Center. Mitch is a Licensed Mental Health Counselor who also maintains a private practice specializing in counseling young adults with Asperger Syndrome and related conditions, with offices in NYC and in Merrick, NY. Mitch can be reached at magler@adelphi.edu.

Stephen M. Shore, EdD was diagnosed with "Atypical Development and strong autistic tendencies" and deemed "too sick" for outpatient treatment. Dr. Shore was recommended for institutionalization.

see Supporting on page 32

Transforming Transitional Programs

By Mary Jane Burner, MA
Credit Course Coordinator
New York Institute of Technology
Vocational Independence Program

Walking onto a college campus is the first step to adulthood and true independence. This step can cause excitement, fear and anxiety for most young people. For students with learning disabilities and on the autism spectrum, these emotions are magnified. It is a new world of uncharted territory that they have only dreamed of and possibly thought out of their reach. As excited about that reality as they might be, there are many unsuspected challenges that they will encounter. Most special education public high school programs do not prepare a special-needs student for the demands of college. In fact in many ways, even neuro-typical students are often not prepared for the huge difference between high school and college that they will face, and inevitably often meet that challenge with disappointment, frustration, and a sense of, if not an actual, academic failure. So imagine how a learning disabled or autistic student feels when meeting these challenges. So much of this problem has to do with change in structure from high school to college. In addition to all the other challenges, the lack of structure in college is a huge



Mary Jane Burner, MA

problem for students on the autism spectrum or with a learning disability. Students with autism thrive in a structured environment. It provides predictability and a sense of safety. The step from high school to college can make an ASD/LD student feel completely ungrounded. According to Education News, "More and more students seem to be less prepared for college" (Are Public High School Students Fully Prepared for Col-

lege? 2011). There are many different theories as to why this happens, but "College and K-12 officials blame the performance declines on a myriad factors, from inadequate high school preparation to high school grade inflation, newfound independence and increased partying away from home" (Education News, 2011).

Gery Chico, chairman of the Illinois State Board of Education states that an inconsistent grading system is a real problem. "I don't believe you do anyone any favors by artificially boosting a grade. To do what? All that does is give students a false sense of security" (Education News, 2011). As far as boosting and ballooning grades, this is especially true in a special needs environment. "Translating each student's performance into a letter grade can be a challenge – and inevitably, the most troublesome questions relate to the fairness and accuracy of the grades given to exceptional learners" (Lee Ann Jung 2010). Students with disabilities learn and engage differently; therefore, making it all the more difficult to fit them within the "box" of grading. Another challenge for disabled students is meeting the necessary traits that are essential for success in an academic setting. Again, these can be traits that a neurotypical student would struggle with. Students on the Autism Spectrum and students with learning disabilities intrinsically struggle with flexi-

bility, communication and organization. Ellen Korin of the Autism Society states, "Students with (AS) frequently find themselves unprepared for the transition to independent life upon graduation from high school. Communication, pragmatic language and social skills are limited. Interactions are awkward, hard work and stressful. While neurotypicals seem to instinctively know "the rules of the road," "Aspies" frequently feel like "aliens who have landed on an unfamiliar planet where they do not know the rules" (Korin 2010). They must be taught these skills in a direct and explicit manner. So, as a comparison, neurotypicals who know the rules of the road so to speak and can naturally integrate, still find college an incredible challenge full of new territory they are not prepared for.

Ideally, the first year of college is a time for young people to strive for adulthood, dreams, friends, and independence. Unfortunately, this is not always the case. Many students are overwhelmed and frankly in a state of shock at the difference in residential college living and living under their parents' rules and guidelines. The scaffold that all good parents build for their children is removed and many times the child falls without that support. Joe Smydo cites students' stories in the Pittsburgh's paper the *Post Gazette*. "The first year of

see *Transforming on page 33*

Letter to the Editor

Dear Editor,

I am writing in reference to an article in your Fall 2012 Issue of *Autism Spectrum News*. In the article on the front page written by Dr. Catherine Lord, she replied when asked what a parent should do when they suspect that their child may have an ASD. Dr. Lord responded rightly to first discuss one's concerns with their pediatrician and, if he/she is in

agreement that an evaluation is appropriate, the parents should ask to be recommended a psychologist specializing in ASD evaluations. I have two problems with this.

The first is that, in my experience through the years, parents will come to me with strong suspicions of an ASD that are not shared by the pediatrician. This is happening less and less given that pediatricians by and large have become better

screeners for the disorders. The bigger problem I have with the article is that Dr. Lord only specifies psychologists as those who should do evaluations for the ASDs. The main qualification of the professional that is asked to do such an evaluation is, in my opinion, experience and expertise in working with individuals diagnosed within the Spectrum. This not only includes some psychologists but also psychiatrists, behavioral pediatricians and

child neurologists. Some but certainly not all professionals within these specialties have such experience and expertise. Again, the main thing is not their title but their experience.

Richard Perry, MD
Clinical Professor of Child and Adolescent Psychiatry
NYU School of Medicine

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who understand their mental health needs and ensuing behaviors.

The Newmark Schools' model also sees Life Skills Training as a crucial component to teaching our students to be successful, independent adults. We are building an on-site life skills apartment to assist in introducing our students to a variety of skills, and to give them ample time and space to practice these skills before they are expected to generalize them out in the community.

We know that educating special needs children takes a multi-disciplinary approach to meet the multitude of their needs. It seems clear from the feedback of the many families we have worked with over the years that the missing piece of this puzzle is often a lack of understanding by educators about how mental health and learning disorders manifest in the classroom, in regard to behavior. Although teachers are expected to

work with children with increasingly complex mental health issues, whether in special or regular education, it appears that they receive very little training about these disorders. The training of educators needs to include mental health, and specifically, what does mental health look like in the classroom. For example, this training needs to go beyond the cursory understanding that a student with ADHD doesn't pay attention. It is important that this training includes the other aspects of the disorder such the associated executive functioning deficits and its impact on social-emotional impairments. More importantly, what does a real student with ADHD look like: yes, unfocused and disorganized, but also perhaps socially inappropriate, agitated, blaming, not interested in learning, oppositional, and dishonest. Quality training will result in an educator who, when presented with a student with ADHD, will be understand the nuances of behavior and find ways to teach to the stu-

dent's strengths and come to understand that the student is not actually dishonest or lazy or not interested in learning. The educator will learn that these negative behaviors are also maladaptive strategies that the student has developed to cope with their deficits.

Investing in mental health education for teachers is also important as a means to address "burn-out." In our experience with teacher training, most educators report that their most challenging aspect of their job is to have a classroom with students who are dealing with significant mental health and learning issues, and to feel ineffective in dealing with the associated behavior. These teachers feel competent to teach the academic requirements, but are often frustrated by a lack of confidence in dealing with behavior. However, once teachers truly understand what is driving the behavior they tend to feel more empowered and in control of the interventions available to them. They also report that, once they un-

derstand how mental health issues impact executive functioning, they are better able to differentiate instruction to meet the specific needs of their students.

Cathleen M. George, LCSW, is Clinical Director of Newmark Schools. Ms. George has fourteen years of experience in the mental health field, with the last 10 spent as a school counselor at Newmark Schools. She has also worked in foster care and in a hospital setting. In addition to providing counseling services to students, she focuses on training staff on mental health issues, and shaping student behavior.

Ms. George received her Bachelor of Science degree from Caldwell College, and her MSW from Fordham University. She also maintains a private therapy practice and is a member of the National Association of Social Workers. For more information about Newmark Schools, please visit www.NewmarkEducation.com.

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Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*, the critically acclaimed *Understanding Autism for Dummies*, and the newly released DVD *Living Along the Autism Spectrum: What it Means to Have Autism or Asperger Syndrome*.

President emeritus of the Asperger's Association of New England and former

board member of the Autism Society, Dr. Shore serves on the boards of the Asperger Syndrome and High Functioning Autism Association, the Autism Services Association, and other autism related organizations.

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Transition from page 10

process. Check your state's PTI for similar resources.

Be a Detective

If you are buying a car, you don't just walk into the lot, listen quietly to what the salesperson tells you, sign the paperwork, and drive off in your new car (at least I hope not!). You do your homework. You find out as much as you can about the vehicle you are interested in by reading Edmunds or the Kelley Blue Book, talking to other owners, and taking it for a test drive. Although the school program your child attends is far more important than the car he gets there in, the research you need to do to find out if it is the correct program is similar.

Read about the program on the school district's web page. Scour the state Department of Education's website for information about your city/town's educational system. Talk to other parents by contacting the school's special needs parents' group (if your town does not have such a group, ask your Early Intervention coordinator if they will contact a former client who is currently in the school program. Most parents are thrilled to help other parents.) Finally, schedule a visit to view the programs that sound appropriate. Talk to the teachers, the aides, the therapists. Ask questions of the principal, the team leader, the special education director. Hang around the playground after

school and introduce yourself to preschool parents and ask them about their experience. Knowledge is power, and the more you know about the existing programs in the school, the more empowered you will be when it comes time to formulate an educational plan for your child.

Get Third Opinions

The school will be doing their own set of evaluations. Your Early Intervention team will also provide reports on your child. That is not enough. If at all possible, get third opinions from outside evaluators such as a developmental-behavioral pediatrician, a psychologist, a speech language pathologist, an occupational or physical therapist, and/or behavioral specialist, depending on your child's specific challenges. The more information you can gather about your child's needs, the more evidence you will have to demonstrate the level of service required to meet those needs.

Although the school is not required to adopt the recommendations of outside evaluators, they are required to consider them. And having those reports can sway opinion in the educational plan meeting. If you are saying your child needs behavioral services, for example, and the Early Intervention team says the same based on their work with your child, and private evaluators concur based on their testing, it is harder for the school to say that your child doesn't need these services.

Start the Process EARLY!

The final piece of advice I always give parents is to start the transition process as early as possible, ideally six months before your child turns three, in order for you to have the maximum amount of time to hold as many meetings as necessary to ensure that your child's needs are fully met when he goes to school.

Special education law governs how long the evaluation process, eligibility determination, and educational plan development process is allowed to take, so beginning the process when your child is two years and six months will give you the optimal amount of time to ensure that all of the steps are taken and additional meetings can still be held if you do not agree with the proposed plan the school provides after the first meeting. If your child is already older than 30 months, do not despair. Start the process today, recognizing that time is of the essence and you will have to move more quickly in accomplishing the steps above.

