

## Supporting Adolescents with Autism

### The Importance of Self-Advocacy Skills for Adolescents on the Autism Spectrum

By Casey Schmalacker, BA  
and Samantha Feinman, MEd, TSSH  
New Frontiers in Learning

**S**elf-advocacy is the ability of an individual to speak on behalf of oneself, and is a critical skill to acquire when it comes to moving towards independence. Self-advocacy includes the quest for finding information, the process of making decisions, seeking help in times of need, understanding one's rights and responsibilities, problem solving as issues arise, and the ability to broadly incorporate these skills as necessary. As important as advocating for oneself is, it can be a challenging skill for individuals to develop naturally, and especially for those diagnosed on the autism spectrum.

Self-advocacy skills begin to develop at a very early age and continue to mature through adolescence and young adulthood, setting individuals up to have the ability to think and make decisions for themselves as they become less dependent on others. Individuals diagnosed on the autism spec-



trum, however, may have a difficult time developing such skills through general life experiences. Self-advocacy skills are made up of several different characteristics and skill sets, including self-awareness and un-

derstanding one's rights, communication skills, the use of executive functioning, and one's ability to generalize in novel situations. Such skill deficits, especially those in the area of communication, can act as a

barrier to students on the autism spectrum (Adreon & Durocher, 2007). In order to proactively set up individuals for success through high school, college, and beyond, it is necessary to teach self-advocacy skills explicitly during adolescence.

#### Why is Teaching Self-Advocacy Important?

There are many changes occurring during the adolescent years that require the development of self-advocacy skills. Further, once students reach the college and postsecondary environment, they are fully responsible for utilizing their self-advocacy skills to seek out the office of disability services on campus, disclose and provide documentation of their disability, and request specifically the testing and environmental accommodations they need. The same holds true for the career and employment environment as well. Because there is often a shift during middle school and a student's teenage years in which adolescents

*see Self-Advocacy on page 8*

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# Plugged In: Helping Teens with ASD Navigate Life with Technology

By Danielle Francois, MS  
and Shana Nichols, PhD  
ASPIRE Center for  
Learning and Development

Technology use is ubiquitous among today's youth (Rideout, Foehr, & Roberts, 2010). This probably does not come as a surprise because it seems that kids and their gadgets are everywhere. The current generation of youth has even been referred to as the iGeneration or the app generation. From 2004 to 2009, the proportion of 8- to 18-year-olds owning their own cell phone grew from 39% to 66% and the proportion owning an iPod or MP3 player jumped from 18% to 76% (Rideout et al., 2010). Today, these numbers are likely to be even higher.

## Youth with ASD and Technology

Although all youth are frequent users of technology, research indicates that youth with ASD are using technology even more than their typically developing peers. One recent study found that youth with ASD spent more time engaged with TV and video games than any other leisure activity and that their tech use out-paced that of their typically developing siblings (Mazurek & Wenstrup, 2013). Specifically, youth with ASD spent 62% more time watching TV and playing vid-



Danielle Francois, MS

eo games than in all other non-screen activities combined. However, the research also shows that youth with ASD spent less time using social media or socially interactive video games than their typically developing siblings.

## Risks of Technology Use

Unfortunately, youth with ASD are more likely to have problematic or addictive patterns of technology use and



Shana Nichols, PhD

are more vulnerable online. Researchers have found high levels of addictive video game use and Internet use among ASD youth (Mazurek & Wenstrup, 2013; MacMullin, Lunsy & Weiss, 2016). Among boys with ASD, problematic video game use was also associated with troublesome symptoms such as inattention and oppositional behavior (Mazurek & Engelhardt, 2013). Youth with ASD may be more vulnerable online than their typically developing friends. For example, youth with

ASD are more likely to encounter bullying, victimization, and social exclusion (Lough, Flynn, & Riby, 2015). Furthermore, interacting through digital devices comes with a distinct set of social rules to understand and abide by. Learning such rules could be another pitfall for teens with ASD.

## Benefits of Technology Use

Everything is not doom and gloom, however! Technology presents several unique benefits for youth with ASD. Online, youth with ASD can meet others and spend time researching and engaging with their special interests (Gillespie-Lynch, Kapp, Shane-Simpson, Smith & Hutman, 2014). They can form social connections in a different way and bond over mutual interests. One recent study described two important benefits of communicating via technology for people with ASD (Gillespie-Lynch et al., 2014). First, individuals have increased comprehension of and control over communication. A teen with ASD can take time to craft a reply via a text message or email. Second, there is increased contact with and social support from similar others who may be geographically distant. Mutually satisfying friendships can develop with others across the world.

see *Plugged In* on page 27



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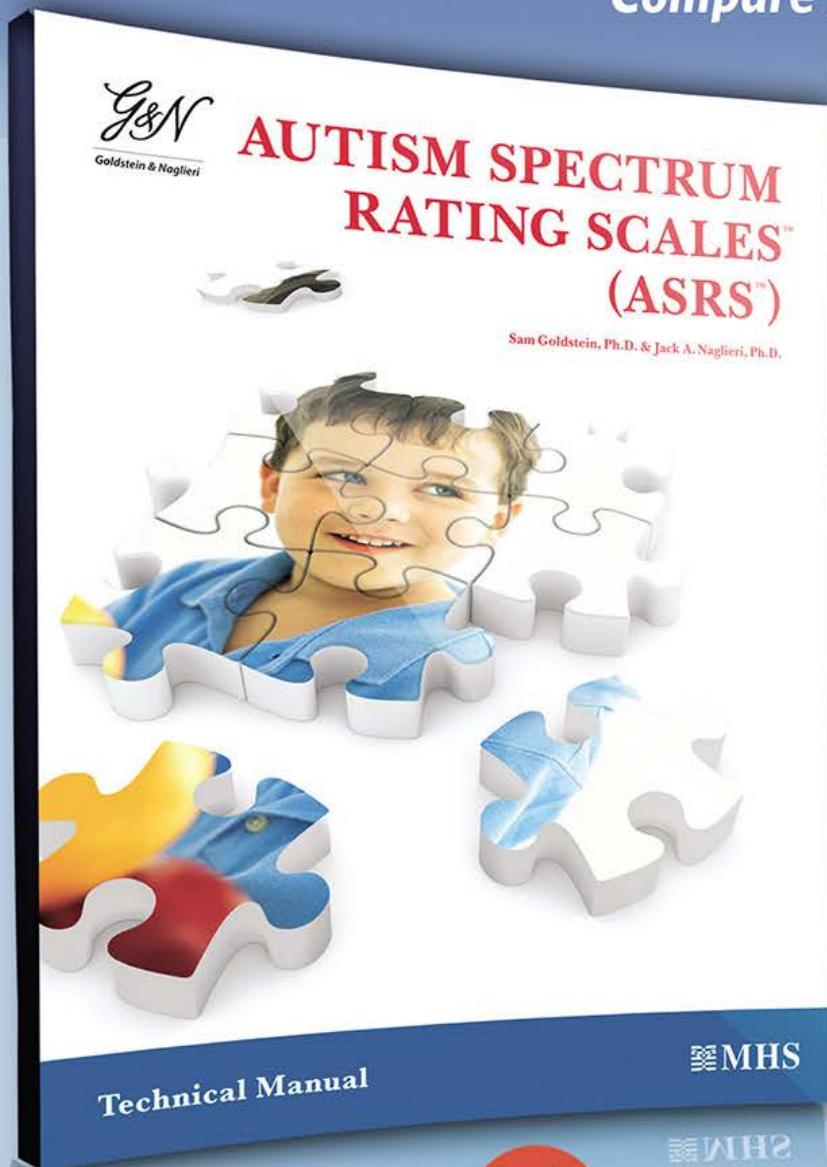
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## Addressing the Care and Treatment of Children with Autism Spectrum Disorders and Other Complex Disabilities

By Rebecca Girard, MSW, LCSW  
Children's Residential Program  
Developmental Disabilities Institute's  
Center of Excellence

There are currently 492 children living in 12 Children's Residential Programs (CRPs) in New York State. Children who live in residential placements often present with complex learning and behavioral profiles that require highly individualized care and support. Children with severe and complex autism experience difficulty in learning self-care and communication skills and are more vulnerable to a number of co-occurring medical and psychiatric conditions that make their care intensive, restrictive, and costly. Recently, New York State's Office for People with Developmental Disabilities (OPWDD) asked the following questions: what are the best ways we support children with complex autism in residential care? What are the various psychiatric, medical, and wellness profiles they are likely to have? What ways can we improve service delivery to ensure cost-effectiveness and optimal outcomes for these most vulnerable children?

To begin answering these important questions, a partnership was made possible through an award of federal Balancing



Rebecca Girard, MSW, LCSW

Incentive Program (BIP) funding administered through OPWDD, in coordination with the New York State Education Department and the New York State Department of Health to create three Centers of Excellence. The Children's Residential Programs (CRPs) at the Center for Discovery, Upstate Cerebral Palsy, and Developmental Disabilities Institute, in coordination with Cerebral Palsy Associations of NYS,

are engaged in a collective effort to identify best practices, develop new treatments and intervention strategies, and create infrastructure that will improve the quality and efficiency of care for children with autism and various complex needs. This includes several goals to define more effective and efficient supports for children and their providers in six key areas:

1. Create a centralized data repository
2. Identify best practices and quality of care models
3. Conduct applied research
4. Propose a value-based payment methodology
5. Establish a continuum of care and capacity building
6. Initiate a training and education program

### Centralized Data Repository

The COEs are developing an interactive, web-based data repository to improve information gathering and sharing with federal, state, and local agencies in an effort to provide more timely and cost effective approaches to care. Upon completion, this

data repository has the capacity to gather data relevant to the CRPs, clinicians, and others in the care and support of those with autism spectrum disorders and complex disabilities. The COEs are working to gather demographic, health, behavioral, and cost data, which will provide invaluable information for better understanding complexity, identifying supports and services, and cost of care. In addition, the COEs have begun work with Department of Health to review and capture all the costs associated with the care of children in CRPs in the data repository, with the primary goal of developing of a new model for reimbursement for the CRPs in New York State.

### Best Practices and Quality Care

Autism spectrum disorder, by definition, is a disorder with a wide-range of expression and no two children experience autism the same way. When a child is diagnosed with autism families and providers can expect an increased possibility of co-occurring medical and psychiatric conditions (Mannion, Leader & Healy, 2013) as well as additional challenges to the maintenance of overall wellness and independence. The children who live in residential placements frequently present a number of challenging

see Care on page 30



Developmental Disabilities Institute (DDI) was founded in 1961 to address the special education needs of children with autism and other developmental disabilities and provide therapeutic intervention. Today, DDI is a dynamic, non-profit, multi-site agency, each day serving hundreds of children and adults with autism and other developmental disabilities, providing educational, residential, habilitative, vocational, transportation and service coordination support to the Long Island community. DDI's Children's Residential Program is one of three programs in New York officially designated as a Center of Excellence for children with complex disabilities.

DDI's supports are as diverse as the people we serve. Through more than 50 years of sustained effort, DDI has grown substantially. Today, we are the leading service provider of services and programs for children and adults with autism across Long Island, and we are acknowledged by the State and among our peers for our unmatched expertise in supporting both children and adults with the greatest service intensity needs due to complex and challenging behaviors.



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# Technology Makes Things Possible

**By Jordan Jankus**  
**Coordinator of Person-Centered**  
**and Cognitive Supports**  
**Arc of Westchester**

*For people without disabilities, technology can make things easier, but for people with cognitive disabilities, technology makes things possible.*

“At some point, Max’s communication by text seemed so different from the past that I called my wife and asked her, ‘Are you coaching Max when he responds to my texts?’ He was responding with full sentences, when in the past it had been mostly ‘yes’ or ‘no’ answers to questions. That’s why I was surprised. But, in fact, my wife wasn’t coaching Max. It’s just that with expert training, he has gotten so much more comfortable with being able to text.”

- Bernard (Bernie) A. Krooks, Esq., Parent

Bernie’s anecdote about his son Max is a simple but moving example of the power of personal technology in transforming everyday life in our community today. It may not sound like a “big deal,” but for a parent of a child with autism or other developmental disabilities, communication through technology is life changing.



**From left: Max, Robin and Bernie Krooks practice their texting**

We are living in an age when technology offers enormous possibilities for communication – something most of us already take for granted. However, we have only scratched the surface of how these technologies can support people with autism and other developmental disabilities as they work towards personal goals and living more independently in the community.

Unlike many older assistive technologies, the devices at the heart of new technologies – especially smart phones and tablets – are small, portable, and do not mark a person as being “different.” This is a huge plus in protecting the dignity of the people involved, and in meshing seamlessly with the society around them. This is especially true for young people, for whom

peer interaction is so important.

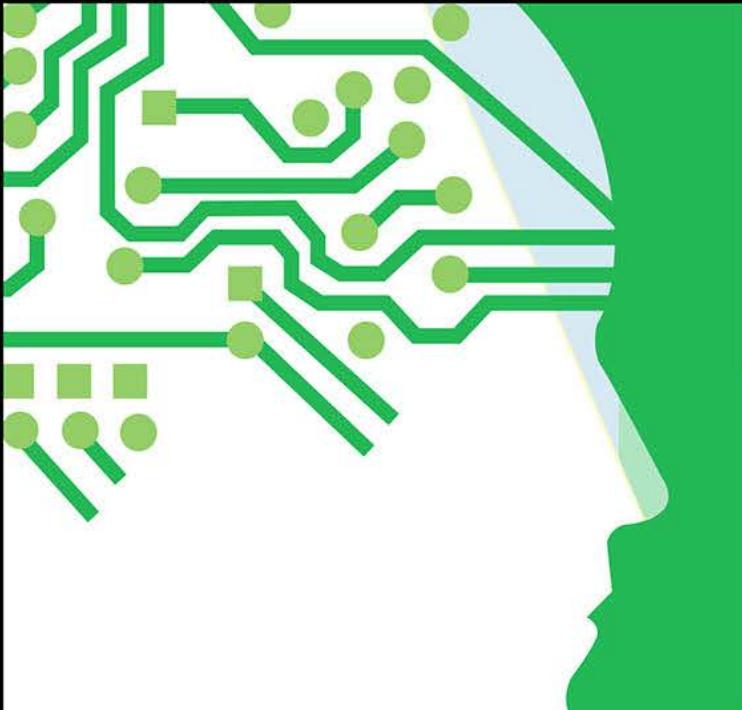
The key in the effective use of personal technology is to first identify the need, establish the personal goal, and then develop tech solutions to help address both.

Max’s developmental disability limits the use of his right hand. His parents and his three siblings wanted to more easily stay in touch with Max and he wanted to master texting, so he could connect with his family and friends.

We began to work on the predictive text capabilities of his MacBook laptop and then used the keyboard and voice-to-text features of his iPhone’s messaging app to develop efficient ways to send texts to his family. Remarkably, the more Max texted, the more his reading skills improved and he began to initiate communications and respond with more than one or two word replies. Now, his father says text exchanges with Max after school are one of the highlights of his day.

The Arc of Westchester is committed to applying these new personal and affordable technologies in creative ways to help people like Max reach their goals. It might mean using scheduling and task apps like *CanPlan* and *First-Then-Visual-Schedule* to help someone get ready for work in the morning or to remember the steps and timing of a job function. There are grocery buying apps, home chores apps, navigation

see *Technology* on page 34



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**Peter Blanck, Ph.D., J.D.**, is a professor at Syracuse University and author of *e-Quality: The Struggle for Web Accessibility by People with Cognitive Disabilities* (2014). Commissioned by the Coleman Institute, this exceptional book examines the rights of individuals with cognitive disabilities to equal access to web content protected under law.

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*Self-Advocacy from page 1*

become more resistant to parental support, adolescence is a perfect opportunity to begin the move from parents having the primary role as advocate for the child to guiding and shifting the responsibility to the students themselves. By using this drive of the adolescent to move towards independence as a teachable moment, it allows the parent, teacher, and/or coach to model for the student the types of support they have been utilizing with the goals of transitioning the ownership to the student. This is especially relevant to students diagnosed on the autism spectrum, as research has demonstrated that individuals diagnosed with autism spectrum disorders (ASD) may recall their own experiences less confidently than the experiences of others that they observe (Lind, William, Bowler, Peel, & Raber, 2014).

An emphasis on teaching and coaching a student to self-advocate should be a focus as early as adolescence so that students have time to develop a thorough understanding of who they are as a learner and what they need to help them learn most efficiently. Further, students need to debrief help-seeking scenarios in order to accurately identify situations in which they have the right and responsibility to ask for help, where to receive it, and how to follow through with putting it in place. Studies have demonstrated that when students learn from their parents and others, such as their teachers and peers, how to self-advocate early in life through role modeling, they are more likely to utilize those skills before and during their college years (Kimball, et. al, 2016).

**Casey Schmalacker, BA****What Self-Advocacy Skills Need to Be Taught?**

According to a model of self-advocacy as defined by Daly-Cano, Vaccaro, and Newman (2015), students with various learning differences, including ASD, can be taught to utilize self-advocacy skills proactively, reactively and retrospectively. The proactive view of self-advocacy teaches a student to seek out supports to be put in place prior to actually needing them. One example of proactive self-advocacy is when a student demonstrates that he/she is eligible to receive extended time on an exam prior to needing it and receives and schedules the accommodation. Rather than setting up accommodations for students

**Samantha Feinman, MSED, TSSH**

in middle school and high school, and for standardized tests such as the ACTs or SATs, students should be encouraged to be a part of the process. This can be practiced to obtain such accommodations for when it becomes their responsibility. Reactive self-advocacy occurs when a student seeks out help after facing a specific challenge. For instance, if a student for some reason is not offered the accommodations they are eligible for and do poorly on an exam, they will need to advocate for themselves the next time the opportunity arises. Retroactive self-advocacy occurs when a student advocates for support after they recognize they have not done well and need support moving forward. In both of these examples, this is where teaching and modeling

self-awareness, communication skills, and executive functioning become essential.

Here is the breakdown of skills needed in order to advocate from beginning to end to understand the whole process:

*Self-Awareness:* In order to self-advocate, it is essential to have a clear understanding of one's self and past experiences, current or upcoming situations, and potential solutions to the situations at hand. This includes:

- Understanding one's relative strengths and weaknesses
- Being able to identify when a problem is faced and recognize if the problem can be solved on one's own using a previously successful problem solving method or whether help is needed to solve the problem
- Identifying available resources and individuals who can assist with the problem

*Communication:* Once an individual recognizes that they need help, they have to be able to communicate their needs to others. Whether it is a co-worker, professor, or other professionals, individuals need to explain what they are struggling with and what help they are searching for. It is also essential to ask any questions to clarify what the next steps are to solving a problem. This includes:

- Reaching out and setting up a time for individuals to assist with the obstacle

*see Self-Advocacy on page 36*



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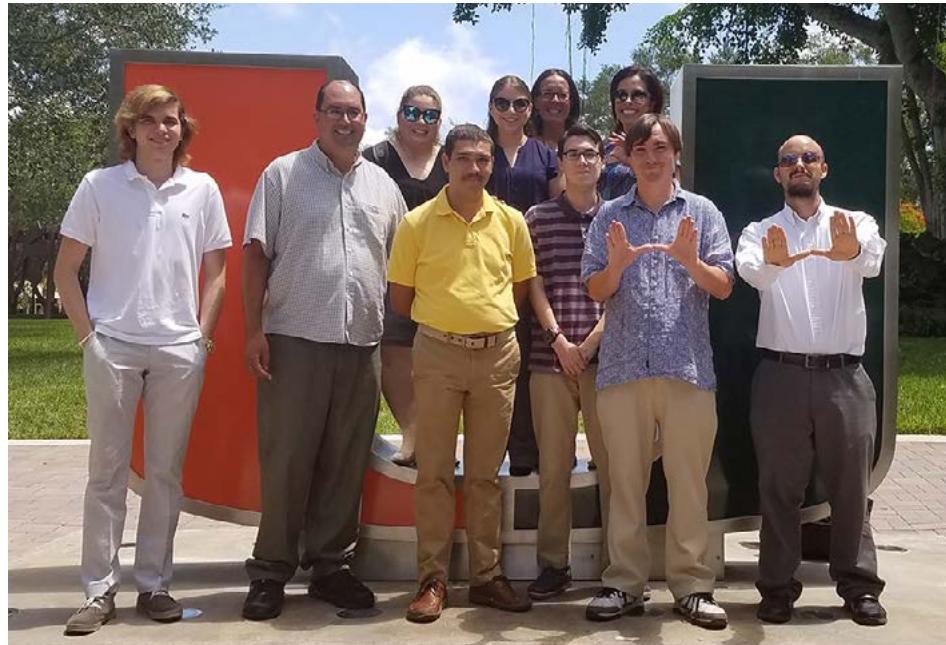
## Responding to the Changing Needs of Job-Seeking Adults and Adolescents with Autism

By Deborah Chin, MA  
The Daniel Jordan Fiddle Foundation  
Transition and Adult Programs  
University of Miami - NSU CARD

The process of finding, applying for and obtaining employment is one that is constantly evolving. These changes often present new challenges for adolescents and adults with autism and related disabilities. For providers and clinicians, this means it is more important than ever to evaluate the success of community programming and make adjustments.

Project EAARN (Employment for Adults with Autism Resource Network) began in 2010 as an employment initiative at the University of Miami-Nova Southeastern Center for Autism Related Disabilities (UM-NSU CARD). Through The Daniel Jordan Fiddle Foundation Transition and Adult Programs at UM-NSU CARD, the initiative aims to improve employment outcomes for individuals with ASD. In 2013, Employment Boot Camp was introduced as a core concept that would provide one-week of intensive employment training focused on helping adults gain the skills needed to obtain and maintain employment.

After offering Employment Boot Camps for 3 years, the facilitators recognized that



Job SEEKers at the University of Miami-Nova  
Southeastern Center for Autism Related Disabilities

the program's structure needed to be adjusted to meet the needs of the participants. To start, community members pointed out that the name "Employment Boot Camp" could have a literal, and therefore negative, connotation which could deter potential participants. While the team at UM-NSU

CARD agreed that using "boot camp" could be misleading, the feedback also prompted an evaluation of the program's entire structure. Through their assessment, it became apparent that the week-long intensive program was not allowing clinicians or participants to make the most of

the experience. From the clinicians' standpoint, the week of all-day Employment Boot Camp was exhausting and didn't allow time for homework assignments or thorough follow-up. Additionally, participants did not have time to reflect on the daily lessons and therefore weren't able to discuss questions or challenges that arose throughout the week. These factors, along with other observations, prompted the program's re-design.

The first two changes were simple and addressed the misleading name and intensive condensed format of the program. The team at UM-NSU CARD opted to name the program Job SEEKers (Seeking and Enhancing Employment Knowledge) and expand the format from one-week of intensive training to a once per week meeting over the course of 6 weeks. The changes allowed for additional areas of focus and hands-on instruction.

When developing the original curriculum, the team strategically selected the topics and skills to address in order to make the greatest impact for participants. Through the re-evaluation of the Boot Camp, it was apparent that original areas of focus were still relevant and necessary when addressing the unique needs of adults with ASD seeking employment. However,

see *Job Seeking* on page 28

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### This is what an adult living with autism looks like!

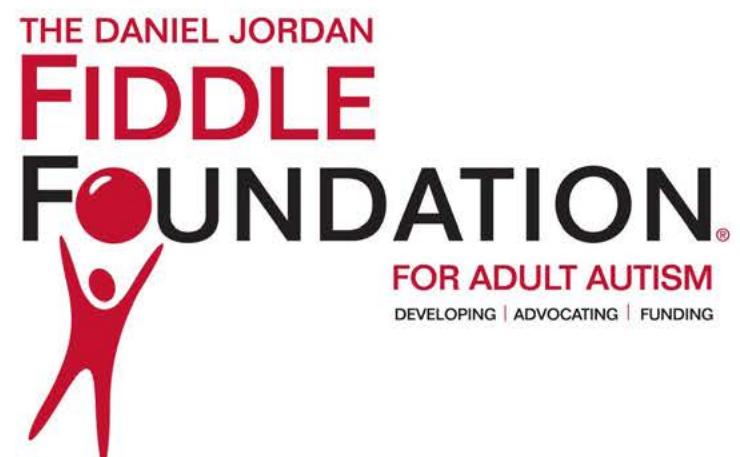
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## Finding David's Space

By Lucas Steuber, MA-T, MS, CCC/SLP  
Educational Technology Consultant

I want to share a story from my recent experience or, more accurately, a story about the long journey leading to the experience. As I'm sure many of you know, the job of a speech-language pathologist is hard sometimes, but those challenging days also make the work overwhelmingly worthwhile. I'm proud of this particular student's progress. I've never had a hand in anything quite like it and I may never experience an opportunity like this one again. I want to share it—not because of ego or of being creative or effective—but rather to share the magic that can happen from meeting kids in their “space,” metaphorically and physically, instead of asking them to come to ours.

### The First Three Buildings

Three years ago I met David, a middle school student with a complex set of needs. He has diagnosis of autism spectrum disorder, acute anxiety disorder and hydrocephalus acquired due to his birth mother's prenatal drug and alcohol use. He now has fantastic adoptive parents, but in the ten years the family was together before I met David, they'd never been able to persuade him to see a specialist of any kind. No doctors, no psychologists, no occupational therapist, physical therapist, or SLP. They couldn't even convince him to go into a school. Dental trips included full sedation and resulted in days of silence and agitation.

His situation was even more extreme. When I first met him, other than unconscious trips to the dentist, he'd only been three places since age five—home, a local aquarium, and Chuck E Cheese—and those last two occurred before or after hours by special arrangement and only involved wearing a mask for the entire trip. His main interests include fish and lizards—about which he's absurdly knowledgeable—Minecraft, and what I guess I would call “fantasy,” which in his case incorporates everything from superhero movies to documentaries about Bigfoot. Any deviations from this rhythm escalated to screaming, vomiting, incontinence and self-harm.

I met the family through some unusual circumstances, heard the story and offered to try and help David. They assured me he wouldn't come to my office and they didn't want to waste my time. I offered to come to him. For the first few months, I met him at the aquarium. I made it clear why I was there and how I wanted to help, but let him be the expert. He taught me about fish, frogs and other things I absolutely didn't know. Over time he pushed me out of my comfort zone pretty well, particularly in the snake-handling category (yuck), so I asked him if I could push him a little too—just not too far.

For the next few sessions, we met at Chuck E Cheese. We'd get there before opening and he'd use a watch to time each animatronic event, explain each one to me, show me the games and more. If staff got close, the mask came on—usu-



Lucas Steuber, MA-T, MS, CCC/SLP

ally of a gorilla or Mickey Mouse—and he'd go fully into character as a social defense mechanism. I started bringing LEGOs and small motor devices. Over a few months we built a model of the animatronic display. Then we built the rest of the restaurant and parking lot. Then we made little mini figures of each staff member and watched what they did, talking through why they did it, what they were probably thinking, or how they felt on an average day. Soon when those staff came over, David didn't put on the mask anymore.

### The Fourth Building

I happily witnessed growth in those few months, but we needed to move beyond the familiar. I started mailing letters to him at home with fragments of a Hogwarts-style invitation. There were parts of a map on the back to come investigate the wildlife outside his local middle school (this is Oregon, after all—there's wildlife everywhere). He was absolutely terrified, so I partnered with the school to take some photos and video that he watched at home to get familiar with the environment. One day his parents informed me he was on his way down there after the last piece of the invitation map arrived, so I raced down to meet him. For the next several weeks, we explored the woods around the school, then gradually started walking on the track, looking through the windows a bit, and one day, he finally went in through a back door to a cleared-out resource room wearing a mask.

### The Fifth Building

We started doing adapted academics with school support—like launching toy rockets in the soccer field to calculate distance or counting the number of bricks in a Minecraft house. Gradually I didn't always need to be right beside him, although it took months for the mask to go away. We eventually asked peer partners join in his

see *David's Space* on page 23

## Debbie Pantin and Robert Ring Named Event Co-Chairs of MHNE's June 29th Leadership Awards Reception

Staff Writer  
Autism Spectrum News

**M**ental Health News Education, Inc. (MHNE), the NY-based nonprofit organization that publishes *Behavioral Health News* and *Autism Spectrum News*, announced today that Board Members Debra Pantin, MSW, MS Healthcare Management, Chief Executive Officer, VIP Community Services and Vice Chair of the MHNE Board of Directors and Robert H. Ring, PhD, Adjunct Professor, Drexel University College of Medicine and member of the HHS Interagency Autism Coordinating Committee (IACC), have been named Event Co-Chair of MHNE's [Annual Leadership Awards Reception](#). The event, celebrating leaders making a difference in people's lives, will take place on Thursday, June 29, 2017 at 5:00 PM at the NYU Kimmel Center in New York City.

Honorees at MHNE's June 29th Leadership Awards Reception include: Donna Colonna, Chief Executive Officer, Services for the UnderServed; Gary Lind, Executive Director, AHRC New York City; Arlene González-Sánchez, Commissioner, NYS OASAS; and Dr. Fred Volkmar, Professor, Yale University Child Study Center. Constance Y. Brown-Bellamy, MPA,



**Debbie Pantin, MSW**

Board Chair of MHNE, made the announcement saying, "We are deeply grateful to Debra and Robert for accepting the position of Event Co-Chairs for our upcoming June Awards Reception. This year's event will be the first time MHNE will be honoring leaders from both the autism and behavioral health communities together. Ms. Pantin and Dr. Ring will serve as MHNE's ambas-



**Robert H. Ring, PhD**

sadors as we look to cultivate relationships and reach out for support in honor of our fantastic honorees."

Debra Pantin joined VIP Community Services in 2013 as the Associate Executive Director. She has over 25 years of experience in the human services industry, specializing in the fields of mental health, substance use disorder treatment,

homelessness, supportive housing, vocational and employment services, primary care, and HIV prevention and services. Leading agency-wide changes and managing organizational transitions are the hallmarks of Ms. Pantin's experience and reputation. Her professional experience includes staff training and development, and conference presentations and planning. She participates in various national, state, and local boards. Ms. Pantin has extensive knowledge of program development and services, as well as budget management. Most recently, Ms. Pantin served as the COO of Palladia Inc., a not-for-profit agency in New York City. At Palladia, she directed program and operational services, which collectively serviced approximately 17,500 clients per year; a staff of 470 employees, and an annual budget of \$45 million. As a key member of the leadership team, Ms. Pantin was tasked with influencing systematic changes. She campaigned key agency initiatives; Outpatient Substance Abuse Services and Mental Health Services, Quality Improvement processes - namely the NIATx (Network for the Improvement of Addiction Services) process, and the use of Data Driven Management. Ms. Pantin has been a driving force in educating her team, and staff in Health Care

*see Awards Reception on [page 31](#)*

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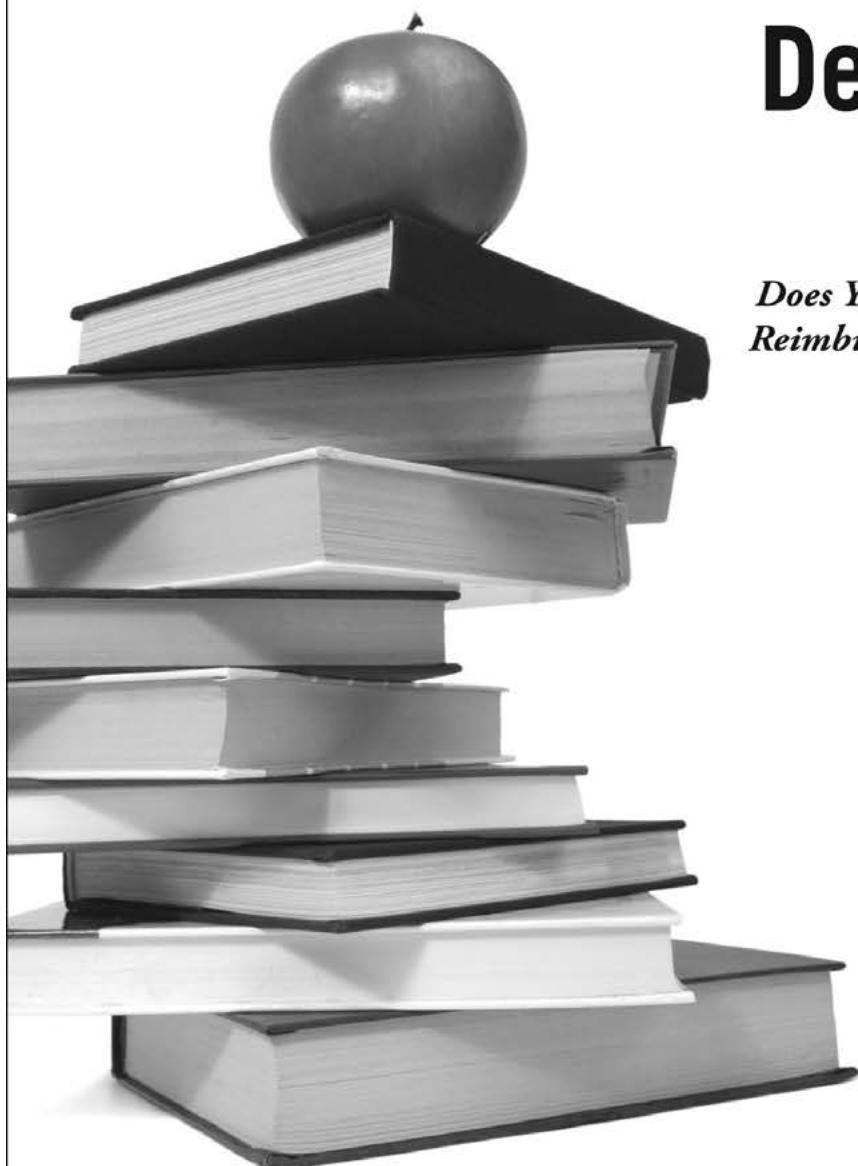
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## Providing a Safe Haven for Special Siblings

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

We know that, in most families, the longest lasting relationship one has is with his or her sibling. When one of those siblings has a special need, the dynamic of this lifetime relationship can be significantly impacted. For some, a brother or sister learns to quickly adapt to new routines of therapists in the home, multiple medical and therapeutic appointments, and a general disruption to the typical flow of a household. While some children adapt easily and quickly, this shift in family functioning can cause distress, anger, and resentment for many siblings. These overwhelming and confusing feelings may stem from the disproportionate amount of parental attention given, different expectations, and the sense of responsibility the “typical” sibling feels.