So, how do you start the process? Your local PTI (described earlier) is the place to get information specific to your state. Also ask your Early Intervention provider for guidance as well. However, their specialty is providing services and not informing families of special education procedures, so be sure to check with the experts at the PTI as well.

Important: If you feel that you simply are not able to effectively advocate for your child for whatever reason, or if you are unable to get what your child needs despite your best efforts, consider get-

ting a professional advocate. Pro bono advocates do exist, but they are in very high demand and thus, almost impossible to get. Although advocates cost far less than attorneys, the price can still seem high to many families but good professional advice is usually a one-time cost and can be a very important investment in your child's early education. The first educational plan you develop for your child is the most important, as it sets the stage for the level of service your child will get during their preschool years, so I urge parents do whatever they have to in order to ensure that their child's needs are met. For advocate recommendations, ask your PTI, your Early Intervention providers, and the best resource of all, other parents.

Although moving to school services from home services can be intimidating for parents, it is also very exciting and opens up a new world of learning and experiences for your child. Do your homework as outlined above, be open-minded and optimistic, and the transition can be very successful for your entire family. The clock is striking three years whether you are ready or not, so get moving today!

Bernadette Murphy Bentley, MPA, is the Autism Resource Specialist at Tufts Medical Center, the Editorial Director of the Autism Consortium's monthly E-News, and the mother of an adolescent with ASD. Sign up for E-News by going to www.autismconsortium.org/home/newletter-archive.

Dear President from page 29

I heard the doctor tell my mother that one in eighty-eight kids have autism. That seems like a lot of people. How will you make sure that teachers and bus drivers and parents learn about kids like me, kids with autism who hit their red zones and shout out, "I want to light the school on fire," when we really mean, "Math feels hard today." Because we deserve to be understood.

And will you try to find out why so many more of us have autism now?

I may not use a wheelchair to move or sign language to speak, but I still need certain things to help me get through my day, to help me do what my therapists call *integrate* and *learn* like everybody else does. Will my school still be able to afford people like my paraprofessional, Miss Anne? And therapists for speech and occupational therapy? They've helped me come so far.

What's going to happen to me when my parents die?

Now, close your eyes and think about Tuesday, the day our country decided you will be the President of the States again. Do you see yellow?

If you do, then maybe you do understand me just the tiniest bit, maybe you will make decisions to help me lead a full, productive life. Decisions to help those around me know me and my beautiful autism even better.

Maybe you'll help me see Wyoming.

Sincerely,
Jack

P.S. What kind of car do you drive?

Carrie Cariello lives in New Hampshire with her husband and five children. You can read her weekly blog and learn more about her online at www.WhatColorIsMonday.com

Sensory from page 21

Before a person can begin to scan, it is important to first ensure that the individual knows what the sensory systems are. You'd be surprised how many people on the autism spectrum have never been provided with this information, even though our sensory experiences impact our day-to-day lives in very profound ways. Using a worksheet like the excerpt shown in figure 2 from the ISA Sensory Scan Toolkit can be useful in supporting a person in discovering the sensory systems.

Another method of pre-teaching the sensory systems before scanning is to emphasize more concrete learning activities, such as a cooking project that is

used to review and model the different systems and how they function. For example, if we cook pizza together, we can investigate what the nose smells, what the mouth tastes, what the eyes see, and so forth. In addition to the five traditional sensory systems we often think of when asked to identify the senses, there are also two more internal senses: vestibular and proprioceptive. Together these systems involve important aspects of body movement, balance, location in space and more. Though sometimes difficult to define in words, the proprioceptive and vestibular sensory systems are very easy to portray using visual supports, such as the illustration in figure 3 from the Sensory Scan library.

The last step in conducting a Sensory Scan is to take the data that's collected and use it to develop an Advocacy Plan. The data usually identifies items in an environment that make it uncomfortable or impossible to be in without a modification of some kind. A very good example of this often occurs in schools or in work settings when a teacher or co-worker regularly wears perfume. Developing an Advocacy Plan to address the situation can be life changing to someone on the spectrum who might be attempting to endure significant discomfort, pain, nausea or distraction due this input. This Advocacy Plan might involve creating a diplomatic script (that can be rehearsed and role-played in advance), so that the individual with sensory chal-

lenges can help the person wearing perfume understand the medical/sensory concerns involved, including a polite request that the person not wear perfume to school or work.

The ISA Sensory Scan™ is an evidence-based tool that has been used in schools, colleges, summer camps, residential settings, fitness programs and other locations in the US and abroad to support people with autism. To learn more about the ISA curriculum, visit www.autismselfadvocacy.com.

This article was originally printed in the AHA Association's Fall 2012 issue of On The Spectrum and has been reprinted with permission. For more information, please visit www.ahany.org.

Figure 1:

Auditory ISA Sensory Scan™				
				
Pay attention to the sound in this environment. What do you hear? Is it ok or not ok (distracting or annoying)?				
	OK 	NOT OK 	Notes:	
Keyboard sound (clicking, typing)				

Figure 2:

ISA Sensory Scan™ Pre-Teaching Worksheet Learning the Sensory Systems			
Sensory Picture	What is its name?	How does it function?	Do you sense anything in this environment?
			
			
			
			
			

Figure 3:

Vestibular & Proprioceptive ISA Sensory Scan™				
				
My Body				
	YES 	NO 	Notes:	
Sitting for long time				

Transforming from page 31

college is an opportunity to stretch one's wings, but it's also a minefield that many students struggle to navigate. Students are living on their own for the first time. There's no one to tell them to eat properly, to study, to go to bed at a decent hour or to get up in the morning in time for class" (Smydo 2008). ASD students and LD students are not the only ones who need a comprehensive transition plan, but they are definitely individuals who especially need one. All of our young people struggle with the change which emphasizes both the failure of a transition plan for neurotypical students and especially our students with ASD and LD disorders.

According to Ellen Korin, "Authentic, comprehensive transition plans need to be developed as the student moves to the high school level. These transition plans need to be developed from the results of a formal assessment of the communication, presentation of self, social, organizational and life skills that our teens with AS often do not acquire as easily as their neurotypical peers" (Korin 2010). True, these skills are not as easy for ASD students but they are also a struggle for our neurotypical students. Joe Smydo states in his article that "nearly 33 percent of 20,500 students surveyed last year reported that stress negatively affected their academic performance, and 15.1 percent said excessive use of computer games did so, according to the college health asso-

ciation's National College Health Assessment" (Smydo 2008). These facts just highlight the greater need for disabled students to get a proper transition plan in addition to neurotypical students. ASD and LD students are known for their propensity for video games and their inclination to become addicted and therefore completely distracted from a healthy college experience. As stated in *Wordpress* where many mothers were interviewed about the maturation of their Asperger's child, one mother speaks to the video game problem. "I tried to limit the tv and computer. Daniel would completely melt down – biting, kicking, screaming. I noticed he really wasn't progressing in his speech at all. He wasn't interacting with anyone. He had no interest in anything outside the electronic world of tv and video games. When I eliminated those, every day was hellish from the moment he woke up until he went to sleep" (2011).

From the onset, ASD and LD children need interventions for a myriad of behaviors, but this shouldn't stop in high school. There is an incredible need to prepare both our disabled and neurotypical young people for the world that lies ahead. Clearly, ASD and LD young people will have significantly more challenges, but transition needs to be addressed for both populations, especially in order to highlight the struggle of the disabled person and the incredible need for preparation. "Some students find that their educational background or their lack

of effort has not prepared them for the academic demands of the college they have chosen. They may need remedial programs to make up for past deficiencies" (Causes of Failure in College, 2010). In other words, many neurotypical students are entering college as freshmen and failing both the writing and math placement tests that would put them in a credit-bearing class. This is clearly a failure on the part of their high school education. In order to move forward these young people will need to rebuild the scaffold they had at some point in their elementary and high school education and replace it with the support they can find in writing centers and tutors on the college campus.

This scenario is true for both Neurotypical and LD students. The difference is, it might and probably will be a lot easier for the neurotypical student to navigate the classroom, the interaction with professors, the learning center, the writing center and the student solutions center. Their success with support will be more attainable than it will be for the ASD/LD student. The bottom line is the link from high school to college needs to be a lot stronger for both populations in order for them to succeed. All students and especially ASD/LD students need to self-advocate, communicate, organize, manage daily living tasks, manage money, meet deadlines, and schedule their time. There appears to be a huge gap in our high-school education that could be taught to all populations so that our

young people can succeed in their respective lives as they achieve their individual goals with both neurotypical and ASD/LD challenges.

As the situation stands now, only 20 percent of young people who begin their higher education at two-year institutions graduate within three years (Public Agenda Report, 2009). This is a general number and the numbers are even bleaker in a post-secondary college servicing learning disabled and autism spectrum students. The bottom line is both neurotypical and learning disabled and autistic students need to be prepared and taught key transitional topics that will support students when they graduate high school. It is important that students learn to communicate their needs, capitalize on their strengths, seek assistance, schedule time for task completion, handle work in a timely manner, and follow academic rules promulgated by teachers. Basic skills must also be addressed – management of daily living tasks, cooking and laundry, money management, transportation options and self-care and self-knowledge and advocacy skills. Until this crucial learning agenda is addressed, all of our young people are going to struggle from home to college and the on the road to independence.

The Vocational Independence Program is a U.S. Department of Education approved Comprehensive Transition and Postsecondary (CTP) Program. To learn more, please visit www.nyit.edu/vip.

Competence from page 8

learning assessments are based on student strengths, not deficits that often define ASD. The approach enables the design of differentiated instruction through use of multiple learning environments and, when necessary, multiple means of assessment and expression (Zager, Alpern, McKeon, Maxam, & Mulvey, 2013).

Understanding students' learning characteristics, including strengths and weaknesses, is a prerequisite to effective instruction. Through UDL, it is possible to motivate learners at different levels and with disparate interests through multiple means of engagement. Learning material may be presented in a variety of ways to present information in a manner that is understandable and meaningful to everyone by employing multiple means of representation. In addition, assessment may come in different forms to empower students to demonstrate their mastery of content matter in a format suited to their learning style through multiple means of expression (Hall, Meyer, & Rose, 2012).