There has been much written about the impact of intellectual disabilities on siblings and families, and how such experiences shape family members in various ways. Blacher and Baker (2007) discuss three levels in which positive impact could be assessed. The first level is considered “low negative” and is characterized by the absence of stress, depression, and oth-



Suzanne Muench, MSS, LCSW

er forms of negative impact. The second level, “common benefits,” is noted to include increased sensitivity and tolerance of family members and improved family dynamics. Finally, the third level is “special benefits” and includes things that are uniquely experienced by families of individuals with intellectual disabilities.

Specifically addressing the needs of siblings, studies have shown there to be a mix of outcomes in terms of children who

are positively impacted, and those who are more negatively impacted. Angell et al. (2012) report positive outcomes may include increased social competence and self esteem while negative outcomes can include increased loneliness, anxiety, and problem behavior. Being able to support siblings in their feelings and experiences is not only integral to the continued development of self in these individuals, but also to the development of the relationship with their sibling throughout their lifetimes.

Having a place where the typical sibling can go to meet other children with brothers or sisters facing similar needs can provide a so-called shelter in what can seem like a storm for them. One such meeting place is Sibshops. Don Meyer developed Sibshops out of the Sibling Support Project in Seattle, WA. Meyer describes Sibshops as “pedal-to-the-metal events where children will meet other sibs (usually for the first time), have fun, laugh, talk about the good and not-so-good parts of having a brother or sister with special needs, play games, learn something about the services their siblings receive, and have some more fun.” Currently there are over 475 Sibshops in over eight countries. More recently, SibTeen programs have also been developed, as well as online forums utilizing social media.

Melmark in Berwyn, Pennsylvania has been running Sibshops for four years, and this year launched a SibTeen group. An average of ten children ages seven to twelve

come together once a month for two hours between the months of September and June. The group is a mix of fast-paced games to get the children moving and talking with one other, and more reflective activities to get them to think on a deeper level about their relationship with their siblings and families. When I first started the group, we spent a lot of time playing games, and I really underestimated the kids’ abilities and desires to have more in-depth conversations about what it means to have a brother or sister with special needs, and how that affects them and their families as a whole. Over the years, I have incorporated more time for these discussions, and have been pleasantly surprised at how the children rise to the challenge and really open up to their own feelings, as well as show empathy and concern for their peers. Last season we developed a newsletter for the siblings to discuss Sibshop and what it means to them. Jamie, a Sibshop participant, noted that she enjoyed Sibshop “because no one judged her by her sibling, and while the discussions can sometimes be uncomfortable, they are mostly helpful in helping to understand my own sibling, and be more helpful to others.” Discussions can range from how to cope with siblings’ challenging behaviors at home and in the community to worries about the future. Wise beyond their years, the exuberant group settles

see *Siblings* on page 22

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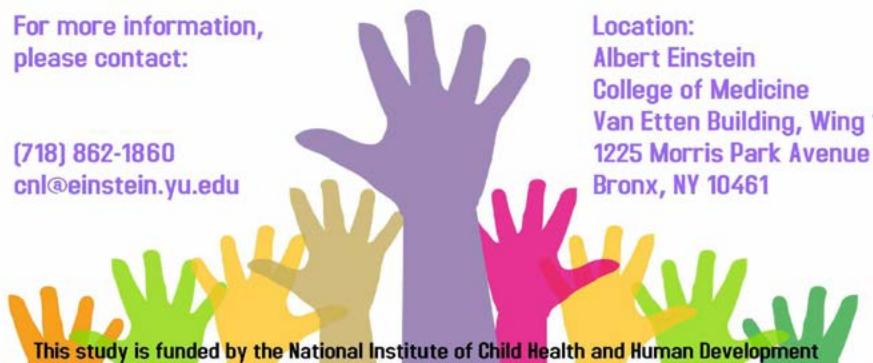
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This study is funded by the National Institute of Child Health and Human Development

## Facilitating Self-Advocacy for Adolescent Students with ASD Through Person-Centered Internet Sites

By Estefania Flores,  
Andrew Winfrey,  
AHRC New York City  
and James Lawler,  
PACE University

Adolescents with Autism Spectrum Disorder (ASD) who attend AHRC New York City Middle / High School (M/HS) in Brooklyn are engaged in an exciting collaboration with students from the Seidenberg School of Computer Science and Information Systems of Pace University. M/HS students are participating in challenge-driven opportunity projects with their peers who do not have disabilities, and they are exploring their hopes and dreams through person-centered internet sites. These projects, with the assistance and help of the students of Pace University, are facilitating a foundation for growth in self-advocacy.

### Coming to a College Course

The college course is a *Web Design for Non-Profit Organizations* entrepreneurial lab consisting of projects based on the goals of the M/HS students. The Seidenberg students are paired with M/HS students based on the affinity of anticipated



**Estefania Flores**

interests and experiences. According to Dr. Lawler, Course Professor, "The objective is to expand upon interests of the M/HS students and to create a project that reflects in-depth exploration of their preferred topics." Their interests are represented through person-centered, storytelling websites. The course consists of 24 M/HS students and 24 undergraduate Seidenberg students who meet for 3 hours on Tuesdays in the spring and fall semes-



**Andrew Winfrey**

ters of the university over the course of the academic year. The course, which is held at the Pace University labs, provides an opportunity for the M/HS students to experience the demands and the excitements of a college course.

### Developing Person-Centered Websites

The rationale for engagement through the formation of the websites is derived



**James Lawler**

from a disciplined methodology (Felder, 2012). The content of the sites is formed from generic interests articulated as "brag nuggets" (Klaus, 2012) in categories such as culture, entertainment, history, politics or sports. For example, the M/HS students may identify Dr. Martin Luther King, Jr. as a culture exemplar, Hillary Clinton and gender rights as a political model, or

*see Internet Sites on page 29*

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# Walking the Tightrope: Promoting Success in the Adolescent with ASD

By Shuli Sandler, PsyD  
Clinical Psychologist  
Private Practice

It is tough being an adolescent. Adolescence is a time fraught with changes at many levels. Physically, the body is growing and changing, evolving from the body of a child to an adult, and becoming physiologically capable of bearing children. There is a tremendous surge of hormones that allow for many of the physical and sexual changes that can affect the adolescent's mood and sense of stability. Socially, there is an evolution of many of the friend groups, with complicated social dynamics that shift from the more straightforward experiences of the latency-age child. In addition, romantic and sexual feelings come to the forefront with a vengeance. As I said, it's tough.

It's also a tremendous challenge being on the Autism Spectrum. Two of the prominent characteristics of being on the spectrum are social difficulties and difficulties with being independent. Social difficulties characterize the individual with ASD from early on in life, but the difficulties can become more problematic as the individual enters middle school and later, and social relationships take on a more central role developmentally for all children. Similarly, while all children feel a desire to be autonomous and independent throughout



Shuli Sandler, PsyD

childhood to some extent or another, it becomes much more prominent in the adolescent phase. It is for these reasons that an adolescent on the Spectrum likely will have a more difficult time getting through this time period because of the specific and unique challenges that being on the spectrum poses combined with the typical challenges that all adolescents face.

Despite these challenges, I find it grat-

ifying to work with adolescents and their parents during this time period. The time is fraught with the possibilities of the future, and the sense of accomplishment and success when the adolescent comes to a place of understanding or solidifies an aspect of identity. It is wonderful to hear him on a quest to understand himself while he struggles with questions and crises related to the formation of the self that are specifically unique to that time period. Once the adolescent grows into adulthood, there are fewer crises, but it is also harder to access these life questions and decisions. As such, this time period is filled with hope and certainty, but also frequently stress, and often a sense of drama and despair.

The challenge in working with adolescents on the spectrum is to support them in this developmental phase and help them work through the typical crisis of adolescence. This includes the quest for personal identification, independence, and the increased focus on social relationships, including romantic interests, while at the same time allowing for the unique challenges encountered. At times, supporting the unique needs of autism may seem contrary to some of these important goals of adolescence. Because individuals with ASD struggle with social relationships, it does not mean they do not have the same desire and interest in social and romantic relationships of adolescence. Similarly, even though the individual with ASD is

more reliant on parents and caregivers than their neurotypical peers, they still crave the desire for autonomy and independence as their counterparts.

As a result, parents and caregivers are in a unique position to try to promote the adolescent with ASD's developmental process consistent with all adolescents, while simultaneously supporting the unique needs related to Autism. Unfortunately, many well-meaning caregivers err on the side of squelching their desire for autonomy totting the Autism difficulties, or the opposite, in an effort to promote independence, give them too much freedom, not taking into account some of the difficulties their Autism presents. This can lead to much frustration and anger for the adolescent and caregiver. The caregiver can do a lot to help the adolescent get through this possibly rocky time and turn it into one of success.

Some parents may argue that their child is not capable of being independent and exercises poor judgment, citing examples where they "trusted" their child to set up a Facebook account or travel somewhere with disastrous results. My response is that everyone is capable of some level of independence, though obviously that depends on each individual's abilities and weaknesses. Independence is something that can be cultivated through teaching and modeling. A child who is taught how to

see *Success on page 28*

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## Parent and Adolescent Outcomes Following Participation in the PEERS<sup>®</sup> Program

By Laura L. Corona, MA,  
Erica Davis, LMSW,  
Jane Ann Worlock, MSEd,  
Melissa L. Rinaldi, PhD,  
and Kristin V. Christodulu, PhD  
CARD Albany

As youth with autism spectrum disorder (ASD) navigate the complex social world of adolescence, they frequently have difficulty forming and maintaining friendships. Past research indicates that adolescents with ASD report lower quality friendships than their typically-developing peers (Bauminger & Kasari, 2000). Adolescents with ASD also report higher rates of loneliness and social isolation (Locke, Ishijima, Kasari, & London, 2010). In addition, compared to parents of typically-developing adolescents, parents of adolescents with ASD report higher levels of stress during this period, partly attributed to the social difficulties experienced by their children (Barker, Mailick, & Smith, 2014). In recent years, the development of social skills programming targeted specifically at adolescents with ASD has shown promising results for both adolescents (Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012) and their parents (Karst et al., 2015).

Among available social skills programs



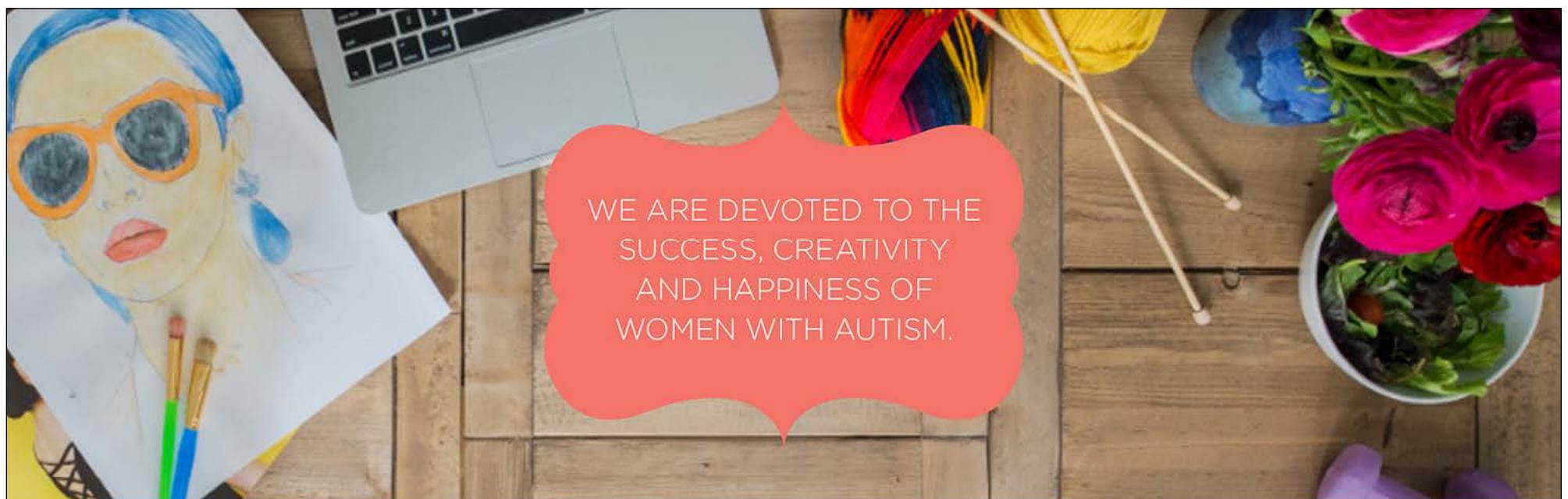
for children and adolescents with ASD, the Program for the Education and Enrichment of Relational Skills (PEERS<sup>®</sup>; Laugeson & Frankel, 2010) has garnered the largest evidence base (e.g., Laugeson et al., 2012; Schohl et al., 2014). The PEERS<sup>®</sup> program is a group-based, parent-assisted social skills program created for the purpose of enhancing social skills among adolescents with ASD. Parents and adolescents attend weekly, 90 minute ses-

sions over the course of 14 weeks. Adolescent sessions cover social skills including having conversations, entering and exiting conversations, electronic communication, use of humor, sportsmanship, and handling teasing, bullying, and gossip. Adolescent sessions follow a consistent format that includes homework review, didactic presentations from group leaders, modeling of appropriate social skills, and opportunities for adolescents to practice new skills with

one another while receiving coaching and feedback from group leaders. Concurrent parent sessions meet in a separate room and focus on strategies to support adolescent social skill development and practice. Weekly homework for adolescents provides opportunities to practice social skills between sessions.

The goal of the present study was to replicate prior findings from the PEERS<sup>®</sup> program and extend research on parent outcomes of participation in the program. Past research on PEERS<sup>®</sup> has reported positive outcomes for adolescents including increased social skills knowledge, social responsiveness, and social skills such as cooperation and responsibility (Laugeson et al., 2012). Initial research on family outcomes indicates that PEERS<sup>®</sup> also has broader impacts on parents and families, including reducing family chaos and enhancing parenting self-efficacy (Karst et al., 2015). Given the stress that parents of adolescents with ASD often report, parenting stress has also been examined among parents participating in PEERS<sup>®</sup>. Initial research by Karst et al. (2015) indicated no change in parenting stress following the program. However, this research assessed parenting stress broadly. It is possible that PEERS<sup>®</sup> may have an impact on specific

see PEERS on page 36



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## Promoting Student Independence and Successful Inclusion Through Systematic Use and Fading of Supports

By Amy Golden, MS, BCBA  
Behavior Therapy Associates

Being able to be as independent as possible often substantially impacts future success in all aspects of life (Causton-Theoharis, 2009; Hume, Loftin, & Lantz, 2009). Therefore, as a student moves through adolescence, it is essential for the educational team and family to place increasing emphasis on promoting student independence. This should be carefully considered when developing the individualized educational plan (IEP) for the student.

IEPs often focus on short-term goals and objectives projected for the year ahead, with supports and services to help the student achieve those skills. However, it is suggested that the IEP should be developed as a plan emphasizing independence, with long-term goals always on the forefront of the discussion. With this framework in mind, the team should focus on supports the student needs now to ultimately require less intrusive supports in the future. Goals for independent functional skills should be included in addition to those that are academically oriented. A variety of accommodations and modifications should center on promoting both student progress and independence (Asher, Gordon, Selbst



Amy Golden, MS, BCBA

& Cooperberg, 2010; Twachtman-Cullen, 2000). Areas of independence may include behaviors such as initiating tasks, transitioning between activities or locations, organizing materials, caring for one's own daily needs, and more.

Paraprofessionals are routinely assigned to support students with autism spectrum disorders in the school environment (Gi-

angreco, Halvorsen, Doyle, & Broer, 2004). There are many clear advantages and disadvantages to this approach. Paraprofessionals often provide the assistance students require to access less restrictive settings. Some of their responsibilities may include taking the lead for implementing behavior plans, gathering important information about the student's skills and deficits, promoting social interactions with peers, and collecting data (Twachtman-Cullen, 2000).

A key advantage of the use of paraprofessional supports includes the ability to promote generalization for the student across environments. Having detailed knowledge of the student's abilities and challenges allows them to plan ahead as well as prepare to assist the student in new situations and settings. While these are all reasonable tasks and often necessary benefits, providing 1:1 adult assistance can also be considered most restrictive and significantly impact the student's autonomy. Peers may be less likely to approach and interact with the student due to an adult's presence (Giangreco, Edelman, Luiselli, & MacFarland, 1997). The student may engage in spontaneous conversation more readily with the adult, creating an unnatural division from the student's classmates. The potential for prompt dependency is also heightened when an adult is always present (Causton-Theoharis, 2009). Best

intentions to provide support for the individual may result in too much being done for the student or the use of intrusive prompts without a careful fading plan.

Therefore, prior to establishing the need for 1:1 staffing, a thorough assessment of the specific areas for support should be completed. Teams should convene to determine what they anticipate achieving by using 1:1 supports and review if these needs can be met more effectively in other ways to promote student independence (Causton-Theoharis, 2009). For example, students may benefit from using communication devices, technology, additional visual cues, peer modeling, and environmental adaptations. Additionally, providing teachers and paraprofessionals with more advanced training can encourage the use of alternative and creative ways to assist the student (Stockall, 2014; Giangreco, Edelman, Luiselli, & MacFarland, 1997). Instructing staff on the principles of applied behavior analysis, such as content included in the training for Registered Behavior Technicians (RBT), can improve upon educators' utilization of effective prompting and fading strategies (Behavior Analyst Certification Board, 2013).

Once 1:1 support is in place for a student, collecting data on the paraprofessional's

see *Independence on page 27*

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## Developing Independence: Teaching Goal Setting Skills to Adolescents on the Autism Spectrum

By **Monica E. Carr, PhD**  
Autism Specialist and Research Fellow  
University of Melbourne, Australia

**R**esearch conducted amongst the broader population has reported that goal setting is a teachable and effective support strategy, yet it is one that remains under-utilized by the Autism community.

The ability to live a meaningful life, with as little reliance on others as possible, is the aim of many families with a loved one on the Autism spectrum. As a result of the wide spread success of early intervention during the 1990's and subsequent school based supports grounded in Applied Behavior Analysis (ABA), many students diagnosed with high functioning Autism or Asperger's syndrome are today both capable and motivated to pursue tertiary education (Pinder-Amaker, 2014; VanBergeijk, Klin, & Volkmar, 2008).

As this growing group of adolescents and young adults often face challenges in accessing ongoing support, self-management training is of critical significance. The techniques necessary to independently focus on required tasks, achieve optimal productivity, and work towards their own meaningful life goals may be taught to many people on the Autism spectrum by



**Monica E. Carr, PhD**

drawing on goal setting literature. Empowering adolescents with the necessary skills to develop and achieve their own realistically attainable goals is an important, yet often overlooked, component of self-management support strategies.

The US Department of Education has long considered self-determination to be an important outcome for students with

disabilities (Algozzine, Browder, Karvonen, Test, & Wood, 2001). The Division of Career Development and Transition (DCDT) suggested that by the age of 14 years, students should be encouraged to assume a maximum amount of responsibility in planning their futures, to the full extent of their capabilities (Halpern, 1994).

Research conducted with students with various developmental or learning disabilities has reported that goal setting and goal attainment are important components of self-determination (Algozzine et al., 2001; Fowler, Konrad, Walker, Test & Wood, 2007; Konrad, Fowler, Walker, Test, & Wood, 2007; Palmer and Wehmeyer, 2003). The skills required to develop self-determination include developing an understanding of the relationship of time to goal attainment (Field, Martin, Miller, Ward, & Wehmeyer, 1998).

In the seminal literature on goal setting and task performance, Locke, Shaw, Saari, & Latham (1981) reported that in 90% of the studies, specific and challenging goals lead to higher performance than easy goals, "do your best" goals, or no goals. Locke et al. (1981) reported that goals affect performance by directing attention, and increasing effort, persistence and motivation. Locke et al. (1981) noted that in a supportive environment, and for individuals with sufficient ability, goal setting is most

likely to improve task performance when goals are specific, sufficiently challenging, feedback is provided to show progress in relation to goal attainment, and rewards are provided for goal attainment.

While evidence of success in teaching goal setting techniques has been reported in the literature for individuals with mental retardation or cognitive disabilities, a recent review of self-management interventions for students with ASD reported a paucity of goal setting research for students on the Autism spectrum (Carr, Moore, & Anderson, 2014a). Carr, Moore & Anderson (2014b) conducted a broader systematic literature review of goal setting research to address the knowledge gap regarding implications of goal setting for students with ASD. Their review was limited to single-case research designs (SCDs) to better examine the effects of individualized interventions, as is typical in special education research (Horner, Carr, Halle, McGee, Odom, & Wolery 2005).

Carr et al. (2014b) reported that, while the data set they developed from published literature provided preliminary support for the effectiveness of goal setting techniques in a wide variety of interventions, little SCD research on goal setting has been conducted with students on the Autism

*see Goal Setting on page 37*

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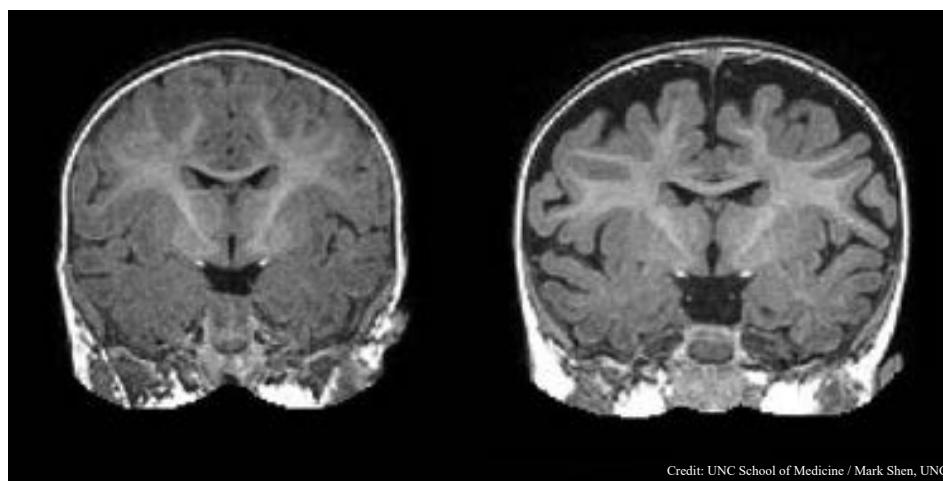
## Researchers Link Increased Infant Brain Fluid to Autism

By Mark Derewicz  
UNC Health Care

*MRIs show a brain anomaly in nearly 70 percent of babies at high risk of developing the condition who go on to be diagnosed, laying the groundwork for a predictive aid for pediatricians and the search for a potential treatment.*

**A** national research network led by UNC School of Medicine's Joseph Piven, MD, found that many toddlers diagnosed with autism at two years of age had a substantially greater amount of extra-axial cerebrospinal fluid (CSF) at six and 12 months of age, before diagnosis is possible. They also found that the more CSF at six months – as measured through MRIs – the more severe the autism symptoms were at two years of age.

"The CSF is easy to see on standard MRIs and points to a potential biomarker of autism before symptoms appear years later," said Piven, co-senior author of the study, the Thomas E. Castelleo Distinguished Professor of Psychiatry, and director of the Carolina Institute for Developmental Disabilities (CIDD). "We also think this finding provides a potential therapeutic target for a subset of people with autism." The findings, published in *Biological Psy-*



**Right: MRI of a baby at 6 months who was diagnosed with autism at 2 years. The dark space between the brain folds and skull indicate increased amounts of cerebrospinal fluid.**

**Left: MRI of a baby who was not diagnosed with autism at age 2.**

*chiatry*, point to faulty CSF flow as one of the possible causes of autism for a large subset of people.

"We know that CSF is very important for brain health, and our data suggest that in this large subset of kids, the fluid is not flowing properly," said Mark Shen, PhD, CIDD post-doctoral fellow and first author of the study. "We don't expect there's a single mechanism that explains the cause of the condition for every child. But we think improper CSF flow could be one important mechanism."

Until the last decade, the scientific and medical communities viewed CSF as merely a protective layer of fluid between the brain and skull, not necessarily important for proper brain development and behavioral health. But scientists then discovered that CSF acted as a crucial filtration system for byproducts of brain metabolism.

Every day, brain cells communicate with each other. These communications cause brain cells to continuously secrete byproducts, such as inflammatory proteins that

must be filtered out several times a day. The CSF handles this, and then it is replenished with fresh CSF four times a day in babies and adults.

In 2013, Shen co-led a study of CSF in infants at UC Davis, where he worked with David Amaral, PhD, co-senior author of the current *Biological Psychiatry* study. Using MRIs, they found substantially greater volumes of CSF in babies that went on to develop autism. But they cautioned the study was small – it included 55 babies, 10 of whom developed autism later – and so it needed to be replicated in a larger study of infants.

When he came to UNC, Shen teamed up with Piven and colleagues of the Infant Brain Imaging Study (IBIS), a network of autism clinical assessment sites at UNC, the University of Pennsylvania, Washington University in St. Louis, and the University of Washington.

In this most recent study of CSF, the researchers enrolled 343 infants, 221 of which were at high risk of developing autism due to having an older sibling with the condition. Forty-seven of these infants were diagnosed with autism at 24 months, and their infant brain MRIs were compared to MRIs of other infants who were not diagnosed with autism at 24 months of age.

The six-month olds who went on to develop autism had 18 percent more CSF

*see Infant Brain on page 31*

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

By Carrie Cariello

## I Know Why He Has Autism

**H**i, my name is Carrie Cariello. I am forty-two years old. I am married to a man named **Joe** and we have five children. Twelve years ago, I gave birth to a baby boy with a neurological disorder called **autism**. It impacts the way he eats, sleeps, talks, and thinks.

He is considered special needs, because his needs are special. For example, he needs to ask me thirty-six thousand times what the *plan for the day* is, even if it's just a regular old Monday and we've had the same plan every Monday since the beginning of September.

He needs to sleep with six pillows every night or he flips out at bedtime. He needs **medicine** to cope with his overwhelming feeling of fear and anxiety. He needs to roll all of his food between his fingers before he eats it, even meatballs.

I have a child with special needs. Sometimes, I can't believe it myself. I mean, it's easy to understand the *who* and the *what* and the *where* and the *how* of it all.

My child has autism and it is in his brain and his heart and his soul and his body. It is the result of a complicated mutation in **genetics** and DNA. Also, my in-laws. (I mention my in-laws here because I usually



Jack Cariello

try to blame Joe's side of the family for the autism gene. As you can imagine, this only helps to strengthen our relationship.)

And yet there are times when I don't understand the *why*.

Why did I, of all people, have a boy who needs medicine every night just to sleep and has to touch all of the food on his plate at the dinner table - a boy I hurt for and hope for and love so much that my heart

squeezes together?

I have to admit I don't spend a whole lot of time trying to answer this question because frankly, it's pretty pointless. It doesn't change anything. But every once in a while, when I'm feeling particularly pensive or sad or nervous, it flashes across my subconscious like a lightning bolt. It is bright, and hot, and I don't want to reach out and touch it because I'm afraid I'll get burned.

*Why me?* Why did God or the universe or the complicated twist of genetics give me a child with special needs?

Why do I have to think about the long-term effects of medication and wipe greasy meatball fingerprints off the counter every single day? Why do I lie awake at night, worrying about what will happen when I'm not here anymore? Maybe it was so I would stay married.

Oh, don't get me wrong, I love my **husband**. I have loved him for twenty-three years. I love that I know his favorite band is Rush and I love the way he stands at the sink in the morning and brushes his hair. I love the sound of his laugh when he hears a good joke, and I love that whenever we sit down in a restaurant and open the menu and there is calamari, I know that's what he's going to order.

There is no good way to explain the way autism has affected our marriage except to

say that it should have broken us. I mean, I don't know how it hasn't broken us already. It should have broken us, and we are somehow still standing. Perhaps the very thing that is trying to tear us apart has actually kept us together all this time.

I am a much different mother than I expected to be. I am the kind of mother who cares less about grades on a report card and more about teaching my kids how to load the dishwasher. I worry less about trophies on the mantle and more about kindness on the bus.

Perhaps God/the universe/genetics/my in-laws decided to give me a child with special needs so I would learn how to wait. The best things in my life so far are the ones I have waited for; an unexpected sentence, a surprise smile, a quick one-armed hug in the hallway.

The thing is, I will probably never know why I gave birth to a baby with autism, any more than I know why six is the magic number of pillows at bedtime. Some things in life are simply meant to remain a mystery.

But I do know that no matter how hard I think it is to have a child with special needs, it is a million times harder for him. On the days my heart is squeezing, this child's heart is shattering. When I am gasping for

see *I Know* on page 25



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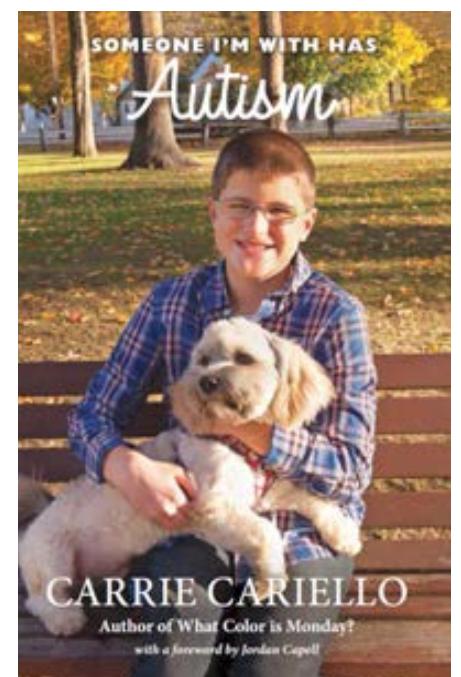
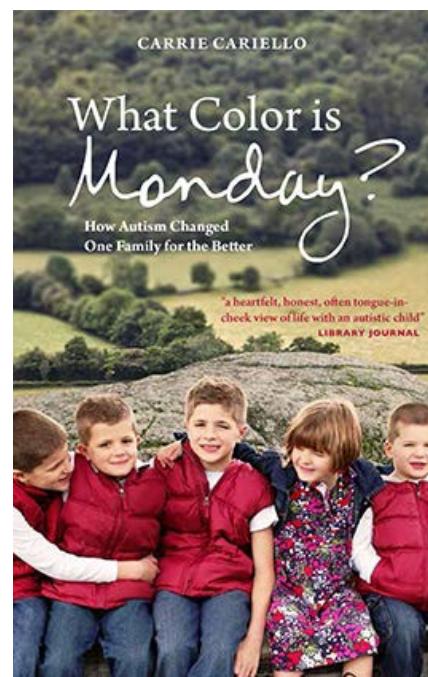
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## Berklee to Launch the Institute for Arts Education and Special Needs This Fall

By Tori Donahue  
Berklee College of Music

**B**erklee will launch the [Berklee Institute for Arts Education and Special Needs](#) in the fall of 2017. The institute will provide opportunities for individuals with special needs to learn about, experience, and create in the arts. It will offer community programs, learning opportunities for undergraduate and graduate students, professional development for teachers, and partnerships with international, national, and regional organizations.

This one-of-a-kind institute will further the impressive work led by [Rhoda Bernard](#), who will be its managing director, and build on the 10 years of Boston Conservatory's successful [Autism Spectrum Programs](#), which offer several arts education programs for individuals with autism: music classes for young children, private instrument lessons, dance classes, sensory-friendly theater and dance programs, and a choral ensemble for children and adults with autism as well as their family and friends.

In addition to local partnerships, the institute will expand its list of national and international relationships, which includes Music for Autism International, and United Sound.

Boston Conservatory at Berklee currently hosts professional development workshops and consultations on teaching the arts to students with special needs, and will



### Rhoda Bernard will lead the Berklee Institute for Arts Education and Special Needs

continue to expand these opportunities as it grows. Its annual two-day conference, Teaching Music to Students with Autism, will take place this year from April 28-29.

The recent merger between the Conservatory and the College provides the perfect opportunity to create this institute, and to bring the vibrant array of offerings in special education and the arts to the [Music Education Department](#) at Berklee. Students will be able to earn a Master of Music degree in music education (autism concentration) or a graduate certificate in music education (autism concentration).

"The Berklee Institute for Arts Education and Special Needs will create new opportunities to teach the arts to students of all ages with special needs," said Bernard. "With this institute, we can serve a larger population who will benefit from arts education. These individuals face many challenges, but when they come to our programs, they are celebrated for their love of music and their artistic accomplishments. Our existing programs will continue to grow while we expose new teachers, students, and communities to the power of art for all."

Boston Conservatory at Berklee serves

as a leader in the field of music education and autism; the opening of the institute will create new opportunities to expand its focus into additional areas of special education. The Conservatory was the first performing arts college to offer private music lessons to individuals on the autism spectrum in 2007 and, under the leadership of the Conservatory's external relations director, Kim Haack, was first school in Boston to present autism-friendly performances in 2013. In 2015, it was also the first conservatory in the nation to launch graduate training programs specifically in music education and autism.