In UDL, through flexible articulation of goals, methods, materials and assessments, all students are able to enter the curriculum at a point that is comfortable for them. Evidence-based methods that are tied to goals and differentiated to address learner variability define good instruction. Through differentiation of instruction, materials may be multi-dimensional or multi-media as learners acquire information in varied ways. Finally, UDL assessment reduces barriers for students by allowing them to demonstrate knowledge and skills in a manner that enables them to articulate what they know so that they may be assessed on specific content, rather than on their test taking ability.

System-Wide Positive Behavior Supports

In some ways similar to UDL, positive behavior supports also involve redesign of the environment to increase productive engagement of people with challenging behaviors. As with UDL, positive behavior supports (PBS) focus on modifying the environment, rather than the individual. PBS is grounded in a commitment to inclusion of all students in their educational community. In striving to improve executive functioning that will enable students to manage their academic programs, ful-

fill academic responsibilities, and engage in community life with more ease; educators will find it helpful to utilize systemic school-wide supports that take into account students' communication, social and behavioral challenges.

Positive behavior supports are derived from principles of behavior analysis. When systemic PBS is employed, using the entire school as the intervention unit, rather than a specific individual, behavior and socialization within the school community has been shown to improve (Taylor-Greene, et al., 1997). Classrooms and other environments can be redesigned to reduce maladaptive behaviors and increase socialization and learning in varied ways. Educators can modify the physical layout, daily schedule, curriculum, and instructional materials.

When redesigning physical space and instructional presentation, it is first necessary to understand the behaviors that we are trying to reduce and the behaviors that we are attempting to build in relation to the individual and the environment. This is accomplished through functional analysis of behavior. Functional analysis of behavior is the process of identifying consequences and/or precursors of the behavior that can predict the onset of the behavior or maintain the behavior. Functional analysis yields information about when, where, and why a behavior is occurring. By using interviews and direct observation, important and useful information about the antecedents and consequences that sustain behaviors can be obtained (Horner, 2000). This information should be considered in planning the design of the school environment and instructional situation in order to facilitate successful interactions.

Developmental Individual Difference Relationship Model

The Developmental Individual Difference Relationship (DIR) model provides a framework to understand the functional emotional development and unique profile of individual students and can be used as a guide to create emotionally meaningful learning interactions that promote critical functional emotional developmental capacities, including executive functions. Through the DIR model, educators can gain understanding of the unique ways each person takes in, regulates, and responds to information. The DIR model focuses on building relationships with parents, educators, and peers to increase

positive interactions and improve learning outcomes. While most of the literature on DIR discusses young children, it is a logical extension of the theories underlying this model that relationships are central to learning at all age levels. The principles of understanding strengths and weaknesses and building upon strengths through trusting relationships can significantly impact high school learning and behavior for students with autism spectrum disorders. This is an area that merits further research targeted toward building positive school communities. Such school environments have the potential to increase participation in the academic and social domains, and to foster development of executive competence.

Conclusion

Parents and educators, alike, recognize the importance of strategies that build reciprocal teacher-student relationships, support appropriate behaviors for learning, and present instruction through means that enable all learners to be full participants. Positive school environments can reduce stress and anxiety that are common problems in adolescents with ASD, and which can often result in executive functioning problems. Three models, which have been shown to be promising for students on the autism spectrum include Universal Design for Learning, Positive Behavior Supports, and the Developmental Individual Differences Relationship model. Importantly, these practices have a common theme, in that they each consider the need to modify the environment rather than to change the student. UDL, PBS and DIR build on student strengths. By modifying activities and tasks, as well as environmental settings, the focus is shifted from trying to remedy problems within the student to empowering and enabling students to utilize their strengths to build success. By employing these three approaches in a complementary manner, educators can create a new configuration of evidence-based practices with synergistic potential to enhance learning.

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Government from page 19

support it, tell them you would like them to vote "yes" and why it would benefit an individual with a disability and the general public. The opposite is also true for issues that could negatively impact people with disabilities, so communicate why they should vote "no."

Be sure to include family and friends close to the issue as part of your outreach strategy. If needed, ask them to write letters, emails or call local officials. An additional benefit of developing as wide an outreach network as possible is that one of your contacts may personally know the official and could assist in setting up a meeting. Another key resource is economic information. As part of the education process, cite

specific dollar figures on how an issue will impact individuals presently served (and those on a waiting list), their families, providers in the region (reference the number of full-time equivalent employees and operating budgets) and potential job growth or cutbacks.

Some of you might be thinking *I work and can't go to events*. Legislators have many different opportunities available to interact with them or their staff. The staff members who work for our elected and appointed officials are critical and exceptionally influential in the policy and position development of the legislator. Please recognize the importance of communicating with staff members. You can stop in to a local office to speak with a staff or perhaps even the legislator if they are available. Try to set an appointment if you

can. Do you visit Washington D.C. on business or for a vacation? Why not take an hour and find your local Congressman's office and stop in? Most times constituents are welcomed and whenever possible provided time with at least a staff member to say "hi."

One easy way to stay up on what is going on with your elected officials is by signing up for an email newsletter. Most elected officials have regular email newsletters to inform you of what is happening in your area, and to provide opportunities for you to interact with them. Another great tool is to visit a local provider's or advocacy group's (e.g. ANCOR) website; most sites have a page (or contact person) focusing on current topics and advocacy issues. By visiting these sites regularly, you can stay in-

formed on current events that may impact children and adults with an intellectual disability. Finally, be sure you know the current elected officials who represent you. Visit their websites and review where they stand on issues relating to our field.

We will all advocate for something at some time. Why not make it count for the people we care for and support?

Melmark is a non-profit provider of educational, therapeutic, vocational and residential programs for children and adults diagnosed with intellectual disabilities, autism and traumatic brain injury. Melmark offers program locations in Berwyn, Pennsylvania and Andover, Massachusetts. For more information, visit melmark.org or call 1-888-MELMARK.

Trends from page 7

of growth, even more than jobs requiring higher levels of education. The amount of growth for jobs requiring an associate degree level of education will exceed 18%. Furthermore, there will be more job openings for people with an associate degree than there will be qualified job applicants who possess an associate degree. For higher functioning individuals on the autism spectrum, an associate degree is a worthwhile educational goal.

The Value of Earning An Associate Degree

Earning an associate degree makes sense not only in terms of protecting against unemployment and increasing life time earnings, but in other ways as well. Associate degrees are often more directly tied to a future job. Unlike a bachelor degree in liberal arts, where the education is designed to provide the student with a broad foundation of knowledge, associate degree training is often job specific. The training is more practical and less theoretical and abstract in nature. Many higher functioning students on the autism spectrum do not see the value or point of taking a humanities or English literature course as a part of a distribution pattern for a bachelor degree when he or she is primarily interested in computer programming.

Associate degrees are also a good value. The length of time a student needs to complete a degree and begin working is two years as opposed to the traditional four-year undergraduate degree. In fact, the four-year bachelor degree is becoming the exception, with many more students taking more than four years to complete a four-year degree (Turner, 2004; National Center for Education Statistics, 2012). This at least doubles the cost of tuition. However, tuition is not the only cost of attendance. There are transportation, books, lab fees, meal plans, and dorm costs to consider. Obtaining an associate degree at a local community college is ideal for a student on the spectrum who is willing to live at home while earning a degree and is not necessarily interested in the social and independent living experiences she would have going away to school. Furthermore, obtaining an as-

sociate degree will decrease the potential amount of money a student needs to borrow for student loans, and decreases his or her debt to potential earnings ratio.

Which Degree to Pursue?

How does a higher functioning student on the autism spectrum decide whether or not he or she should pursue a vocational certificate, an associate or a bachelor degree? The student along with his or her parents and educators should first obtain an accurate assessment of his or her abilities, aptitudes, strengths, and interests. This can be done through the school district as well as state agencies, such as a state office of vocational rehabilitative services, or an office of persons with developmental disability services (the formal name of the agency varies from state to state). Special education ends once a student either completes a high school degree or reaches 21 years of age. Therefore, a student on the autism spectrum, must be "otherwise qualified" under the Americans with Disabilities Act (ADA) to pursue a college degree. The assessment should determine if the student has the capability of reading, writing, and conducting mathematics at a college level, but also has the social and executive functioning skills necessary to complete college level assignments and negotiate the complex social environment of a college campus.

Part of the exploration process should include consulting with the Occupational Outlook Handbook, which is published annually by the U.S. Department of Labor. This free resource is available at www.bls.gov/ooh. The Handbook is a searchable document that provides job projections through 2020. The searches can be done by education or training level. The student will find out whether or not there will be projected job growth in a field he or she is interested in, what level of education or training is required, and the amount of typical wages for that job. The document also suggests similar job titles to the reader for consideration (U.S. Department of Labor, Bureau of Labor Statistics, 2012).

The next step is to locate the vocational training center, college, or Comprehensive Transition and Postsecondary (CTP) program that best fits the student's needs. This may involve

working with the school guidance counselor, transition coordinator, case manager at a state agency to locate a program or college with a good fit to the student's needs. Three web sites that can aid in the search for a suitable post-secondary program are:

1 - Think College (www.thinkcollege.net) which hosts three information clearing houses:

- The Consortium for Postsecondary Education for Individuals with Developmental Disabilities (www.thinkcollege.net/about-us/think-college-initiatives/consortium-to-enhance-postsecondary-education-for-individuals-with-developmental-disabilities)
- The Center for Postsecondary Education for Individuals with Intellectual Disabilities (www.thinkcollege.net/about-us/think-college-initiatives/center-for-postsecondary-education-for-individuals-with-intellectual-disabilities)
- The National Coordinating Center (www.thinkcollege.net/about-us/think-college-initiatives/national-coordinating-center)

2 - Heath Center at George Washington University (www.heath.gwu.edu) which contains a web page entitled: New Postsecondary Programs for Students with Intellectual Disabilities (www.heath.gwu.edu/assets/50/pse_id_final_edition.pdf) that describes programs around the country that serve students with a variety of disabilities; and

3 - The US Department of Education Federal Student Aid (www.fafsa.ed.gov) which is the home page for federal student aid. By typing in the term "intellectual disabilities" in the local web page search, it will link the reader to <http://studentaid.ed.gov/eligibility/intellectual-disabilities>. At the bottom of this web page is a list of the federally approved CTPs across the U.S. which can offer financial aid to students who qualify.

New York Institute of Technology Vocational Independence Program is proud to announce the creation of its Associate Assistance Program beginning fall 2013.

Qualified students with autism and other neurologically based learning abilities will be able to earn an associate degree over the course of three years with enhanced and specialized support services.