*This article has been reprinted with permission and first appeared on March 1, 2017 at [www.berklee.edu/news/fall-berklee-institute-arts-education-and-special-needs-opens-its-doors-students-educators-and?ss=203706](http://www.berklee.edu/news/fall-berklee-institute-arts-education-and-special-needs-opens-its-doors-students-educators-and?ss=203706).*

*Rhoda Bernard, EdD, is Chair of the Music Education Department and Director of Autism Spectrum Programs at Boston Conservatory at Berklee. For more information on the autism spectrum programs currently available, visit [www.bostonconservatory.berklee.edu/extension-programs/autism](http://www.bostonconservatory.berklee.edu/extension-programs/autism). For information on the Institute for Arts Education and Special Needs, please visit [www.berklee.edu/institutes/institute-arts-education-and-special-needs](http://www.berklee.edu/institutes/institute-arts-education-and-special-needs). To contact Dr. Bernard, email [rbernard@berklee.edu](mailto:rbernard@berklee.edu) or call (617) 912-9104.*



### Siblings from page 12

into discussions about what they worry and dream about, and what they hope for themselves and their siblings. The support, encouragement, laughter, and community the kids provide for each other serve as a great testament to the power of Sibshops to help meet these kids where they are and to allow safe space for the exploration of their feelings with no judgment or shame.

The SibTeen group started this year currently has five boys and girls ages 13-15, and all but one were a participant in the Sibshop program in previous years. Most of these teens also come back to help as Teen Helpers in the monthly Sibshop meeting and serve as role models for the younger children. We currently meet every other month from 6:00 p.m. to 9:00 p.m. to make

dinner together, play games, and then have time for a more lengthy discussion about a particular topic of concern. Not only are these teens having to deal with more complex fears and anxieties about their siblings, but they are also going through adolescence in a time when, more than ever, they are being judged and evaluated on a number of social expectations that are made that much harder when you have unique family situations to contend with.

Whether playing silly games, or delving into complex emotional thoughts about living with a sibling with special needs, it's clear that there are benefits to providing space for these children and teens to explore their feelings, both positive and negative. By allowing them the opportunity to share their experiences with others in similar situations, we can reduce the likeli-

hood that they will feel lonely and isolated. Hopefully, this will also allow them an increase in their confidence and self-esteem in other areas of life. Given the longevity of the relationship they will likely have with their sibling, starting it off on a solid foundation early on can help assure they will be able to support each other through whatever life may bring.

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## Empowering Parents: Caregiver Support for Youth and Adolescents with ASD

By Kimberly Bean, EdD,  
Barbara Cook, EdD, CCC-SLP,  
Ruth Eren, EdD, and  
Karen Meers, PhD, BCBA  
Southern Connecticut State University

Parents rely on neighbors, friends, family members and other caregivers to provide in-home temporary care, frequently referred to as “babysitting,” for their children while they attend meetings, run errands, and have some “couple” time away from routine family responsibilities. This can be a daunting challenge for parents of youth and adolescents with ASD for various reasons. Most typical individuals in this age group do not “require” in-home temporary care; therefore, there may be a lack of “sitters” available to care for this age group. Those available may be hesitant to care for an adolescent that is near the same age as them, and may be apprehensive based on their lack of knowledge of how to support an individual who may exhibit communication and behavior challenges. Yet these individuals on the spectrum cannot be left alone and more often than not, parents refrain from going out for lack of an appropriate “sitter” for their adolescent.

The following experience from a first year teacher illustrates this difficulty:

*During Ms. Porter’s first open house of her first year of teaching, she had planned*



*to welcome parents into her classroom to inform them about the life skills and vocational curriculum she would be using to teach their adolescents with autism spectrum disorder. To her surprise, only 1 parent attended the Open House, bringing along her 2 children. The parent immediately apologized to Ms. Porter saying “I am so sorry for bringing Johnny and Avery, but I have been unable to find a babysitter capable of caring for Johnny while I am out. Avery is okay with any*

*babysitter, but because of Johnny’s age, size and behaviors, it is just too hard.” Ms. Porter soon realized that this was true for many of her student’s parents, and why many of her parents were unable to attend that Open House.*

Social interaction and communication challenges associated with autism spectrum disorder (ASD) may result in an increased use of disruptive and non-functional behaviors, especially in the context of novel situations, such as those experi-

enced with a temporary caregiver, like a babysitter. The difficulty in understanding the function of these behaviors and their variability lead to frustration for those caring for children of all ages with ASD (McCann, Bull, & Winzenberg, 2015; Pottie & Ingram, 2008). Not only does this impact the temporary caregiver’s ability to be supportive, it results in additional stress for the parents. Mothers of individuals with ASD report higher levels of caregiver burden than parents of typically developing individuals and higher levels of stress or depression than mothers of individuals with other developmental disabilities; including Down Syndrome (Abbeduto et al., 2004; Lee et al., 2008; Pisula, 2007; Roper, et al., 2014). The behavioral difficulties of individuals with ASD play a role in the increased level of need for support for these parents (Siklos & Kerns, 2006). Mothers and fathers of young children with autism also report higher levels of stress related to their parenting responsibilities linked to these challenges (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Fortunately, we know that families who receive more respite care for their youngsters with ASD report lower levels of stress. Therefore, an increase in respite type services (i.e. in-home temporary support, babysitters) for families of individuals with ASD is indicated (Harper et al., 2013).

see *Empowering on page 26*





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### David’s Space from page 10

Minecraft games—virtually from within the building—after they received coaching on what to do and how to interact. Pretty quickly, the special education team started to come in and deliver lessons. Soon he went to school an hour a week, then two—sometimes with a peer partner physically next to him—until one day it was clear I didn’t need to be there anymore.

When he realized I wasn’t going to be present to support him, he went to his parents and asked if he could start going to my office. He’s been coming now for the past year. We’ve worked on everything from emotional regulation to general social thinking to how to interact with women in ways other than what YouTube showed him (my SLP-A was a saint). This was the fifth

building he’d voluntarily entered in eleven years—and yes, he still goes to school.

### The Sixth Building

For all the love he has of fantasy and film, David never saw a movie in a theater. His favorite character of all time is Captain America—he loves how brave he is, how moral, how he always knows the right thing to do, and how he doesn’t always wear a mask. I asked him if he would go see the newest movie with me and after long conversations and visuals about what a movie-going experience entailed, he agreed.

I called and miraculously arranged a special early showing where we could be alone thanks to the generosity of a chain theater manager (if anyone wants to know

the chain for a similar purpose, email me). David was bringing earplugs, fidgets and a weighted blanket, so in the spirit of again meeting him in his space and showing him his needs are OK, I brought mine too. We got popcorn and sat together in an empty theater, weighted down and muffled, where he watched the entire movie without leaving or asking for a break. It’s the longest I’ve ever seen him sit still. He was rapt. I leaned over a few times to check on him and actually got shushed—another first.

When the movie ended and he explained all the parts I (mostly truthfully) didn’t understand, I asked him if we could do something new again next week. David nodded and quietly replied, “What should we do, Mr. Lucas?” In reply, I got to say three words defining the very core of who I want to be as an SLP: “You tell me.”

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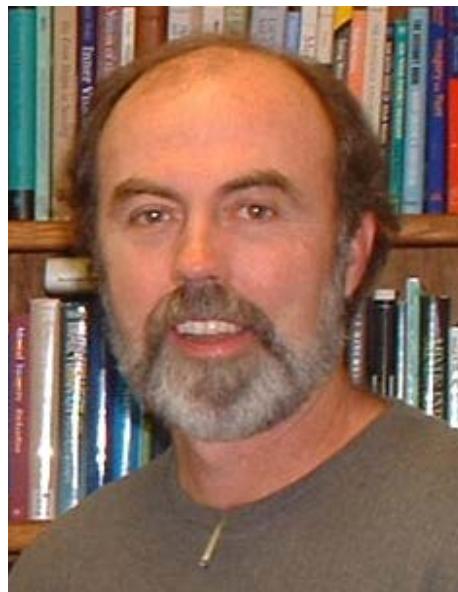
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## Better Language Comprehension Through Brain Connectivity

By Paul Worthington  
Director of Research and Development  
Lindamood-Bell

Autism spectrum disorder (ASD) impairs communication skills, impacting the ability to engage and interact with others. The deficits in communication skills impact classroom performance for students with ASD, since comprehension of the English language is foundational to success within the United States' educational system. With one in 68 persons diagnosed with ASD ("Data and Statistics," 2016, <http://www.cdc.gov/ncbddd/autism/data.html>), 42% of whom have impaired expressive and receptive language skills (Chan, Cheung, Leung, Cheung, and Cheung, n.d., <http://foa.sagepub.com/content/20/2/117.abstract>), a large portion of the student population is affected by this neurodevelopmental disorder.

The challenges of impaired language skills aren't limited to the educational performance. Many students with ASD also experience psychosocial problems that impact peer relationships as well as student-teacher interaction. However, language comprehension can be improved through a scientifically-based and research-validated method, offering a solution that addresses both academic and social concerns for those affected.



Paul Worthington

### Picture It

Language comprehension is a complex brain process involving multiple parts of the brain. The Dual Coding Theory (DCT) of cognition, researched and developed by the late Allan Paivio of the University of Western Ontario, stipulates that both visual and verbal representations of words, sentences, and paragraphs are necessary for memory and language comprehension. A person must be able to associate images

with words, and vice-versa, for effective cognitive processing to take place. Albert Einstein attested to this notion saying, "If I can't picture it, I can't understand it."

Only in recent years have language comprehension deficits been identified as a specific type of learning disability. Previously, the symptoms of comprehension deficits were acknowledged, such as poor recall or difficulty with expression, but the underlying cause was not. As a consequence, treatment was limited to "language only" strategies that attempted to mitigate and remediate the symptoms, instead of addressing the cause of the deficit—a deficit in being able to create mental representations (images).

### In the Classroom

All learning requires a basic foundation of language comprehension, regardless of the subject matter. Curriculum is delivered primarily through language-based media such as textbooks and oral instruction. Students exhibiting at-risk language comprehension skills are exposed more frequently under the assumption that repeated exposure will facilitate learning. However, when the brain centers do not adequately communicate, due to a weak or underdeveloped ability to generate images, no amount of repetition of content-based instruction will remedy language comprehension deficits.

### Social Impacts

Not only are students with language comprehension deficits prone to academic struggles, they also face related social and emotional challenges. They are likely to ask questions repeatedly, attempting to grasp information they do not retain or understand. Similarly, students with ASD fail to connect to the larger picture of the classroom objectives and are likely to make unrelated comments. Teachers may mistake these behaviors as intentionally disruptive and take disciplinary steps. Peers often find the behaviors offensive and distance themselves socially, resulting in alienation of the student with ASD.

### Finding Answers

The prevailing educational model requires students to demonstrate failure to access the curriculum prior to making interventions and accommodations via special education plans. Brain plasticity—the brain's ability to modify its structure—is at its highest capacity in childhood. This indicates the necessity of intervening as soon as language comprehension deficits are identified.

The need to engage in more effective ways to address language comprehension deficits is *essential* given the rise in ASD

see *Connectivity on page 34*

## The Face of Grief Before and After the Autism Spectrum

Leslie Wright-Brown, MS, RN-BC  
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My husband Cedric and I used to joke we should have known from the beginning our extremely introverted daughter preferred not to be bothered with the rest of the world. Despite trying to arrive early at 35 weeks, at 42 weeks labor was induced and Jordan arrived. I remember the nurse saying, "It's a girl, and she is beautiful!" Jordan's smile warmed the hearts of all around her. When she was five months old, I took her to a K-Mart Photography Studio to have her first formal portrait taken. While I entertained her so we could get a good picture, a small crowd gathered to watch the show. But by age three a change occurred. While at the photo studio, Jordan seemed fearful of the flashing lights. She did not smile at all during the session. In fact, she became terrified of a litany of things – falling leaves and snow touching her, the blacktop pavement at the pre-school, insects (flies in particular), popping balloons and the "Scream" character Halloween costume. She could not tolerate the "scary" section of the Halloween store. While eight months pregnant with the twins, her "blind" fear propelled her to release my hand, and without looking run across a street to escape a fly. She also ran from her classroom and yanked on



Leslie and her girls  
visiting Cedric's gravesite

the elementary school door to get out because she saw a fly. The only person she held a meaningful conversation with was me. A child psychologist told me children usually outgrow fears and phobias. I also attributed her introversion to the fact both my husband and I were quiet individuals. So at age twelve, her reaction of silence did not surprise me when I told her and my five-year-old twins in January 2007 that

my husband was diagnosed with cancer of the urethra, which quickly spread to the lymph nodes. By August 2007, there was metastasis to the bone.

A Child Life Specialist advised me no matter how difficult, in order to maintain trust, always be open and honest with the girls. While the twins cried at times, Jordan would just keep asking, "Is dad okay?" I responded, "He has cancer, but is getting medicine to treat it. He is okay right now." Simultaneously we had recently moved, and Jordan was attending the 7<sup>th</sup> grade in a new school district. Her grades went from A's at the prior school to D's. I came home one day and found her in a fetal position. She was being bullied at school. I contacted a pediatric nurse practitioner friend who referred me to a social worker. She became part of a weekly group with other girls who had been bullied. So, while taking my husband for chemotherapy during the day, in the evening the twins and I slept in a waiting room while Jordan participated in her group session. As my husband's health declined, I converted our family room into a "hospital suite." We began hospice in November 2007. One day, while the girls were in school my husband was admitted to the hospital for management of intractable pain. When they got home, I told them what happened. Staring at computer screen with mouse in hand, Jordan sighed and said, "Thank God. I need a break." She never looked up from the computer. Once Cedric became unre-

sponsive, I knew his death was imminent. I encouraged the twins to continue to play in the family room. Jordan stood outside the room saying, "I want to go in, but it's scary." I responded, "You don't have to go in if you don't want to, but Dad wanted to be home so he can hear your voice. He can still hear everything going on. Hearing you guys laugh makes him very happy." She smiled and we hugged. Forty-eight hours later Cedric passed away in February 2008. The first time I saw Jordan publicly cry was at the funeral.

Thirty-six days later, on his 47<sup>th</sup> birthday, the girls and I visited the cemetery for the first time. Both twins went to the gravesite. Jordan did not get out of the car. Two weeks after Cedric's death, Jordan wrote me a six-page letter discussing the emergence of an imaginary male friend named Jaime. Since Jaime appeared in February, Jordan said, "Although his real birthday was in February, I changed it to May, because February is such a sad month." Jordan then became a social recluse. She disclosed she had no friends in high school. Suspecting some delayed grieving, I took Jordan to see a licensed psychologist. After an initial evaluation, she stated, "I think your daughter is grieving, but I also think she has Asperger's Syndrome. Has anyone ever mentioned this to you?" "No," I responded. "What is it?" She gave me the book entitled *Asperger's and Girls*

see *Grief on page 37*

# Autism, Sexuality, and Postsecondary Education

By Laura Albee, MA, BCBA,  
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Stephen Monroe Tomczak, PhD, LMSW,  
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Approximately 50,000 students with Autism Spectrum Disorder (ASD) will turn 18 (Autism Speaks, 2012) with many high functioning ASD students completing high school in anticipation of enrolling in, and graduating from postsecondary institutions (Camarena & Sarigiani, 2009; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012; Cox, Mintz, Locks, Thompson, Anderson, Morgan, Edlestein, & Wolz, 2015). However, only 34.7 percent of high functioning ASD (HFASD) students will attempt college within 6 years of having graduated (Shattuck, Narendorf, Cooper, Sterzing, Wagner, and Taylor, 2012; Cox et al., 2015). Despite their academic preparedness, deficits in social reciprocity, communication, and stereotypic behaviors leave them isolated, ostracized, and misunderstood.

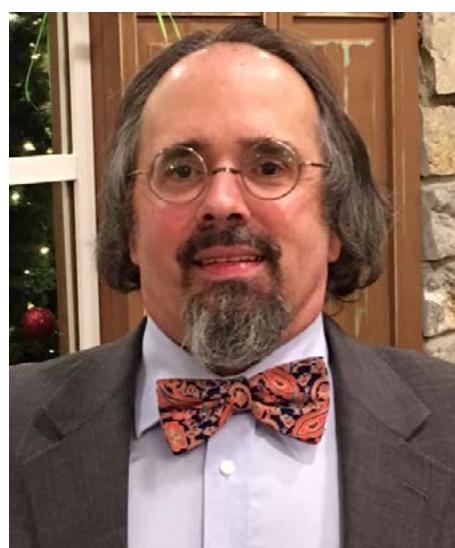
Research suggests parents remain present in the lives of their adult child with autism (Goode, Howlin, & Rutter, 1999; Howlin, Mawhood, and Rutter, 2000; Mawhood, Howlin, and Rutter, 2000; Szatmari, Bartolucci, Bremner, Bond, and Rich, 1989; Tantam, 1991; and Balfe and Tantum, 2010), with many reporting either living with their



Laura Albee, MA, BCBA

parents, or residing in supported residential settings (Greiart, 2016). Few described dating, having a significant other, or having intimate social experiences (Goode, Howlin, & Rutter, 1999; Howlin, Mawhood, & Rutter, 2000; Szatmari et al., 1989; Tantam, 1991; Greiart, 2016), and almost half of the adult participants according to Goode, Howlin, and Rutter (1999) reported having no friends (Greiart, 2016).