Ernst VanBergeijk is the Associate Dean and Executive Director, and Paul Cavanagh, is the Director of Academics and Evaluation, at New York Institute of Technology Vocational Independence Program (VIP). The Vocational Independence Program is a U.S. Department of Education approved Comprehensive Transition and Postsecondary (CTP) program. www.nyit.edu/vip. The authors also administer Introduction to Independence (I to I) a seven week summer college preview program for students ages 16 and up.

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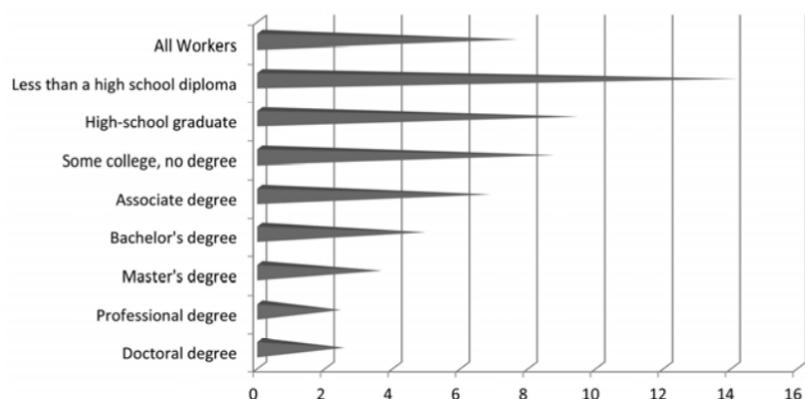
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Table 1: Unemployment Rate in Percentages (2011)



Source: Current Population Survey, 2012 Bureau of Labor Statistics

Table 2: Education and Life Time Earnings

Educational attainment	Synthetic work-life earnings
• None to 8th grade.	936,000
• 9th to 12th grade.	1,099,000
• High school graduate.	1,371,000
• Some college.	1,632,000
• Associate's degree .	1,813,000
• Bachelor's degree.	2,422,000
• Master's degree.	2,834,000
• Professional degree.	4,159,000
• Doctorate degree.	3,525,000



Source: Work-Life Earnings by Field of Degree and Occupation for People With a Bachelor's Degree: 2011
By Tiffany Julian. Issued October 2012. *American Community Survey Briefs*

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travel training they received when something out of the ordinary occurs. It covers such topics as: What if you lose your fare? What if you miss your stop? What if you get lost?

Dr. Leary states, "Easter Seals is pleased to have added our knowledge of the needs of people with autism and our expertise on accessible transportation to that of The Daniel Jordan Fiddle Foundation to produce this new pocket guide, which will provide support to people with autism as they independently use public transportation to get to the places they want to go."

According to transportation expert and project collaborator Cecilia Feeley, "The ability to travel independently allows one to take control of their lives and their choices. Those who can't or don't drive can take public transit to meet their daily needs and maintain a high quality of life. However, using the local bus or train can be overwhelming, especially when something goes wrong. The *GET Going Pocket Guide* allows individuals to get quick answers to common problems that happen when riding the bus or train."

The *GET Going Pocket Guide* will be available nationally in January 2013. De-

veloped collaboratively, the process involved public transit service providers and operators, travel trainers, transit researchers and disability experts. The goal is to provide simple solutions to problems and avoid potential crisis situations while getting people back on their route and to their destinations safely. To download or order a *GET Going Pocket Guide* in January, go to The Daniel Jordan Fiddle Foundation at www.djfiddlefoundation.org or Easter Seals Project Action at www.projectaction.org.

Helping Adults with Dating and Social Relationships

Another area that The Daniel Jordan Fiddle Foundation Signature Programs have focused on in 2012 that has also been inspired by the needs expressed by adults on the spectrum: how to become a better dater and cultivate social relationships. This past year, the first *Daniel Jordan Fiddle Foundation Ignition Grant Program* that is co-funded by UJA Federation of New York was launched. The idea of the Ignition Grant is to fan the flame of program development for adults living with autism within the UJA Federation of New York agencies and service provider entities. UJA-Federation of New York sup-

ports a broad range of services for children and adults with developmental, behavioral, and physical disabilities including those on the autism spectrum. The first recipient of the Ignition Grant that was awarded last April is the JCC of Manhattan Adaptations Program led by Allison Kleinman.

The Jewish Community Center of Manhattan (JCC) has developed a unique set of programs to help adults who live with autism and related challenges attain the skills they need to socialize, date, and form relationships. The JCC programs combine professional guidance with practical "real world" experiences to help participants navigate areas such as body awareness, making small talk, splitting a dinner check, creating a dating profile, meeting new people, intimacy, and sexuality. The funding also has allowed the JCC to expand its roster of social gatherings to provide 20- and 30-something participants a place to go to hang out and meet new friends. Allison Kleinman, Director of the Adaptations Programs at the JCC of Manhattan says, "The Daniel Jordan Fiddle Foundation Ignition Grant has allowed us to work with participants on building the skills and confidence they need to form friendships and romantic relationships."

In the year ahead, these and other innova-

tive projects will help to educate and prepare adults living with autism with the skills and support they have asked for to participate in and contribute to community life. The Daniel Jordan Fiddle Foundation's decade of volunteer-service to the Autism community will continue as we enter our second decade with the goal we have had from day to one: to help create the most fulfilling lives possible for all people living with Autism in a world that respects each person and encourages their strengths and talents.

Linda Walder Fiddle leads The Daniel Jordan Fiddle Foundation that she founded in 2002 in honor and memory of her son Danny who lived with autism. The Daniel Jordan Fiddle Foundation was the first national autism organization to focus exclusively on adults living with autism spectrum challenges. Since its inception, the all-volunteer run organization has developed and funded over one hundred programs as well as cutting-edge public service materials and resources for the autism community. In addition, DJF Foundation is a leading advocacy organization and has received numerous awards for its leadership in support of all people living with autism. For more information, please visit www.djfiddlefoundation.org.

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Many are seeking a specialized field of interest such as film-making or computer systems design and may not appreciate the variety of courses one is exposed to in a comprehensive liberal arts education. Neuropsychological profiles of these students often indicate specific weaknesses in areas such as languages or math, which suggests the more comprehensive curriculum may not be the best option. Other opportunities may be available for these students in technology institutes, art schools or other professional training and certification programs.

A promising solution for helping non-academically inclined individuals involves an approach that assesses and addresses needs in the areas of vocational, educational and interpersonal skills as they relate to potential success in the world of work. All of these aspects of an individual's development are closely interrelated; however it unfortunately seems there are few programs out there that successfully address all of these components in a cohesive way.

Vocational Goals and Educational Needs Assessment

When a client comes to seek guidance from an organization such as Jewish Child Care Association's Compass Project, either independently, via referral from NY State Adult Career and Continuing Educational Services (ACCES-VR) or as students through partnership with the OASIS program at Pace University, we first evaluate the most important factor that will help determine potential for success: Do they want our help? If a young person has not reached the emotional maturity to understand why help and guidance would be beneficial, then it is not the right time to pursue support services.

Once a client is ready to receive help, we allow the space to fully explore dreams and goals. This not only helps build a trusting relationship, but it also helps a client to become excited about the prospect of de-

termining on a career, rather than focusing only on feelings of doubt or anxiety. Sometimes the goals a client brings to the table are realistic and attainable with their current level of education and experience, but often times a person will come to the program with potentially unrealistic goals and without a real understanding of what it might take to actually pursue a career in a given field. In either case, we work with individuals on a one-on-one, individualized basis to guide them on the process of self-discovery and career exploration.

Activities included in the process of self and career exploration are all geared towards helping an individual come to a conclusion about how realistic and attainable a certain set of goals are. Activities to accomplish this task will often include career interest and aptitude assessments, discussions about values with relationship to work, basic educational assessments to determine the viability of pursuing some form of higher education, measures of executive functioning difficulty to identify areas of needed support, and practice in the art of conversation so individuals may begin to connect with professionals in their fields of interest. All of these activities help a client to develop valuable insight while also working towards a clear goal.

Once an individual has identified a direction they would like to go, there are varieties of different educational directions that will help a client move towards attaining short and long term goals. Many people get stuck on the idea that college is the only answer, even without having a clear idea of why attending college is a good idea or what the potential degree (including time and money invested) will help achieve. With this idea in mind, it has become clear that for people on the spectrum, education can come in many forms. An associate's degree or bachelor's degree are two obvious forms, but certificate programs, trade schools, vocational schools, apprenticeships, internships, part-time jobs and volunteer opportunities are also meaningful and valuable experiences that can move an individual towards a desirable direction.

All of these experiences, if done in the pursuit of a clear goal, have the potential to enhance a person's skills and increase their competitive advantage in the marketplace.

A Strengths-Based Orientation and Supportive Learning Environments

It is a well-known fact that a disproportionate number of people on the autism spectrum are either unemployed or underemployed. Some may argue that this is due to the fact that a person's challenges or disabilities are getting in the way of their success. We would argue that these individuals have not had appropriate support in identifying their areas of greatest potential, nor have they had appropriate support in getting connected to a variety of educational opportunities in supportive environments that will aid in their long term success.

The supportive environment component, be it an educational or work situation, is the elephant in the room that is often the toughest component to tackle. Despite this notion and because of the thoughtful efforts of people who invest a little extra time and energy towards individuals on the spectrum, school systems and employers have begun to see that people on the spectrum can have a place and be a valuable asset to an organization. Finding a unique place for individuals is the component that we all must strive to continue to promote, because everyone does have a place, but it may just take some time and a little bit of extra effort to help each individual find it.

Overall we seek to strike a balance between a strengths-based perspective of helping with the more traditional medical model of identifying deficits that an individual has. It is important to note that our focus is leaning more towards the strengths-based view because that is ultimately the driver towards helping an individual find a place within the world of work. It would be delusional to think we could "fix" all of an individual's problems; however we can help people to develop coping strategies and advocacy skills to deal with the things that may be challenge throughout life.

Importance of Research-Based Outcomes

Having observed methods that appear to have impact on successful vocational and educational development, we have also begun to work towards developing empirically-based programmatic research to help measure the effectiveness of these methods. Two tools we have begun to consider utilizing to measure changes over time are the Clinical Global Impression (CGI) Scale and the behavior Rating Inventory of Executive Functioning (BRIEF). For starters, our aim is to measure specific components with relation to social competency and its impact on transition. The specifics of our research are still in development, but we understand the need to do measured evaluation if we are to effectively evaluate interventions and eventually replicate outcomes.