Social scientists have identified four distinct features including *social isolation* (the relative absence of social relationships);



Stephen M. Tomczak, PhD, LMSW

*social integration* (informal involvement with a spouse / partner, and the formal affiliation with religious, volunteer, or community groups); *quality of relationships* (emotional support of a significant other, and the stress impacting the relationship); and *social networks* (the constellation of associations surrounding the individual) as the impetus for overall health and well-being (Smith & Christakis, 2008; Umberson & Montez, 2010). By nature of their autism, including the absence of understanding the social rules of engagement associated with dating, romantic relationships, or everyday



Julie Piepenbring, PhD, LCSW

social exchanges, many individuals with ASD are put at a disadvantage. They often misinterpret the emotions associated with attraction and rejection, leaving them susceptible to committing an inappropriate act without the realization that what they are doing is wrong (Ray, Marks, & Bray-Garretson, 2004; Travers & Tincani, 2010). Unlike neuro-typicals who gain much of their knowledge through peer engagement in naturalistic settings, individuals with ASD have led more restrictive lives.

see *Sexuality* on page 38





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## I Know from page 19

air amidst autism's rising tide, this child is nearly drowning.

Underneath it all - the tantrums about a missing pillow and the small orange vial with the little white pills and hundreds of questions about the schedule, I know he's trying to tell me something else entirely.

## Make room for me. I am here.

The thing is, once in a lifetime, you get the chance to meet a person who is unlike any other person you have ever met. A person who is complicated, and honest, and tenacious, and pure. This person, well, he changes who you thought you were. And who you planned to become. He is traveling a lonesome journey of one, yet chang-

ing the lives of many.

He is a boy named Jack. He is my child. He is my son.

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

The viewpoints expressed in "The Lighter Side of the Spectrum" do not reflect the opinion of the Autism Spectrum News Editorial Board or the Publisher, Mental Health News Education, Inc. "The Lighter Side of the Spectrum" is intended as a means for self-advocates, family members and others impacted by Autism Spectrum Disorder to share their stories.

### Empowering from page 23

Parents have limited access to resources to help them cope with behaviors and communication difficulties due to extreme cost and time of intervention (Davis & Carter, 2008). As a result, increased resources to provide support within the home and community environments is needed (Schleien, Miller, Walton, & Pruett, 2014). Services such as baby-sitting and/or in-home care for individuals with ASD are increasingly being recommended for these families (Siklos & Kerns, 2006) and this additional in-home care needs to be from trained and trusted individuals (Thompson & Emira, 2011). One approach would be to provide training opportunities for both potential temporary caregivers and families to learn about ways they can support their young child or young adult (Cridland, Jones, Magee, & Caputi, 2014). Providing training and workshops for the primary and secondary caregivers, including in-home care providers, is a unique way to teach these individuals the essential strategies to use in the home during short-term care.

#### Sit for Autism

Referred to as *Sit for Autism*, our program was designed to teach families, caregivers, babysitters, and those who may serve as temporary care providers, general information regarding autism spectrum disorders. Content of the training emphasizes strengths and challenges associated with autism, common characteristics of individuals with autism, and explanation of key evidence-based practices to engage individuals with autism and reduce their problematic behaviors during short-term care.

The *Sit for Autism* program consists of one, 2 hour training session that blends lecture with hands-on activities. The initial part of the training involves the use of a PowerPoint presentation that shares information focusing on the common social, behavior, and communication characteristics of individuals with ASD. The second part of the training session includes instruction and modeling of the implementation of 4 evidence-based practices that may be used in the home or community setting. Participants are given a kit that contains these tools, including, a visual support for the use of the "Premack Principle" (Premack, 1959), visual schedules, a self-management tool to assist with transition, and a visual support choice board (Wong, et al., 2013). Example scenarios are reviewed and each participant is given the opportunity to

practice: (a) An individual may adhere to a specific routine at home that is unfamiliar to the temporary caregiver. The parent may support their child by arranging a visual schedule designed with pictures or written words of the activities that he or she will participate in while the parent is away. The caregiver is instructed to remove or erase each activity as it is completed to assist the individual in understanding what will be next as well as to support awareness that the parent will soon be home. (b) In a situation where an individual should complete a task of low preference such as a household chore, the caregiver is encouraged to use a First-Then card, writing "First vacuum, Then (favorite activity)." The caregiver is instructed to show this visual to the individual right before it is time to begin their vacuuming task. The caregiver would say "First vacuum, Then TV" while pointing to the visual support. Provided that the individual wants to watch a particular TV show, this should serve to encourage and motivate the individual to engage in the household task of vacuuming. (c) For time limited activities or those of least interest to an individual, the temporary caregiver is taught to use either a sound or visual timer to indicate when the activity will or must end. As soon as the timer rings, the individual is allowed to end the activity. (d) An individual may have increased anxiety with the parent away and struggle to access language to request choice. The temporary caregiver is encouraged to use a choice board that will have a visual representation of all of the activities, or food, that may be selected by the individual while the parent is away.

In addition to the evidence-based practice tools, the training provides the participants with a booklet referred to as the "Sit-Kit." This booklet is completed by the parent and includes critical information about the individual that will further support the caregiver in supporting the individual while the parent is away. The "Sit-Kit" is a modified version of a booklet designed by the Connecticut Lifespan Respite Coalition, Inc (2008), with permission from Joy Liebeskind. This modified version adds components that are critical for parents of individuals with ASD.

Over the course of a two-year period, a total of 112 participants of various ethnic and socio-economic backgrounds were included in the training sessions, including parents, family members, caregivers, and babysitters. During its pilot year, pre and post survey outcomes revealed that all participants were "satisfied" or "highly

satisfied" with the training program (83% highly satisfied). All participants would recommend this training program to others. *Sit for Autism* can be an effective training program for the family members, service providers, and caregivers of individuals with autism spectrum disorders.

Programs such as this type of training can provide those additional supports needed for families and community members to cope with and manage the severe and unique needs of individuals with ASD of any age.

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*For more information about Sit for Autism, contact Dr. Kimberly Bean at [bean2@southernct.edu](mailto:bean2@southernct.edu) or the SCSU Center of Excellence on Autism Spectrum Disorders at <https://www.southernct.edu/academics/schools/education/asd-center/>.*

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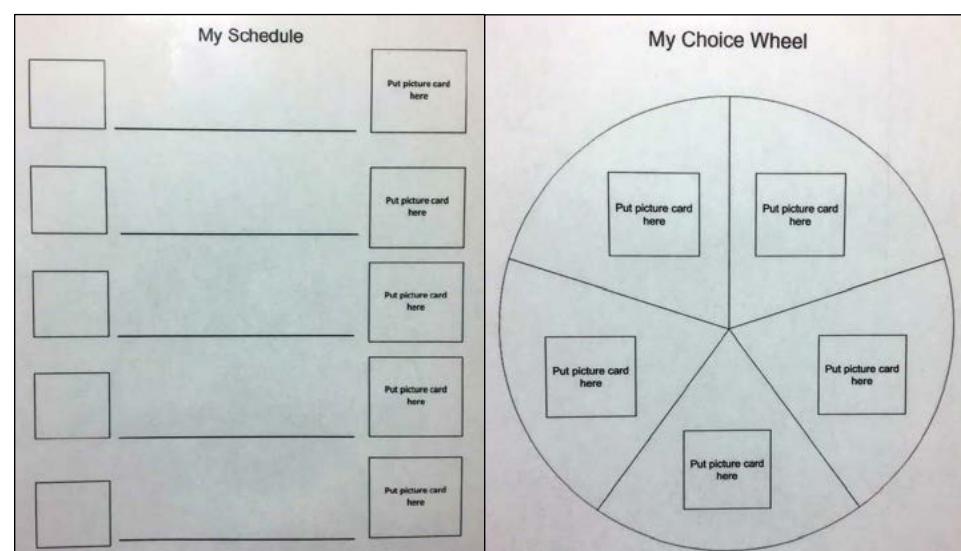
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*see Empowering on page 38*



Visual Schedule

Visual Choice Board

Communication		Behavior Support	
The best way to communicate with me is:		When I feel _____ I usually react this way:	
Things I usually say or do to get my needs met for:		How to handle:	
Toileting:		Helpful hints for calming me down:	
Hunger:		Things that usually upset me:	
Feeling tired:		How to handle:	
Feeling ill:		Things that get me excited, obsessive, attention:	
Playing:		How to redirect when I get stuck:	
Other:		Where to go to relax:	
Subjects I like to talk/hear about:	Subjects that should be avoided:	Special instructions:	

Sample page from "Sit Kit" Manual

**Plugged In from page 4**Tips for Parents  
and Professionals

So, how can parents and professionals help minimize the risks and maximize the benefits of technology for teens with ASD?

*Setting Rules and Limits* - Research has shown that setting rules and limits around technology use is very important. Youth who have rules and limits on their technology use spend less time engaged with their devices and show lower rates of problematic behavior (Engelhardt & Mazurek, 2014). The following are some specific examples of rules and limits (Engelhardt & Mazurek, 2014; Gold, 2015):

- Limit in-room access to video games
- Establish clear time limits for game and internet use
- Use a large timer that is not on a phone or computer
- Start giving warnings 15 minutes prior to shutdown
- Give reminders every 5 minutes prior to shutdown
- Help with the transition by clearly indicating what the next activity will be
- Provide encouragement when the teen is able to unplug successfully

*Guiding Appropriate Online Behavior* - You can help teens to have successful and satisfying interactions with others through technology. Explicit “dos” and don’ts” for technology etiquette can help demystify digital relationships for teens. The following recommendations are from Gold (2015):

- Help the teenager present his or her *real* self on social media and the internet
- Help the teen cultivate both digital *and* real-life relationships
- Encourage the teen to connect to real-life friends and classmates via texts and social media
- Encourage and guide online disclosure in moderation
- Encourage the teen to use the internet for self-expression and social connection
- If online interactions are making the teen anxious, encourage him/her to take a break
- Be wary of overdependence, excessive reassurance seeking, and preoccupation with online relationships.

*Attitude is Important* - How can you set limits and rules, and encourage appropriate behavior with your teen? What is the best way to go about all of this? Maintaining an open and curious attitude is crucial. Explore technology with the teen and be careful about using language that might be perceived as judgmental. Make it clear

that you are available should something confusing or concerning happen – the teen will not get in trouble for seeking help. Remember that for youth with ASD, socialization and communication can be experienced differently. Technology presents a myriad of new opportunities for youth with ASD to connect to others in ways that are comfortable for them. With your help, the teen can unlock a new world that plays to their strengths and potential.

## Resources

Want more? Check out *Screen Smart Parenting: How to Find Balance and Benefit in Your Child's Use of Social Media, Apps, and Digital Devices*. By Jodi Gold, MD.

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For more information, please visit our website at [www.aspirecenterforlearning.com](http://www.aspirecenterforlearning.com) or contact the ASPIRE team at [info@aspirecenterforlearning.com](mailto:info@aspirecenterforlearning.com).

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**Independence from page 16**

role can provide great insight into the student's ongoing needs. While it is customary to collect data focusing on student behavior, it is suggested that staff also self-monitor their own involvement with the student throughout the day. Sample content may include the types of prompts being used, the number of prompts required, and the proximity of the paraprofessional to the student. This information can be used to describe how the services are being used to support the student and point to areas in which the student requires further assistance. For example, if a student has consistent difficulty with unpacking and organizing his belongings each day, a visual list or schedule can be implemented to orient the student to the required tasks with the goal of gradually removing the adult from the prompt. The visual prompt can remain in place long-term and allow the student to work independent of adult assistance. Continuous documentation indicating the need for verbal prompting can signal a potential concern, thus leading to the development of new intervention strategies specific to promoting self-sufficiency for the student. Ongoing assessment should also help

to determine if the 1:1 support is needed throughout the entire day or just for specific subjects or activities. By reviewing the student's schedule and targeted needs across environments, the paraprofessional can be scheduled for support only when necessary. Thus, student independence can be promoted by fading the adult support from specific activities or subjects. Fading may be done gradually, with the paraprofessional taking increasingly greater steps away from supporting the individual in each setting. For example, a student may be accustomed to being escorted to the bathroom, between classes, or to the bus at the end of the day. A plan for promoting the student's independence would consider whether the student could learn to navigate these transitions on their own or perhaps with a peer. Rather than relying on the adult to prompt the student, alternate strategies should be investigated.

As educational teams plan how to support students, focusing on long-term goals for greater independence will serve a student well by preparing him/her for the future. Collecting data throughout the fading process can help to pinpoint any new concerns, allowing the team to consider novel strategies for helping the student and maximizing opportunities for self-sufficiency.

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## The Soft Skills - A Call to Remember the (Not so Easy) Steps to Success

**By Vicki Ofmani, MEd, LDT-C**  
**Supervisor/SLE Coordinator**  
**The Forum School**

**A**s we prepare our students for transitions from school to work, we put much emphasis on academics and trade skills. However, more and more, the employers are putting an emphasis on hiring individuals with the right soft skill set. For our students to be successful, we need to assist them in making this shift. It will be important to our students' learning of these skills to remember to showcase their individual strengths within the soft skills realm; looking at each independently. Some of the common soft skills that employers are searching for and some ways of addressing learning need to be taught similarly to how other tasks are taught to each individual student.

Let's start with professionalism. Like it or not, others make judgment about us within the first few moments of meeting. This appears to be human nature. In the workplace, employers and fellow employees hear what you say and observe how you look. Teaching our students to look professional is paramount. Putting their "best face" out-there should be a mantra. As with other areas that we teach, there is a correct and incorrect way of presenting a professional demeanor. *Skills to Pay the Bills* distributed by the US Department of



**Vicki Ofmani, MEd, LDT-C**

Labor and the Office of Disability Employment Policy is an excellent resource.

Then there's a positive personality. Common sense tells us that the important skills are those that impact all aspects of our life. A favorite excerpt from the book, *All I Really Need to Know I Learned in Kindergarten*, hangs in my office. One line catches my eye daily: "...share...play fair.

Put things back where you found them. Clean up your own mess....Live a balanced life – learn some and think some and draw and paint and sing and dance and play and work every day...." Soft skills aide in success in life no matter what one does. It is reasonable to believe that employers' statements are true: hiring friendly, high-energy positive people is their choice. If one is timid, defined efforts should be made to teach steps towards reality-based confidence. The caring part of a job should shine through, and this typically comes with a "good fit." A good match between the students' strengths and the job itself must be the root and planted firmly into a plan of instruction. Confidence comes with continued practice and good work being recognized. The student will pump up and get positive feeling flowing with each new experience. Showing true *passion* for a career comes with the belief that it is a job well done.

These positive professional skills flow over into other aspects of an individuals' life enhancing social life, post-secondary studies and allowing for more success in fulfilling and maintaining job choices. Hard skills may get a job, but the soft skills will keep it.

Preparation is something seldom considered as a standalone skill, yet if one is unprepared, it is assumed that one doesn't care. This can be summed up as work ethic. Equipping our students with the right

stuff is vital. It is a statement about who the individual is and the gift they have to share with the community. It is our duty to assist our students in finding that specific gift and preparing them to share it. We are equipping them for the future, just as much as reading for understanding, speaking so they can be understood, and listening actively. Our students can and must be instructed in ways that allow for responsible and thoughtful planning and decision making in the workplace. This doesn't mean always knowing the answer to a question - it means always knowing where (or whom) to go to for that answer.

Proving lifelong skills like reading and math calculations have always been the educational plan. Now, for our students' success we must lead them to be reflective and pliable. Job duties and requirements can change quickly; this is one of the most difficult of areas for our students to deal with. One may want to focus on one project, but circumstances may draw to another. Completion of one item at a time may not be an option. Employers want individuals who are able to accept change and adapt. Flexibility is necessary and knowing when to ask for assistance is just as essential.

Learning these skills is a process - across many environments. Observation of others is a beginning, so a model/imitation paradigm is encouraged. However, knowing

*see Soft Skills on page 35*

### *Job Seeking from page 9*

the team also concluded that there was potential to expand. In the program's original structure, the areas of focus included: personal care, creating a resume, interview skills, money management and social skills in the workplace. However, facilitators agreed that there were other aspects of job seeking that should be fully addressed.

By expanding the length of the program, facilitators and clinicians were also able to identify areas of focus that required additional time and practice. A frequent challenge that needed to be addressed was the technological side of seeking employment. As participants applied for jobs, they were numerous skills needed to complete the job search. For example, on most platforms, participants were required to create accounts with usernames and log-ins, keep track of passwords, and learn different methods of uploading and submitting materials. Most times, it was imperative for job seekers to understand and accomplish these

tasks in order to submit an application.

In the original structure of the Employment Boot Camp, social skills instruction was embedded in various activities with more formal instruction on the last day. However, facilitators recognized that despite incorporating social skills into the curriculum, participants needed more. Now, within Job SEEKers, clinicians facilitate an icebreaker to start each day and then transition to an hour-long social skills lesson. By doing this, the program is now able to thoroughly address things like small talk, interrupting, asking for help, and accepting feedback.

Additionally, with the expanded schedule, the team was able to address the need for more opportunities to apply learning by assigning homework and tasks between the weekly meetings. New topics such as deconstructing job posts to better understand eligibility and requirements were also added. In turn, adults in the program are able to receive more support and assistance with various aspects of the applica-

tion process. The slower pace of the program allows time for reflection, increased engagement among participants, and more opportunities for social interaction around what it means to be a job seeker.

As the clinicians and facilitators of The Daniel Jordan Fiddle Foundation Transition and Adult Programs continue to provide programming and support for adolescents and adults with ASD, they are reminded of the ever-changing needs of the community. To supplement the newly structured Job SEEKers program, the team has also created Job Club, which is a monthly support group to help adults who are looking for work or are employed. The group focuses on job searching techniques, networking, resume building, interviewing skills, and goal setting. These programs, along with support groups for caregivers, social opportunities for teens and adults, and a variety of workshops have been essential in creating connections in the community between families and constituents with similar needs.

Over the past three years, 56 adults with autism have participated in the employment programs at UM-NSU CARD. Forty-eight participants were contacted during the most recent follow-up in January 2017. Of these, 50% are employed at least half time and another 16% are in school and not seeking employment.

As the population of adults and adolescents with ASD and related disabilities continues to grow, the demand for programs is sure to follow. As with UM-NSU CARD, it is essential for clinicians and facilitators to consistently evaluate programs and employment trends in order to best support the growing population of employment seekers with ASD.

*Deborah Chin, MA, is manager of The Daniel Jordan Fiddle Foundation Transition and Adult Programs at the University of Miami and Nova-Southeastern University Center for Autism Related Disabilities. For more information, please visit <http://www.umcard.org/adults-asd/>.*

### *Success from page 14*

use the internet properly with a parent's involvement, at least initially, is being taught how to be independent. A parent who goes through the steps with a child to teach him or her to travel, which may include doing a dry run with them several times, then slowly phasing out, is promoting independence.

Similarly there are parents who believe their child has no interest in socialization. More often than not, when I have met these children, they are very much interested in social relationships but are afraid of getting

"burned" like they have in the past. This may be a time when social skills groups are valuable, not just in teaching social skills, but helping the adolescent forge social relationships. Parents can also be in touch with school personnel to help determine if there are particular students in the class that would be a good match with their child and facilitate interactions with that child. Romantic interests come to the forefront as well. Parents can be present to provide an open environment for questions on this topic, providing appropriate books, but also encouraging a sense of privacy as the

adolescent's body grows and changes with signs of puberty. I encourage parents to be proactive in this area and teach their child about puberty and sexuality in an appropriate manner so the child does not unwittingly engage in any socially inappropriate or embarrassing actions without understanding the social ramifications of what they mean. This continues to encourage a sense of personal agency in the adolescent.

There is nothing more exciting than watching a smile of success when an adolescent feels a sense of personal accomplishment, when he or she feels inde-

pendent, autonomous, and successful. It increases and promotes self-esteem and sets them on a good pathway toward adulthood.

*Shuli Sandler, PsyD, is a clinical psychologist. Among her areas of focus in her practice are children and adolescents with ASD and their families, as well as those who are experiencing a variety of difficulties in school, and young adults struggling with issues of achieving independence. Dr. Sandler has offices in Manhattan and Teaneck, New Jersey. She can be reached at [shulisandlerpsyd@gmail.com](mailto:shulisandlerpsyd@gmail.com).*

# Early Start: Preparing Adolescents for the Transition Years

By Lois Trusler, BSW  
and Todd Harris, PhD  
Devereux Advanced Behavioral Health

The transition years prepare adolescents for life as an adult, including living as independently as possible, securing and maintaining employment and effectively interacting in the community. Children with autism spectrum disorders approaching adolescence and their families are faced with great challenges achieving a successful transition. The best transitions begin with preparation long before adolescence, focusing on the acquisition of self-care and daily living skills that increase success in the school, home, and community settings.

Just as the most effective transitions center around a team approach that includes parents, educators, and specialists all focused on unified goals, the same philosophy will help children approaching adolescence succeed. This collaborative commitment helps foster a deeper understanding of the vastly evolving needs of a child growing into adolescence and supports a more comprehensive and inclusive approach to problem-solving across multiple settings the child will encounter throughout life.

Schools and educational programs can provide rich teaching environments, helping students develop skills within a



Lois Trusler, BSW

functional context, generalizing from the classroom to home and community (Harris and Trusler, 2012). As an example, wiping a table is a skill that can be taught in the classroom following snack, and transferred to the home to be generalized after family meals. Eventually the development of this skill can lead to the employable skill of setting tables in a dining room or restaurant in the community.



Todd Harris, PhD

## Instructional Considerations

Prior to instruction it is essential to determine what resources and supports are needed for success. Instructional strategies must be consistent with current evidence based practices, as outlined in the National Standards Project Phase 2, (2015). Examples of instructional considerations include:

- transportation and staff support needs;
- individual or group instruction;
- lesson formats (i.e. forward or backward chaining, total task presentation);
- appropriate prompting strategies;
- reinforcement procedures;
- visual supports;
- and ongoing data systems to assess student progress.

Routinely performed relevant and meaningful activities not only help students master skills, they also create a foundation for the transition years ahead. Opportunities for instruction in communication, social, and academic skills should be blended into all activities. Schools and educational programs are positive training grounds where students participating in a functional program can “begin to practice some of the skills that require intense training over an extended period of time for the student to succeed” (V. Lundine & C. Smith, 2006). When classroom teams are actively planning how to enhance the weekly class schedule by increasing in-situ instruction, the following should be considered:

see *Early Start* on page 32

## Internet Sites from page 13

Michael Jordon as a minority model in sports. This type of content has individualized meanings for the students. The design of the sites is based on the interests of the M/HS students and devised from bite-sized pieces of information posted in the labs and from posted prototyping sketches of storyboarding with the students, using different format styles for the websites (Lynch and Horton, 2016, & McNeil, 2014).

Once the design is finalized for each of the M/HS students, development of the pages of the sites is formed by a *Biography, Exemplars, Goals, Interests and Skills* format chosen from different Web layout tools (e.g., Weebly, Wix or WordPress). These tools are not difficult to use for either the Seidenberg students or the M/HS students. The interests expressed by the students are illustrated both in the information presentations and in the multimedia photographic formats (McNeil, 2014). These sites are formed further from diverse fun-to-play tools (e.g., iMovie and Movie Maker). “If the AHRC student has an interest in cooking, the Seidenberg student may, as a consequence of this interest, arrange interviews with chefs at local restaurants near the university,” according to Ms. Flores, the Transitional Coordinator of the M/HS. The interviews may then be posted on to the websites as videos. The sites are found on a cloud-hosted platform controlled by the M/HS for privacy and shared during festive presentations of the websites by the M/HS with the Seidenberg students at the end of the semesters during the year. Parents, school staff, and community mem-

bers attend these events.

The oversight of the collaboration between the two schools is the responsibility of the Professor, James Lawler at the Seidenberg School and the Transitional Coordinator, Estefania Flores at the M/HS. The professor monitors the projects via journal postings and project samples of the websites through an easy-to-learn e-Portfolio tool (i.e. Mahara), furnished by the internal technology department of the university. The Transitional Coordinator monitors the projects with the participating M/HS students.

Though most of the Seidenberg students are not familiar with students with ASD before taking the course, they are introduced to autism through disability literature, such as Suskind’s *Life Animated* and Grandin’s *The Autistic Brain*, furnished by the professor.

Most of the M/HS students are actively involved in creating and maintaining the websites with the Seidenberg students. M/HS students who have previously attended the program can update the sites during following semesters at the labs of the university. Since 2010, approximately 200 M/HS students and 200 Seidenberg students have participated in this program.

## Enabling a Foundation for Growth

The college course benefits the M/HS students by developing a foundation for further growth of their interests, which in turn promotes new opportunities for occupational skills. According to Principal Andrew Winfrey of the M/HS, “By furnishing partnership interactions with

Seidenberg students on personalized websites, the course is helping many of the M/HS students to be more imaginative and interested in possibilities within society.” Furthermore, he states that the Seidenberg students are helping the M/HS students to be more motivated about interests as a lifeline, an impact indicated in the literature (Heasley, 2017), through the websites. As storytellers, the M/HS students are also helping the Seidenberg students to become sensitive technologists in their interactions with a frequently neglected and misunderstood population of students. The course of *Web Design for Non-Profit Organizations* is engaging for all of the students in a journey of learning through storytelling on the Web. The course allows students first-hand experience in a college course and may motivate them to attend college in the future.

## Conclusion

Traveling to and attending a course in a downtown college in Manhattan is a big deal for the AHRC New York City M/HS students. They enjoy greatly the facilities of the state-of-the-art labs of the Seidenberg School of Computer Science and Information Systems of Pace University. The projects of storytelling and person-centered websites facilitate higher engagement of both groups of students, evident notably in impacts in improved self-determination and increased self-esteem for the M/HS students. In short, this unique journey embarked upon by the students on the autism spectrum, aided by the technology of AHRC New York City and Pace University, is a venture that may be replicated in

other similar institutions.

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## Promote Your Organization, Clinical Trial, or Event to Parents and Professionals in the Autism Community

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### Care from page 6

behaviors such as aggression, self-injury, irritability, and hyperactivity, for examples. The COEs are particularly interested in how the presence of unacknowledged medical and psychiatric comorbidities may contribute to severe and challenging behaviors for children with limited cognitive and language abilities living in our care.

Children with limited verbal skills and challenging behaviors have historically been understudied, and many co-occurring conditions go unacknowledged and untreated. Medical problems such as gastro-intestinal issues (McElhanon, McCracken, Karpen & Sharp, 2014), sleep disturbance (Mazurek & Sohl, 2016), eating and feeding problems (Johnson, Turner, Steward, Schmidt, Shui, Macklin, Reynolds, James, Johnson, Manning & Hyman, 2014), and obesity (Presmanes Hill, Zuckerman & Frombonne, 2015) are commonly associated with ASD. Common co-occurring psychiatric conditions include anxiety (White et al, 2009), AD/HD (Gadow & DeVincent, 2005, Lundstrom et al, 2015), Post-Traumatic Stress Disorder (Mehtar & Mukaddes, 2011), and depression (Simonoff et al, 2008).

Proper treatment begins with acknowledgment and accurate diagnosis. Children who are experiencing serious behavior challenges may also be experiencing undiagnosed medical or mental health conditions that need specialized treatment separate from interventions for autism and developmental disabilities alone. Research is being conducted at all three COE sites to develop valid and reliable screening instruments that will detect various symptoms in children who are unable to self-report. The use of sensitive screening can expedite proper treatment and prevent conditions from worsening over time.

There has also been extensive work on a comparing individual intervention models, exploring literature on evidence-based practices (including a systematic review of the literature), and identifying a group of

common practices that are utilized across all three centers. These practices will be shared statewide as a comprehensive clinical Resource Guide.

#### Education and Training Program

Information sharing and education of COE activities is essential as we hope to provide useful strategies and information to all agencies in New York State working with this population. Four, 30 minute online training modules are being developed to educate families, providers, and professionals to be made available free on OP-WDD's website. Modules include:

1. Medical Issues in Autism Spectrum Disorder
2. Autism and Co-occurring Psychiatric Conditions
3. General Wellness
4. Family Partnerships

The COEs have also utilized telemedicine technologies to interface with leading medical providers in the field and enhance the dissemination of cutting edge information regarding treatment protocol and best practice. The Centers of Excellence have utilized HIPAA-compliant cloud-based video conferencing to facilitate consultations, observe treatment techniques, demonstrate aspects of research projects, and provide training and education opportunities.

Two conferences will be held to discuss the latest research, epidemiology, and treatment of comorbid psychiatric disorders and ASD: May 19<sup>th</sup> at New York Academy of Medicine and June 7<sup>th</sup> at Stony Brook University.

#### Continuum of Care and Capacity Building

The Centers of Excellence have been assessing current discharge practices, identi-

fying opportunities for improvement in efficiency, and developing a comprehensive discharge-planning model. This includes developing discharge planning timelines that capture the steps needed for a child to age out at each of the COEs as well as identifying the challenges that hinder the aging out and discharge planning process. The data repository, once complete, will provide data to support COEs recommendations for a best practice model for discharge planning.

#### In Summary

All children deserve access to quality care and providers who understand their needs holistically, as the many facets of their care are intimately interconnected and only meaningful in reference to a child's whole self and lifestyle. Children deserve to have access to effective, accurate, and evidence-based treatments. The establishment of the Centers of Excellence in New York State is an ambitious initiative to improve care for children with autism spectrum and severe or challenging behaviors by better understanding co-occurring medical and psychiatric conditions and their impact on health and wellness outcomes, specifically through the reduction of challenging behaviors which may prevent children from learning, making friends, or living their best possible lives. The Center for Discovery, Upstate Cerebral Palsy, and Developmental Disabilities Institute hope to continue this work by being leading providers and sharing knowledge and resources through the implementation of best practices, engagement in research, training and education, and seamless lifetime transitions that provide fulfillment and positive relationships for the people we serve.

To learn more about the Center of Excellence at the Developmental Disabilities Institute, visit [www.ddiny.org](http://www.ddiny.org), e-mail [rebecca.girard@ddiny.org](mailto:rebecca.girard@ddiny.org) or call 631-366-2947. This article was prepared by Rebec-

ca Girard in her capacity as an employee of DDI. The opinions expressed in this article are the author's own and do not necessarily represent the opinions, interpretations or policies of New York State or the Federal Government of the United States.

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# The Road to Adulthood: Planning and Preparing for Transition

By Vanessa Pereira  
and Stephen Kumnick  
Vista Life Innovations

For families of adolescents with autism and other intellectual and developmental disabilities, planning for the future may seem particularly daunting. Parents are often faced with questions about what lies ahead for their son or daughter as they prepare to “age out” of their school district and transition into adulthood.

Perhaps the most pressing question at the forefront of a parent’s mind is what programs and services are available to assist their son or daughter’s transition into adulthood and develop the necessary skills required for adult life. But even before looking into transition programs and services, the student’s goals should first be established.

## Planning for Transition

It is never too early for parents and their sons or daughters to start planning for the future. Under the Individuals with Disabilities Education Act (IDEA) of 2004, transition planning must be included in the first Individualized Education Plan (IEP) that will be in effect when the student turns 16. However, the planning process can begin at an earlier age, if de-



Vanessa Pereira

termined appropriate.

The transition planning process should involve a team of people working together to establish the student’s goals for his or her future. This team—known as the IEP team—should include parents or guardians, the student, school personnel and other professionals who work directly with the student.



Stephen Kumnick

IEPs must focus on measurable goals of both an academic and functional nature. As such, it is important to involve the student in the process as much as possible. Any known interests, passions or personal goals should be at the heart of transition planning.

After goals are identified, the IEP team should consider the services and strate-

gies that are needed to assist the student achieve success as they transition from school to adult life. Factors include potential staffing requirements and one-to-one supports.

## Preparing for Transition at Home

If one of the student’s goals is to live independently or to share a home with a roommate, there are steps that can be taken within the family home in preparation. Parents can create increased opportunities for their son or daughter to practice tasks and skills that are necessary for independent living. These can include doing their own laundry, setting medication reminders, preparing basic meals, making grocery lists, and learning to complete basic household chores.

The key is to start small and focus on building routines and strategies where the individual is not dependent upon others. Practicing in the home provides the student with a safe and supportive environment in which they can make mistakes, and more importantly, learn from them.

Parents can also incorporate opportunities for their son or daughter to demonstrate their skills outside of the family home. As an example, the student can accompany their parents to the grocery store and select items off a grocery list they prepared.

see *Transition on page 32*

## Awards Reception from page 11

Reform. She brings to VIP her exceptional human services management experience and command of the critical policy issues of our times.

Robert H. Ring, PhD, recipient of the *Beacon of Hope Award for Advancing Autism Science* at the 2015 *Autism Spectrum News* Leadership Awards Reception, is a seasoned R&D leader with 16 years of experience spanning executive and technical leadership roles in the pharmaceutical industry, non-profit science foundations and venture philanthropy funds.

Ring most recently served as the Chief Science Officer of Autism Speaks (AS), a global science and advocacy non-profit celebrating over \$300M in awarded R&D funding targeting improving treatment, di-

agnosis and technological innovations for individuals with autism. Among Ring’s accomplishments at AS include the launch of an unprecedented genetics data-basing collaboration with Google called MSSNG ([www.mss.ng](http://www.mss.ng)), the establishment of the annual Autism Investment Conference, and the founding of DELSIA LLC, an innovative venture philanthropy arm of AS supporting newcos and entrepreneurial innovation across the autism space.

Prior to his tenure at AS, Ring served on the executive leadership team of Pfizer’s Neuroscience Unit, and was the director of big pharma’s first dedicated research program focused solely on developing first-in-disease medicines for autism and closely related neurodevelopmental disorders, including rare genetic syndromes such as Fragile X, Rett, Tuberous Sclerosis and

Phelan McDermid. Ring also served on the steering committee for Pfizer’s Asia Strategic Alliance for external R&D.

Appointed by HHS Secretary Burwell in 2015, Ring serves as a public member on the Interagency Autism Coordinating Committee (IACC), a federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder.

Ira H. Minot, LMSW, Founder and Executive Director of MHNE stated, “Our Leadership Awards Reception this June will celebrate our 18th year providing vital behavioral health and autism education to the community. We are very honored to have this opportunity to pay tribute to four outstanding leaders of community and hope everyone will come out in support of

their lifetimes of achievement.”