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Interventions from page 12

others perceive and respond to them, and how these interactions affect their own emotions and relationships in various social contexts. The goals of a social thinking program include recognizing that they and others have different perceptions and abilities to process social information, learning to navigate through their social thinking, utilizing social interaction and social communication toward more rewarding outcomes, and learning to better adapt and respond to the people and situations around them. The social skills issues that are addressed and integrated include concept formation, theory of mind and perspective taking, executive function (cognitive organization, multi-processing, emotion naming and regulation), and social information processing. There is a strong evidence base for all the components of social thinking which are employed based on a student's individual needs and can be utilized in an individual or group modality.

Developing Empathic Skills

Although students on the autism spectrum are often considered to have poor skills at empathy, the reality is somewhat more complex. Research tells us that individuals on the spectrum often have emotional empathy, that is, the ability to share feelings with others and show compassion (Dziobek et al., 2008). However, they often lack ability to ascertain another's perspective, making it difficult to share in something they do not recognize or understand. Thus an appropriate intervention would be to specify why an individual has difficulty in the recognition of others' perspectives and train the specific deficit that interferes. Contributing factors to such problems with cognitive empathy could include prosopagnosia (poor facial recognition), poor appreciation of nonverbal cues, lack of mental flexibility, alexithymia (impaired recognition of own emotions), difficulty with emotional regulation or other executive function skills. Through specific assessment, which aspects are salient for a particular individual could be identified and then supported utilizing some of the following evidence-based interventions. F.A.C.E. (Facial Expression, Awareness, Compassion, Emotions) provides information about how to learn to recognize signs of emotion in the face. SETT (the Subtle Expression Training Tool) teaches recognition of very small, micro signs of emotion. METT (the Micro Expression Training Tool) is more advanced training to increase people's ability to spot tiny facial signals. All stem from the seminal work of Paul Ekman (Ekman, 2003). In addition, other specific materials have been developed to assist children and

adults on the spectrum to conceptualize, understand, or predict emotional states in other people, by Simon Baron-Cohen. The Mindreading DVD (www.jkp.com/mindreading), for children and adults, and the Transporters DVD (www.thetransporters.com), for younger children have been well researched and help in the development of some of the underlying skills needed for empathy. Many of the elements of the Social Thinking curricula also support the necessary underlying skills for empathy.

Executive Function

Emotion regulation is one of the executive function skills. Emotions are influenced by the meaning we assign to particular occurrences. Regulation includes the physiological responses that activate arousal in preparation for action, the communication of reactions, feelings and intentions through facial patterns, postures, and gestures, the reinforcement of patterns of emotions through social interaction with family, peers, and authority figures, and the modulation of expression. So, emotion regulation encompasses many cognitive and organizational elements that can be a challenge for individuals on the spectrum. Schools, families, and professionals can be helpful by teaching understanding of one's own emotions in a social context (Winner, 2007), utilizing self-advocacy curricula to encourage positive expression of needs and wants before dysregulation occurs (Paradiz, 2009), and changing with way inaccurate thinking patterns are negatively affecting behavior through evidence-based cognitive behavior therapeutic (CBT) approaches (Attwood, 2004, 2008; Gaus, 2007).

Other executive function skills include shifting/flexible thinking, initiation, and organization, and working memory. Although there are multiple evidence-based approaches to remediate deficits in these areas (Meltzer, 2010; Dawson & Guare, 2012), frequently unless there has been a specific effort to include them through the IEP process they are often not well addressed and students continue to struggle and become discouraged. There are no specific patterns of executive function deficit considered to be characteristic of students on the spectrum, so an individualized assessment that pinpoints deficit areas for remediation is critical. There are executive function screening tests that identify areas of functional weaknesses which can direct teachers to develop individualized supports for their students who struggle with these underlying skills (Gioia et al., 2005; Barkley, 2011).

Aggression

There is no specific treatment for aggression. The treatment and management

approach must emerge from a thorough understanding of the unique causes for each student. There is an evidence base for many of the causes but not for "aggression for students with autism spectrum disorders." Sometimes the characteristics specific to the spectrum contribute to behavioral aggression such as rigidity, resistance to deviations from expectancy, difficulty with transitions, and sensory overload. Other times, issues that many students may manifest affect students with autism spectrum disorders. These may include processing issues, emotional dysregulation, deficient social skills, fear and confusion, social anxiety and agitated depression, and sometimes the inadequacy or side effects of prescribed medications. Developing a comprehensive understanding of the etiology of aggression is key to finding solutions. There are evidence-based interventions for many of the underlying issues for verbal and physical aggression.

A functional behavioral assessment is the typical response for problems of aggression. It is critical that such an evaluation assess the etiology of the aggression, not simply its behavioral manifestations. Accompanying evaluations of sensory processing, executive function, uneven cognitive development, assistive technology needs, and pragmatic language can give a much more complete picture of causes and suggest creative solutions. Once the specific elements are identified, there are many evidence-based interventions that can be brought to bear on the presenting problem, including many of those specified above.

Mental Health Issues

Many students on the spectrum have co-occurring mental health issues, such as anxiety and depression. It is important to seek support from professionals who have a good understanding of the underlying neurobiological issues associated with the autism spectrum, the life differences that can occur for these individuals that limit their opportunities to gain more typical skills, and the identification and treatment of co-occurring mental health conditions. Local autism organizations can usually identify professionals who have this kind of orientation. When providers do not have this expertise, under and over diagnosis can occur, which only serves to exacerbate existing problems. Families need to investigate the knowledge base of professionals purporting to provide treatment for those on the autism spectrum and insure that a thorough knowledge of the wide range of evidence based interventions that can benefit children on the spectrum are within that person's arsenal of treatments. Simply being listed on an insurance list of providers does not guarantee this expertise. Having such knowledge and a willingness to cooperate with

school personnel is the most helpful combination for comprehensively dealing with the complicated issues children with ASDs present.

School personnel should also keep in mind that they may be critical in the recognition of co-occurring mental health problems that should be evaluated by a specialist. Depression and anxiety symptoms are more prevalent in the population of children, adolescents, and adults on the spectrum than they are in neurotypical groups. Post-Traumatic Stress Disorder (PTSD) is increasingly being recognized, as well, as so many on the spectrum experience traumatic and inescapable social experiences that produce long-term effects. Effective treatments for these conditions are well documented, but they must be recognized as something separate and treatable, rather than simply the individual's autistic features.

The School Perspective

School personnel by definition need to be generalists who can deal with a wide array of student issues and it is not realistic to expect them to be autism experts. However, it is important that they can respond to the mandate of providing evidence-based interventions for all classified children. For students on the autism spectrum, the best evidence-based intervention is to develop a flexible team willing to learn new skills to address the unique needs of each student on the spectrum and to create a plan based on an accurate assessment of these needs incorporating expert, specialized knowledge to tease out the unique issues of each student presents. Issues of importance in effectively utilizing evidence-based procedures include using manualized treatments, having the knowledge to select appropriate interventions that will have individual effectiveness for particular problem areas, employing consultants who can provide training to school personnel, and developing a school team that truly understands the wide array of possible interventions that can be brought to bear on the complicated issues of students on the autism spectrum.

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- Draw on assessment strategies, including functional assessments of social behavior, to identify those children in need of more intensive interventions as well as target skills for instruction
- Enhance social skills by increasing the frequency of an appropriate behavior in typical environments to address the naturally occurring causes and consequences

According to the American Psychological Association (APA), an evidence-based practice is a treatment that is supported by systematic research studies when conducted by experienced, highly trained clinicians. Treatments considered evidence-based are typically the most highly-regarded and become a standard of care in a field. There are a number of evidence-based techniques known to be effective in teaching social skills and are recommended elements of social skills groups in the schools. These techniques include: typical peer mediators, social stories and video modeling.

Peer mediators are neurotypical peers from the school who can serve as models of appropriate social behavior and provide safe opportunities for children with ASDs to practice learned social skills. The goal of peer mediators is to increase the num-

ber of opportunities for successful social interactions in the natural school environment. An excellent way to achieve this is to conduct the groups within the classroom using a "push-in" model, rather than your traditional "pullout" model, as the typical peer classmates are present at all times. Another evidence-based technique that is often used in social skills groups are social stories, popularized by Carol Gray. Social stories use a storybook format to describe different social situations where the social underpinnings may be unclear or difficult for the children to understand. The stories give details about each situation in a straight-forward manner. This assists in the improvement of the children's understanding of the situation, helps attune their expectations and, thus, increases the likelihood of their responses being appropriate. Rather than change the children's behavior, the goal of social stories is to prepare children for what will occur and set them up for success. Recently, video modeling has also become a popular tool used in social skills groups. Videos displaying appropriate social behavior are shown to group members with the goal that they will act in kind when faced with similar situations in their lives. Video modeling is particularly well-suited for children with ASDs because they are designed to address areas that often cause them difficulties, such as over-selective attention and restricted areas of focus. They

are also applicable for use with children with ASDs, as they typically prefer visual stimuli and tend to be visual learners.

Additionally, to improve the effectiveness of their social skills groups, it is recommended that schools involve parents and other caregivers. Parents and caregivers can give the group leader important information about their child's social functioning in other contexts and help reinforce learned skills at home, promoting generalization of the skills.

Before deciding to enroll their child in a school-based social skills group, parents are encouraged to ask questions and make sure the group is going to meet their child's needs, use the most effect strategies, and employ research supported techniques. In sum, worthwhile social skills groups in the schools:

- Use qualified professionals who have experience working with children with ASDs and within a group therapy context
- Focus on developing the four key sets of social skills recommended by NASP (Survival, Interpersonal, Problem-Solving, Conflict Resolution)
- Make use of evidence-based techniques
- Include group members who are on a similar social skill level

- Be scheduled during a time where students will not miss essential instructional time
- Include parent and caregiver to obtain vital information and assist with generalization

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The Fay J. Lindner Center for Autism and Developmental Disabilities, an affiliate of the North Shore-LIJ Health System, was formed to meet the needs of children and adults with autism and related developmental disabilities and their families. The Lindner Center is located in a state-of-the-art facility on AHRC Nassau's Brookville campus. The Lindner Center offers a wide range of programs, clinical services (including individual, family and group therapy, social skills training and comprehensive and diagnostic evaluations), professional training, and community education. To learn more about the Lindner Center and the services we provide, please visit us on the web at www.FayJLindnerCenter.org.

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Paul, an adult with autism gave a compelling and inspiring account of his journey from childhood to adulthood at the Autism Science Foundation's Science & Sandwiches (<http://www.autismsciencefoundation.org/science-sandwiches>) event last night. Paul asked his psychiatrist, Dr. Andres Martin, Psychiatrist at the Yale Child Study Center, to help him share his story. In a candid discussion, Paul asked Dr. Martin a series of questions about what he was like when he first became his patient, and how he was different as an adult.

During the discussion, Paul explained that he used to be non-verbal and faced significant challenges as a result of his autism. As he grew older, his determination to achieve independence and lead a life comparable to his neurotypical siblings motivated him to become the self-sufficient, happily employed member of society he is today. Remarking on Paul's growth, tenacity, confidence, and passion for autism advocacy, Dr. Martin called Paul a source of inspiration for families affected by autism.

This is a transcript of the speech Paul gave at the event:

Hi,

I have always wanted to do public speaking at various colleges for people who major in psychology and special education. I want to talk about my life with autism. My name is Paul Morris. Many of you know me from the past. Some of you worked with me. I was non-verbal until age five. I had to be taught how to speak, how to listen and how to think. The years were hard. Sometimes I just didn't understand. But look at me now. I graduated from the College Internship Program at the Berkshire Center in Lee, MA.

Autism is a genetic disorder that affects the brain and communication. When I was a little boy I did not know that I was different. When I became an older person, I wanted to do my own things, like hang out with friends, like my brothers Jesse, and Tyler, and my sister Sabrina. I did not know how to hang out with friends.

My parents wanted me to learn how to speak and communicate. It is not only about words, it is about behavior. It took me a long time to learn how to socialize with people. I am still learning what that means.

When I went to Middle School, the kids didn't understand me. I think they were afraid of me because of my autism. It also took a long time for people to know how to socialize with someone like me. I didn't understand when kids told me to do wrongdoings. Sometimes kids are rude.

Then there were the kids that were nice to me. They were kind and they sat next to me in the cafeteria but I did not go to recess because they said it wasn't good for me. Today, I would suggest that Special Ed kids should go to recess and have an aide help them.

I learned that language is not only about speaking. It is about relationships. I was taught relationship development intervention. It was very hard for me. Eye contact was hard for me to do in the beginning, but "Look me in the eye" I am good at now.

I met Dr. Martin in 1999. I couldn't control myself. I would explode. I would obsess. I would cry in pain. He tried to help me with medicine.

The best things about High School were small classes in English and Math. I also enjoyed lunch groups in the guidance office. We made a friendship blanket and everyone signed it. Some of those kids were very nice to me and still contact me by phone, email and Facebook.

I started the College Internship Pro-

gram in Lee, Massachusetts on July 3, 2006. The program was called ASPIRE. I looked up the definition of aspire. It means to dream, to pursue, to try, to wish, to struggle. I struggled in the beginning. Living on my own, I learned about hygiene, cooking, cleaning, how to get a job, self-awareness, taking care of money and how to figure out my problems.

Advising sessions were very important at CIP. We did self-assessment forms. I rated my performance every week, and my advisor did it too. The ratings are listed as Under-Performing, Average, Honors and Mentor. Classes like theory of mind, realizing about how others talk to you and hidden curriculum, were challenging. The C-STEP (Career Skills Training Employment Program) is very important for people who don't go to college. I took classes in Self-awareness, critical thinking, English, Math, Working with people, Office procedures, Succeeding in the world of work, Business correspondence, and Internships. My best internship was at the Norman Rockwell Museum doing data entry and mailings to colleges for Art History Programs.

One day freshman year my parents invited me to a Brewers/Mets game. My Mom gave me an option: A) Do you want to go and find a way to get yourself home? Or B) Do you want to stay at school? I picked A. I researched Peter Pan Bus on the Internet and learned that I could take a bus from Lee, Massachusetts to Danbury, Connecticut. I bought the ticket and traveled by myself. When I stepped off the bus I said, "The mentor has arrived!"

When I graduated in May, I was on Mentor status for 26 weeks in a row. At our graduation convocation ceremony I won the award for Most Improved Student. I also earned a certificate for 44 hours of community service, because I performed in a puppet show for children

and sent toiletries to Africa. My favorite award, which I won 3 years in a row, was for Recreational Excellence. I never missed a meeting on Monday nights, where I made suggestions for weekend activities. I researched directions on map quest, how much it cost and assisted the Residential Coordinator in planning. I also was an officer in student senate.

It has been a very long way for me. I have worked very hard to achieve.

I now live in New York. I work at New York Medical College as a human resource assistant. I do data entry, scanning, shredding, copying, filing, and mailings. My supervisor, Tom is my mentor and friend. I wrote a letter to President Obama in 2009:

Dear President Obama,

My name is Paul Morris and I am a 21 year old guy who is high-functioning autistic. I was non-verbal until the age of five. Now that I am looking for work and living with roommates, I am worried about my life. It's going poorly for autistic adults because the funding is over. I want you to create programs for autism spectrum disorders. Today, you donate lots of money to autism.

From, Paul

I want new interventions to help with autistic people. I want good education for them to learn. I want jobs and help with living. I want to do great things. Thank you for listening.

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diagnostic criteria of the condition in clinical manuals. The ASRS scale structure includes three factorially defined scales (social/communication, unusual behaviors, self-regulation), eight content derived treatment scales (peer socialization, adult socialization, social/emotional reciprocity, atypical language, stereotypy, behavioral rigidity, sensory sensitivity, attention) and a scale based on the currently accepted diagnostic criteria for ASD. A total score is also generated.

The first step in creating a treatment plan once a diagnosis is made is to clarify the specific area or areas of need. We suggest that any nationally normed standard score from a scale like the ASRS that is above one standard deviation (e.g., in the top 16% relative to problem behavior) indicates that the child rated has many behavioral characteristics similar to youth diagnosed with ASD. Taking all the ratings by parents and teachers as a whole, the next step is to identify an intervention plan based on the profile of scores for the ASRS treatment scales. For example, in the case of Donny (see Table 1) we begin by prioritizing the areas of need based on the magnitude of the T-scores. Donny's highest T-scores were on the Social/Emotional Reciprocity scale rated by parents and teachers. This scale involves specific behaviors such as looking at others appropriately while talking with them, understanding the feelings of others, recognizing social cues, responding appropriately to other people's state-

ments, interests or feelings and enjoying interacting with others. In order to have a more precise understanding of the exact behaviors that contributed to this high score or a high score on any of the treatment scales, we conduct an item level analysis to identify the greatest need relative to behaviors to improve. This can be accomplished by determining when an item rating is substantially higher than the item average from the normative group. Analysis of the treatment scales and the items included on those scales can be used to identify which specific behaviors warrant intervention. In our text (Goldstein and Naglieri, 2013) we provide a Quick Solution Guide directly keyed to specific behaviors. This allows us to select interventions associated with each behavioral need. In Donny's case, the next scale that warrants intervention is Peer Socialization. Behaviors in this scale involve seeking the company of other children, talking with other children, choosing to play with peers and responding when spoken to. These behaviors can then be identified and compiled into a functional treatment plan.

Once treatment is begun, it is important to monitor the effect of the interventions over time. We assume that treatment of children with ASD takes time and therefore progress towards goals should be evaluated as frequently as possible during treatment. This may include traditional methods of evaluating specific behavior change (e.g., applied behavioral analysis) but should also include normative data from a rating scale such as the

ASRS to calibrate change from the pre-treatment period. For example, raters who complete the ASRS are informed to evaluate the child based upon the behaviors observed during the previous four weeks. The combination of specific behavioral change and standard scores from a norm referenced measure provides a balanced view of progress. We suggest that evidence of treatment effectiveness is strongest when the pre and post-intervention behaviors related to ASD are evaluated using nationally calibrated scores. The approach we recommend is based on a dual criteria of statistically reliable differences and clinically meaningful change. In order to determine if the differences are related to measurement error or actual change brought about by treatment the statistical difference between the two scores should be determined using sound measures. The values needed for significance in using the ASRS are provided for each treatment scale in the test manual. Table 2 provides an example of the differences needed to demonstrate treatment success over three rating periods. This method helps provide families and treatment providers with a valid and reliable means of assessing difference. Small differences in pre and post ratings with low levels of significance would indicate that the strategies chosen to address specific behaviors were in effective and should be reconsidered.

The process of assessment of ASD requires more than just a diagnostic pronouncement. It requires the collection of

well-defined behavioral data facilitating a smooth transition between assessment, treatment planning and the evaluation of treatment effectiveness. It is critical that families, treatment providers and evaluators understand these issues and the sound psychometric procedures necessary to assess effectiveness over time in children with ASD.

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*Note: This article is abridged from: Evaluation and Treatment Effectiveness in the Field of Autism: Psychometric Considerations and an Illustration by Naglieri, J.A. & Goldstein, S. (in press), in J.A. Naglieri and S. Goldstein *Handbook of Autism Treatment*, New York: Springer Publishers

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Table 1

Case of Donny: Parent and Teacher ASRS T-Scores, Differences Between Raters, and Values Needed for Significance.

	Parent	Teacher	Difference	Difference Needed*	
Total Score	73	73	0	5	NS
Social Communication	77	78	1	6	NS
Unusual Behavior	60	53	-7	6	Sig
Self-Regulation	70	74	4	7	NS
DSM-IV Scale	69	68	-1	6	NS
Treatment Scales					
Peer Socialization	70	73	3	9	NS
Adult Socialization	58	63	5	12	NS
Social/Emotional Reciprocity	77	76	-1	8	NS
Atypical Language	52	44	-8	11	NS
Stereotypy	49	54	5	13	NS
Behavioral Rigidity	72	48	-24	8	Sig
Sensory Sensitivity	44	48	4	12	NS
Attention	71	73	2	7	NS

*Note: Differences needed for significance when comparing Parent and Teacher ratings are found in Table 4.5 of the ASRS Manual. T-scores greater than 59 appear in bold text.

Table 2

Parent T-scores for ASRS Scales Obtained over Three Time Periods.

	Time 1	Time 2	Time 3	Progress Monitoring (Time 2-1)	Progress Monitoring (Time 3-1)
Total Score	73	70	63	-3	NS
Social Communication	77	77	66	0	NS
Unusual Behavior	60	58	58	-2	NS
Self-Regulation	70	67	62	-3	NS
DSM-IV Scale	69	68	63	-1	NS
Treatment Scales					
Peer Socialization	70	69	68	-1	NS
Adult Socialization	58	58	58	0	NS
Social/Emotional Reciprocity	77	77	63	0	NS
Atypical Language	52	52	52	0	NS
Stereotypy	49	49	49	0	NS
Behavioral Rigidity	72	67	67	-5	NS
Sensory Sensitivity	44	44	44	0	NS
Attention	71	68	58	-3	NS

*Note: Differences needed for significance when comparing scores over time for Parent and Teacher ratings are found in Table 4.11 of the ASRS Manual (p = .10 with Bonferroni correction).

T-scores greater than 59 appear in bold text.

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the classroom, the home, or out in the community. This concept is illustrated in Figure 1 (Gerhardt, Zawacki, & Satriale, 2012).

In an effort to improve the generalization of skills from teaching settings to daily use in the real world, comprehensive behavioral interventions have modified traditional applied behavior analysis techniques in a way that permits instruction in natural environments. Rather than being tied to specific procedures, applied behavior analysis includes any method that changes behavior in systematic and measurable ways (Mayer, Sulzer-Azaroff, & Wallace, 2012).

Behavior Analysis is recognized as the pre-eminent educational approach for individuals with ASD. The educational model that has the greatest potential to reduce many of the challenges to the over-

all effectiveness education for individuals with ASD combines behavior analysis and Community Based Instruction (CBI; Sigman, et al., 1999). CBI is *regular and systematic* instruction in meaningful, functional, age-appropriate skills in integrated community settings, using naturally occurring materials and situations, designed to help the student acquire and generalize life skills that enhance opportunities for meaningful experiences and relationships within the general community. The emphasis is on acquisition and application of functional and age-appropriate skills in a naturalistic context. Instruction is driven by the principals of applied behavior analysis and targets individual strengths and needs, using consistent teaching strategies, as well as accommodations designed to enhance the student's participation in typical activities.

Functionally relevant skills are taught in home settings and community surroundings such as shopping centers, convenience stores and/or grocery stores, local recreational centers such as local fitness clubs, movie theaters, and family entertainment centers. Community resources such as public libraries and post offices are also important potential instructional settings. Additionally, skills important to a quality of life such as travel training, pedestrian skills, money use and management, leisure skills, and restaurant use are taught within appropriate community settings. For older students, the community includes vocational settings in order to instruct important skills necessary to be successful in the workplace.

Community-Based Instruction should not be confused with the more traditional field trip that is used in public schools.

CBI is cumulative with frequently used skills targeted intensively, minimally three times per week and are assessed weekly. Field trips are not CBI and are not a legitimate substitute for systematic instruction in functional, age-appropriate skills in natural settings. Because field trips tend to be episodic, one-time activities, student needs for consistency, repeated practice, and systematic generalization are difficult to address in the context of a field trip, no matter how often field trips are scheduled.

CBI and teaching functionally relevant skills within the natural contexts which evoke the proper behavioral responses simply means that teaching the sequences of behaviors (skill sets) necessary to complete a purchase in a store must be taught

see Barrier on page 41

Written Expression from page 1

views and opinions. This unawareness of an “absent audience” may result in writings that are not well-developed, or that lack elaboration.

- Weak central coherence, or a tendency to focus on small details, which can lead to an inability to understand context or see the “big picture,” causing difficulty with distinguishing important from unimportant details.
- Deficits in the areas of language and communication, which make compiling, expressing, and recording thoughts a challenge, resulting in a composition that lacks a clear, central focus, or that is poorly organized.
- Motor/coordination issues that can contribute to difficulty with handwriting and composing, resulting in brief writings that students are unwilling to revise or elaborate because it is physically “too difficult.”
- Deficits in several executive function components, including planning, cognitive flexibility, inhibition, and self-monitoring (Hill, 2004), which directly impact an individual’s ability to maintaining his/her focus on the process of developing a main idea and details to support the topic, and to encourage engagement and continuous motivation throughout the writing process.

How Can You Help?

There are several steps that parents and teachers can take to help students with ASD improve their writing skills and allow them to be more successful in school and in their everyday functioning. Here are five simple tips that you can use to help increase the motivation and written performance of children with ASD:

Make the environment conducive to writing. The home or classroom environment can impact a child’s willingness to write. Be sure that the lighting and noise level are acceptable for your child, given his/her sensory needs. Surround the child in a print-rich environment by posting model letters, book reviews, and other types of writing around the home or classroom. Teachers and parents may also consider

**Kristie Asaro-Saddler, PhD**

providing alternatives to the typical pencil and paper. Vary writing implements to include items such as markers, stamps, stickers and magnetic letters, and allow students to work in a comfortable setting for them, as long as it is appropriate for writing (i.e. has a flat surface).

Create an audience and purpose. Since deficits in theory of mind may impact children with ASD’s ability to write for an absent audience, it is helpful to create an audience for them. It is beneficial for students to know before beginning the writing process that there will be an authentic audience, besides just their parent or teacher, viewing their writing. Different genres of writing offer different options of potential audiences. For example, persuasive letters can be written to a principal, a parent, or the head of a company, whereas fictional stories can be written and shared with younger siblings or students in younger grades. Online blogs for people with ASD provide a natural context for writing, in addition to social and emotional support, and may be used by young adults with ASD and younger students who are supervised by parents or teachers.

Use interests and fascination. In school, students must eventually learn to write in response to a prompt their teacher gives them. However, in order to increase students’ motivation and fluency with writ-

ing, it may help to allow them to start writing about things in which they are interested. These are topics in which children usually have a desire to share information, along with a great deal of background knowledge. For example, a child with ASD who has an interest in digital cameras may write a “how-to” piece about how to take a picture with a digital camera, or a child with a fascination with trains may write a persuasive piece on why trains are a better method of transportation than cars.

Provide supports. Students with ASD may require various types of supports in the classroom or at home. Graphic organizers and semantic maps (visual tools designed to organize thoughts and represent relationships between them) may aid in the planning process (Sansoti, Powell-Smith & Cohan, 2010). Framed paragraphs, which are partially completed paragraphs with a number of blanks strategically placed for the student to fill in, may also be used to scaffold students’ writing (Kluth & Chandler-Olcott, 2008), along with word banks or drawings/pictures (Hillock, 2011) and story starters, which provide a statement to start the story, such as, “I went for a walk in the woods and I found...” that the student has to continue. Siblings or other students in the class can also act as a support for children with ASD through scribing (writing down what the student says aloud) or shared writing, where students take turns making a contribution to the written product. Peers can also help students with the revising process after their first drafts have been completed.

Use technology. Sometimes the physical act of writing makes it difficult for children with ASD to create written products. Allowing the students to use a keyboard or speech-to-text software may reduce the physical burden and allow students to express themselves in another way. Technology can also be used to help children organize their writing. Software programs such as *Kidspiration*® and *Inspiration*® and iPad apps such as *Popplet*™ for example, can be used in the planning stages to help students organize their thoughts before beginning to write.

Conclusion

While writing can be a challenge for many students with ASD, providing sup-

port may prove beneficial. The basic tips offered here can help increase students’ motivation to write, resulting in more frequent writing with less resistance, and ultimately, better written products.

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Behavioral from page 24

education classroom and should be viewed as a starting point in identifying the problem behavior. Research supports that functional behavioral assessments can help facilitate inclusion into the general education classroom. Additionally, functional behavioral assessments have been shown to be effective in decreasing problem behaviors and are also reported to increase appropriate behaviors, which in turn promotes inclusion.

Social skills training are another method that has proven to be effective in helping to decrease problem behaviors and promote inclusion in the general education classroom (von der Embse et al., 2012). Social skills that are taught through games have been shown to decrease inappropriate behaviors, while generalizing these ac-

quired skills to new environments. Video modeling and social stories are other social skill strategies that have been used to teach positive social behaviors, and research supports that they have been shown to increase positive social interactions.

It is important for educators to use research-based methods to facilitate the inclusion of students with ASD in the general education classroom. The strategies that are outlined above are a stepping-stone in the right direction towards effective methods that work. It is important for parents and professionals to understand the barriers that may impede the process of inclusion and work towards viable solutions for families and educators.

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autism or contact YAI LINK for information and referral for services at 1-866-2-YAI-LINK.

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Advocacy from page 22

be happening in this day and age! This call often comes when there is a crisis.

- I usually spend time asking the parents or the young adult if they have their records together. *So many times a family has no idea that everybody else is going by those records except for them!* They do not understand what the records say, and they do not know how to use them to access the care and treatment their loved one needs!
- I usually need copies of the records so that I can write on them and highlight the red flags or important info I want to speak to them about. I will try and organize the originals in a binder so that they are all together and in some kind of order.
- I also use some tools and questionnaires of my own that help me learn about the specific ASD traits and/or skill deficits that may go unrecognized yet are key to helping the child be successful.
- I can usually spot where there may be missing assessments that the parents have not known to ask for, and these can be vital in helping them get a proper diagnosis and/or access the

services that they need. For example I am still surprised by how many children with autism have never had a language and communication evaluation which can be one of the main core issues causing behavior and emotional problems. A child with high functioning autism may speak at a very high level but with little give and take communication. Often times everyone assumes the child can understand and perform at that high level. Imagine 85% of the child's verbal interactions are being misunderstood or not understood at all? No wonder they are acting out or are depressed!

- I might then recommend some classes at our parent center. I might help the parent write a letter to the school district to request some of the key missing assessments. I might ask if the parent is interested in having some private testing done. I keep contact information for several agencies and doctors to make sure that the parents know what's out there and that there is some choice. Most of all I let them know they are not alone.
- Sometimes I am called to attend a school meeting. I hope to have read all of the child's records beforehand but sometimes that is not possible. Asking

for reasonable accommodations is what is needed many times but parents are unaware that they have that right or what some of the best accommodations are.

- I help the parents understand their rights in all of the systems.
- Sometimes I will involve other advocates such as an educational advocate, a legal advocate or a medical advocate. An experienced advocate should be able to say, "This is not my area of expertise," or "I don't know the answer but I will find somebody who can help."
- Many times a family is looking for a support group with others who are experiencing the issues for themselves and their children. This can help them find friends and not feel so isolated and judged.

An advocate's job is changing all the time. I am able to notice trends in the school systems or other areas. I know where the appropriate services can be accessed so that parents are not wasting time. I also know the tricks of the trade that nobody ever tells the parents. I try to create a network of support for families so they are not so isolated. Sometimes I work with extended families so they can

become accepting and supportive. I do my best to create advocates of the parents who seek me out so that they learn how to be the best advocate their child has.

My job has many rewards but there are still many serious challenges and frustrations too! If you suspect your child may have an autism spectrum disorder, I would encourage you to seek out an advocate. Ask what their credentials are; make sure you know what type of an advocate you are getting. Ask if they are well networked. Who do they work for and who else do they know that may be of help to you. Lastly, trust your instincts if the advocate is not a good fit for you and find one that is. It's ok to ask for references and to speak to more than one advocate. Autism is a complex lifelong challenge that affects the whole family in many ways - being alone should never be the way a family has to exist. Finding a good advocate will hopefully make the journey worth the effort and hopefully empower the family and person with autism be the best person they can be.

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Barrier from page 39

in the community in an actual store so that all of the naturally occurring cues that will facilitate long term learning are available. Teaching within natural contexts (the community) versus contrived circumstances (within the classroom) promotes flexibility and coping skills. Teaching in the community allows for repeated practice to function within societal expectations and leads to a successful immersion into the community in which the student is actually expected to function as an adult graduate of the educational system.

There are many indirect benefits of instructing within the community as well. One collateral benefit of teaching within the community is that the community members becomes educated regarding autism and the positive aspects and successes of these individuals. Teaching within the community also provides exposure to the natural supports that exist within the community that will aid the adult individuals who no longer have the resources they had available in the educational system supported by IDEA and the federal mandate to provide a meaningful education.

Of course, instructing within the community has challenges of its own, every approach does. Instructing in the community requires access to and acceptance by the community at large, sufficient financial and supervisory resources

to participate in community activities, and potentially presents liability concerns not ordinarily at issue when education is provided within the predictable, contained environment of a classroom. However, the research supports and common sense dictates that a community-based model of education has the greatest potential to lessen the challenges and increase the chances for developing a comprehensive, productive, functionally independent quality of life for individuals with ASD.

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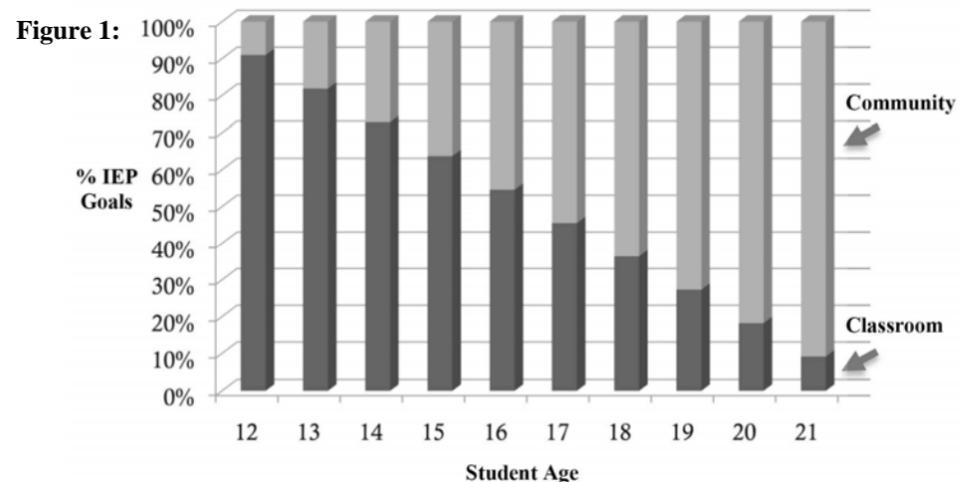
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The percentage of IEP goals (Y axis) focused on classroom-based academics or adaptive community-based, as a function of the age of the student (X axis)

Lifestyle from page 22

only for him but for the whole family.

Outside of school and home, in the community, the same instruction and supports are vital for my son to use those same skills we've taught him with other people and in community events. Our plans enable my son's continued gains in community settings, and this means greater participation in society, greater independence, and greater inclusion. Without plans to teach my son outside of home and school, he may manage through events and situations, but lacks the wherewithal to come to use the skills he possesses successfully.

This planned and purposeful approach to an "education of relevant real-life skills" by teachers and parent is a lifestyle for my son. He receives the same approach, the same assistance, and same expectations, from his educators and his parent. Without this lifestyle, my son would have learned what he "has to do in math class" and "this is what I do for my mother." He would not be performing as successfully in more abstract and generalized ways those life-skills that enable him to know "what I have to do here/now/anywhere" and "how do I figure that out" and "how do I communicate effectively for what I want/need" in spite of his deficits and difficulties. Our lifestyle approach of educators and parent teaching to the same expectations, the same goals/skills 24/7 has indeed taught my son that this is the performance/conduct/participation that "society" expects from you and this is how you can do it.

Simply put, his educators and parent together maximize the learning opportunities that exist in all environments, and with forethought, use a proactive approach that teaches him what we expect and what society expects, and provides him with supports that enable him to know for himself when and how to do as we expect. This is teaching him to participate in society to his greatest potential. This education is preparing him for success in life.

**What Does Education Involve?
Instruction and Motivation**

The expectation or lesson we provide is through direct instruction toward a predetermined goal, delivered proac-

tively (beforehand) not reactively, taught and practiced repeatedly, with supports if needed. In my son's case, we provide visual instruction and supports: written rules, task analyzed steps in a process, social stories, check-lists, etc. These are designed to teach and enable my son to know *by himself* what to do and when to do it; in other words, to promote self-sufficiency as the immediate goal. "Independence" is not an acquisition to hope for in the future. Indeed, his future independence will look different than that of his typically developing siblings and peers. However, he is as self-reliant today as he can be, and a lifetime of daily living as self-sufficiently as possible will build an adulthood of greatest independence as possible. This education we deliver, comprised of instructions and supports, is done so as to truly enable him today and to build on his everydays toward his future. As he has learned and grown through the years, our instructions and support, once very direct and frequent and prominent, are now much more subtle, delivered via iPad and cell phone for visuals and semi-remote supervision. His on-going experiences and successes will allow us to continue to broaden his use of supports so as to enable his greatest functioning, his greatest independence and inclusion in life's opportunities.

Incorporating effective motivation has been a crucial part of my son's development; to give him a good reason to want to do what it is we want him to do. My son has a diminished awareness of others and of what is socially-acceptable, and a diminished need to fit in. Properly encouraging him in a way that is uniquely motivating to him makes the world of difference in his desire to do as we are teaching. Having him meet our expectations, which are achievable, incremental and staged for success, in order to earn his preferred activities is an essential component in his growth. Interestingly and excitingly, this has also served to develop in my son a feeling of self-satisfaction, an enjoyment of socially interacting, and a response to typical reinforcers such as a smile, praise, or free time or money as a reason to do those things teachers or parent or society expects from him. Tailoring a motivation system for him has enabled him to meet our expectations and allowed us to con-

tinuously raise the bar on our expectations through the years with his successes; broadening his world and resulting in him wanting to do things just because he's meant to do them!

The educational instruction, including the use of supports and motivation, begun a decade and a half ago with the intent of increasing my son's awareness of what is going on around him and how he is expected to participate, are succeeding at that throughout the years. This has broadened his learning abilities in that he has developed skills that were once upon a time non-existent, and he's learning with greater ease in more "normal" ways. He is using his skills and rather charming personality, as well as his strengths and smarts, and meeting his tailored-academic goals, participating in school and community events, performing tasks for activities of daily living, and engaging in leisure/recreational situations and pre-vocational opportunities.

How Do We Develop the Relevant Real Life Goals in Home/School/Community?

Surely the most crucial component in education of my son with autism has been the collaboration of parent and educators (teachers and/or administration and/or behaviorists) so as to adapt a lifestyle that maximizes my child's learning and engagement.

Where did we begin? We used the same focus in the beginning as we still use today. We take a good look at my child and his functioning in any/all environments:

- We identify relevant real life skills that are needed in the home, school and community. Through the years this has included, but not limited to: compliance, imitation skills, observational learning, socialization, coping and ability to self-regulate, knowing what to do (visual supports), accountability, and motivation. We think about my child's needs and develop goals and objectives that are SMART – specific, measurable, attainable, realistic and timely. We then plan on how these skills can be taught in the school and home.
- We provide supports that enable my son to rely on himself. He uses these at school and home. These have been

picture schedules, written to-do lists, rule cards, social stories, vibrating watch alarms, point systems, reward systems, behavior contracts, iPad calendars, cell-phone text messages, etc.

- We motivate, at school and home, by giving access to items or activities HE wants contingent upon his meeting our expectations.
- We continuously monitor, assess progress or lack thereof, re-plan as needed and, very importantly, raise the bar with successes by adding more skills or broadening the use of current ones or finding more environments/situations for the skills to be used.

Where Do We Go From Here?

My son's education has been, and continues to be, with the intent of delivering the knowledge and skills to generally prepare him for his adult life. Through the years, I have looked for avenues and opportunities to broaden his world and provide rewarding experiences, personally, socially, pre-vocationally, and recreationally. I try to honestly assess his needs, and his choices, his preferences, so as to help find avenues for enjoyment and purpose, and to provide the structure and supports he needs in order to be successful and thrive.

In some ways I can say the potential is unlimited. This may seem inaccurate, based on my son's deficits, but I feel it's a personal outlook. I speak with a respect and faith in my son's abilities (not disabilities) and the lifetime of worthwhile and systematically-progressive education across broad areas in life, tailored always to my son's performance and success by building in strategies that enable him to achieve expectations and to succeed. He is thriving, living a happy and productive life to his potential, and his todays are leading him to a future of independence and inclusion in life in a way that works well for him. His education has made it so.

Marianne Clancy is the parent of a teenager with autism. She is president of the Autism AIMS LLC - www.autism-aims.com - and a board member of the Association for Science in Autism Treatment - www.asatonline.org.

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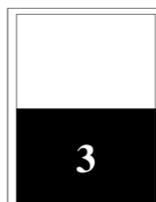
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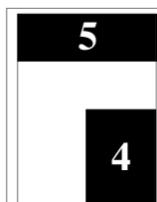
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