Registration is now open for MHNE’s June 29th event. Tickets, Sponsorships, and Journal Ads may be purchased online at [www.mhnews.org/AwardsReception.htm](http://www.mhnews.org/AwardsReception.htm).

About Mental Health News Education, Inc.

Mental Health News Education, Inc. (MHNE), founded in 1999, is the publisher of two award-winning print publications: *Behavioral Health News* and *Autism Spectrum News*. Both quarterly publications provide essential information, education, advocacy, and a roadmap to community resources for individuals and families coping with mental illness, autism spectrum disorders, and substance use disorder issues. To learn more, please visit [www.mhnews.org](http://www.mhnews.org) or [www.mhnews-autism.org](http://www.mhnews-autism.org).

## Infant Brain from page 18

than six-month olds who did not develop autism. The amount of CSF remained elevated at 12 and 24 months. Infants who developed the most severe autism symptoms had an even greater amount of CSF – 24 percent greater at six months.

Also, the greater amounts of CSF at six months were associated with poorer gross motor skills, such as head and limb control.

“Normally, autism is diagnosed when the child is two or three years old and beginning to show behavioral symptoms; there are currently no early biological markers,” said David G. Amaral, director

of research at the UC Davis MIND Institute. “That there’s an alteration in the distribution of cerebrospinal fluid that we can see on MRIs as early as six months, is a major finding.”

The researchers found that increased CSF predicted with nearly 70 percent accuracy which babies would later be diagnosed with autism. It is not a perfect predictor of autism, but the CSF differences are observable on a standard MRI. “In the future, this sort of CSF imaging could be another tool to help pediatricians detect risks for autism as early as possible,” Shen said.

Piven added, “We can’t yet say for certain that improper CSF flow causes autism. But

extra-axial CSF is an early marker, a sign that CSF is not filtering and draining as it should. This is important because improper CSF flow may have downstream effects on the developing brain; it could play a role in the emergence of autism symptoms.”

The National Institutes of Health, Autism Speaks, and the Simons Foundation funded this research.

Other researchers included Sun Hyung Kim, Hongbin Gu, Heather C. Hazlett, Robert W. Emerson, Meghan R. Swanson, and Martin A. Styner at the University of North Carolina; Christine W. Nordahl at UC Davis; Robert C. McKinstry and Kel-

ly N. Botteron at Washington University; Dennis Shaw, Stephen R. Dager, and Annette M. Estes at the University of Washington; Jed T. Elison at the University of Minnesota; Vladimir S. Fonov and Alan C. Evans at McGill University; Guido Gerig at New York University; Sarah Paterson at Temple University; Robert T. Schultz at the University of Pennsylvania; and Lonnie Zwaigenbaum at the University of Alberta.

This article is reprinted with permission. You may view the original article, published on March 6th, 2017, at <http://news.unchealthcare.org/news/2017/march/infant-mris-show-autism-linked-to-increased-cerebrospinal-fluid>.

**Early Start from page 29**

- What meaningful activities can be implemented in the classroom? Ideas include cooking and meal activities, recreation routines, self-care routines, and cleaning routines;
- What can students do outside of the classroom, but in the school? Ideas include exercise routines, school clubs, service learning projects, and school jobs in the cafeteria, office, library, grounds crew;
- What types of weekly community-based instruction can be included? Ideas include purchasing in stores, eating in restaurants, recreation, and community-based job training sites.

Parental involvement is essential in bridging skills from school to home. All resources and strategies used in teaching young students in the educational setting should be shared with the family for their continued use at home. Instruction, as necessary, should also extend to parents who may be unfamiliar with various practices that enhance skill acquisition.

**What Skills Should Be Targeted?**

Attaining skills in self-care, daily living, communication, self-regulation, and social skills promote overall success. It is also vital that these skills be performed in the greater community and in situations where

they will need to be executed. According to Laura Klinger (2015), “Researchers tracking children with autism into middle adulthood have found that the single most important predictor of success is the mastery of self-care skills.”

Teaching self-care skills, including toileting/menstrual care, daily hygiene, and dressing is vital for independence. As an example, dressing can be taught in the home, and as part of a routine prior to changing for exercise at school. This skill can then be transferred to the community when dressing after swimming at a community pool, eliminating the need for direct assistance.

Daily living skills are also essential toward broader independence. Examples of these include: making a snack, taking out the trash, doing laundry, or vacuuming. Teaching daily living skills promotes personal choice for the student in addition to developing skills that are transferrable to employment activities. Being able to perform these activities increases the opportunity for independent living and social interaction. As an example, learning to make a snack in school can transfer to making popcorn for the family at home. This can lead to developing the skills required to fulfill an essential need as an adult: independent meal preparation.

Interacting with the community is an important and challenging skill for many individuals with autism. Community-based instruction (CBI) teaches skills that lead to greater independence and a higher quality of life for the student by enabling them to

successfully navigate community trips and activities. Peter Gerhardt (2011) stated, “Everybody deserves to be included. But I think what we have to do is not just continue to educate people with autism in how to be more social, but we need to educate the community about how to be social with people with autism.”

CBI helps children with autism widen their world. It enhances family life and prepares the student to function successfully in an environment beyond home or school. Embedded within CBI lies the continued development of communication, social skills and appropriate self-regulation of behavior. Performing community activities such as grocery shopping requires communication skills to achieve the correct purchase, social skills to wait in line and interact with the cashier at the check-out, and socially appropriate behavior throughout the interaction. These skills are critical for student success. They must be taught, learned and practiced in a variety of environments and natural situations.

Establishing an early foundation of skills is crucial for children living with autism. Early success in the areas of self-care, daily living, community-based instruction, communication and social skills will offer a replacement to the potentiality of challenging behaviors grounded in frustration. When adolescence arrives and puberty begins, it is important that children with ASD have mastered skills as part of their repertoire to help them navigate more successfully through the transition to adulthood.

*Lois Trusler, BSW, is Employment Training and Transition Coordinator, and Todd Harris, PhD, is Executive Director, Autism Services at Devereux Advanced Behavioral Health. Please contact Lois with any questions or comments regarding this article at (610) 873 4933 or [ltrusler@Devereux.org](mailto:ltrusler@Devereux.org) or visit [www.devereux.org](http://www.devereux.org).*

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**Transition from page 31****The Vocational Factor**

For some individuals, employment is a key component of adulthood. If a student expresses a desire to work, there are steps that can be taken as part of the transition process to help them realize this goal.

It is important to first talk with the student about their vocational interests and goals. From there, the IEP team should seek out a variety of community-based work experiences that may suit the student’s interests. These can include volunteer positions, employment assessments, internships or paid employment.

Work opportunities that align with the student’s interests and skills may be limited or difficult to secure given the current job market. But do not abandon the student’s goal to work. Cast a wider net and explore a range of opportunities.

The more work experiences a student has, the better. By exposing the student to a variety of environments, he or she may discover a passion for something they might not have otherwise considered.

**Community Integration**

Living within a community is an integral element of adulthood, and therefore, an essential element of the transition process.

Students should be provided with ample opportunities to access the community and the various community-based resources available to them, such as libraries, reaction activities and public transportation.

By routinely utilizing community resources, students will learn new systems and gain vital experience, from how to successfully navigate the community to interacting with other individuals in the community setting.

**Choosing the Right Program**

There are a multitude of factors to take into consideration when selecting a transition program. Chief among these is how much support the student will need based on his or her level of ability. For example, does he or she require 24-hour supports? Would the student be better served in a short-term program or one that offers life-long services?

Another important point of consideration for many parents is the range of services available to their son or daughter. For instance, does the program provide a vocational training component? How are students’ social skills developed and strengthened? Are counseling services offered? Does the program incorporate community-based training opportunities?

It is also helpful to know the staff-student ratio and what the overall attitude is among

the staff toward collaborating with parents.

Bringing the process full circle, it is important to take the student’s identified goals into consideration when deciding on a program—the same goals that were established at the start of the transition planning process. Selecting a program that best suits the student’s individual needs and goals is a major life decision and, once again, a team approach is recommended.

Researching transition programs involves diligence. A helpful online resource is the Network of Post-Secondary Programs ([www.specialneedsprograms.org](http://www.specialneedsprograms.org)). But research should extend beyond the Web.

Just as college-bound students and their families visit multiple universities, parents of young adults in transition are encouraged to visit a variety of programs with their son or daughter and take campus tours. Families are also encouraged to ask around. Speaking to other families about different programs and their personal experiences can provide helpful insight.

**Money Matters**

Funding is another factor many families need to consider—especially if looking out-of-state or at a program that provides life-long services—and is a topic that that can raise many questions. Will the school district cover the cost of tuition? Can a student use in-state benefits funding out of

state? These are some of the questions families may find themselves needing to ask.

Regardless of which transition program is selected, parents should know what benefits and entitlements their son or daughter may be eligible for, on both a local and national level. Federal benefits include Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). More information about both programs is available online. ([www.ssa.gov/disability/](http://www.ssa.gov/disability/)).

*Vanessa Pereira is Organizational Communications Coordinator and Stephen Kunnick is Director of Admissions, Marketing and Business Development at Vista Life Innovations.*

*Accredited by the National Commission for the Accreditation of Special Education Services (NCASES), Vista Life Innovations is a post-secondary program supporting the personal success of individuals with disabilities throughout various stages of life. For more information about Vista’s programs and services, visit [www.vistalifeinnovations.org](http://www.vistalifeinnovations.org).*

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### Technology from page 7

apps, and so much more that can help remove barriers.

Because young people are the ones who are likely to adapt quickly and benefit most from new technologies, Arc of Westchester is creating a Technology Enhanced Simulated Studio (TESS) to open in Mount Kisco, NY this fall. This training site will provide a technology-rich home/work environment for young adults to help them learn to use technology and overcome challenges in their transition to adult life. TESS will also be offering in-person and online technology training for families so that they can further enhance their loved ones' learning.

Since 2014, Arc of Westchester has developed alliances with other organizations to focus on the use of everyday technology to help support the functional needs of people with developmental disabilities. For example, the partnership with Mercy College has led to the two organizations co-hosting the second annual tech conference on May 19th in Dobbs Ferry, NY, "**Tech Supports for Cognition and Learning: Everyday Applications & Emerging Trends.**" Professionals, teachers, and family members, will enjoy a full day of workshops and presentations to learn about affordable



**Jordan and Max check out a new app on his smartphone**

personal technology solutions that can result in more functional independence and integration into the community. If you are interested in attending, please see our ad in this issue or visit [arcwestchester.org/tech-conference2017](http://arcwestchester.org/tech-conference2017).

To sample the extensive universe of per-

sonal technology, please visit **The Arc's Tech Toolbox™**, an online database of personal technology options (<https://toolbox.thearc.org>). This is a free web-based tool that offers a simple drop-down menu system to match phone/tablet/computer technology to the needs of individuals. Arc

of Westchester has served as a testing site for this resource, developed through the generous support of Comcast and Google.

In addition, Arc of Westchester has joined nineteen individuals from Arc chapters and other organizations in launching a monthly phone/web forum to share ideas, report successes, and create joint programs to gain funding for technology solutions. If you are interested in learning more, please email me at [jjankus@arcwestchester.org](mailto:jjankus@arcwestchester.org).

*Jordan Jankus is the father of an adult daughter with developmental disabilities and his interest in finding ways to empower her led to his involvement in assistive technology. He now helps support individuals at Arc of Westchester and other organizations with person-centered technology solutions.*

*In 2015, he became one of sixteen Technology Navigator Fellows selected by the national organization, The Arc. Jordan has presented on personal technology at state and national meetings of service providers, sharing insights and resources on helping people with I/DD use technology for personal empowerment.*

*Jordan holds a Master's Degree in Public Health and a Graduate Certificate in Assistive Technology from New York Medical College.*

### Connectivity from page 24

diagnoses. The educational system in the United States must begin to adopt a more effective means of identifying deficits and remediating the underlying brain process, not merely treating the symptoms. Current research is opening the doors to scientifically-based and scientifically-validated interventions.

Functional activation is the foundation of such interventions. Marcel Just, of Carnegie Mellon University, and Nancy Minshew, director of the Center of Excellence in Autism Research, have identified what they call the under-connectivity hypothesis of Autism. Their hypothesis posits that the neural connections in a brain with autism are poorly connected and/or synchronized making complex tasks, such as spatial reasoning and language comprehension, more difficult for persons with ASD.

Strengthening that connection requires functional activation: cognitive exercises that electrochemically stimulate the brain's ability to send messages to and from the areas required to code the incoming language into mental representations (imagery) and then verbally. By strengthening the conduit, information is more readily transferred, allowing images to be associated with words and vice-versa.

DCT emphasizes the need for both the mental representational and the verbal cortical areas to be stimulated for optimal language comprehension. Nanci Bell's Visualizing and Verbalizing program is another promising intervention because it develops what she calls concept imagery as a basis for comprehension and higher order thinking. Concept imagery improves reading and listening comprehension, memory, oral vocabulary, critical thinking, and writing.

The University of Alabama at Birmingham used the Visualizing and Verbalizing program ([http://lindamoodbell.com/press-releases/uab-study-on-children-with-autism-improved-reading-and-brain-activ-](http://lindamoodbell.com/press-releases/uab-study-on-children-with-autism-improved-reading-and-brain-activ-ity-utilized-lindamood-bell-instruction)

[ity-utilized-lindamood-bell-instruction](http://lindamoodbell.com/press-releases/uab-study-on-children-with-autism-improved-reading-and-brain-activ-ity-utilized-lindamood-bell-instruction)) to conduct a study to assess the legitimacy of DCT and the neurological validity of its premises as applied to ASD students. Here are the findings:

Thirty-one students who had been diagnosed with ASD participated; 16 received instruction; 15 did not. Another 22 typically-developing students also participated as a point of comparison. The 16 students who underwent intensive instruction received four hours of instruction for five days a week for 10 weeks. Each of the students was subject to two functional MRI (fMRI) scans to document their brain function(s), at the beginning of the 10-weeks, and again at the end. The initial scans of students with ASD showed loose connectivity between the imaginal and verbal cortical centers. At the conclusion of the study, the imaginal-verbal connection showed marked improvement in those who had received the Visualizing and Verbalizing program. Those students who did not receive the instruction showed no substantive change in the connection between cortical centers (whether ASD or typically developing). Furthermore, after 10 weeks, the 16 students with ASD who received the intensive instruction showed significant improvement (16.4%) on comprehension tests whereas those who did not receive instruction had little change (2.6%).

#### Worth the Consideration and Effort

Both parents and educators of children with ASD aim to provide them with the best means to live a fulfilling life with meaningful relationships and the increased ability to grasp what's happening in the world around them. When students fall behind their peers academically and socially by a year or more, rigorous and intense interventions are necessary to close the gap. Weekly appointments for 20-60 minutes simply won't be sufficient. As students make gains in language comprehension,

they become better able to manage their own learning. Students can begin to visualize what they learn and apply it to all subjects, naturally reinforcing the strengthened connection between brain centers.

Identifying brain-processing issues is imperative to remediating language comprehension deficits. To evaluate whether a child has impaired concept imagery, consider the following indicators, taken from Nanci Bell's book, Visualizing and Verbalizing (used with permission):

- Difficulty with critical, logical, abstract thinking and problem solving.
- Difficulty with written language comprehension.
- Difficulty with oral language comprehension.
- Difficulty following directions.
- Difficulty in expressing language orally.
- Difficulty expressing language in writing.
- Difficulty grasping language-based humor.
- Difficulty interpreting social situations.
- Difficulty with cause and effect.
- Difficulty with attention and focus.
- Difficulty responding to a communicating world.
- Difficulty with mental mapping.

While none of these symptoms alone indicates weak conceptual imagery as an underlying cause of language comprehension deficits, they do raise the flag of concern. If multiple factors are present, they give reason for further investigation or referral to a professional for evaluation.

#### Cause for Optimism

Language comprehension deficits for children with Autism Spectrum Disorder, not to mention children who are not on the Autism spectrum, are not necessarily permanent. They can be improved through stimulating and strengthening the connection between the verbal and imaginal centers of the brain. What's most important is to recognize the brain process that underlies language comprehension and remediate impairment with a scientifically-validated intervention. Language comprehension is foundational to learning—both social and academic—in the educational environment. With a better understanding of subject matter and social relationships, students are poised for greater success in all areas of life.

*Paul Worthington is Director of Research and Development for Lindamood-Bell. For nearly 30 years, the company's research-validated instruction has consistently changed the lives of individuals with learning challenges such as dyslexia, ADHD, and autism. In addition to their nearly 100 Learning Centers and Seasonal Learning Clinics nationally and internationally, their efforts include research collaborations with MIT, UAB, and previously with Wake Forest, and Georgetown University. For additional information, please visit [www.lindamoodbell.com](http://www.lindamoodbell.com) or call 800-300-1818.*

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**Soft Skills from page 28**

that our students learn by doing, teachers and coaches should be instructing in a direct manner. Teach in black and white - no gray areas. For example, "When work begins at 9:00, one arrives at 8:50." Rather than, "Be at work on time."

We must also assist our students in building a clear vocabulary for the workplace. Included with this is the idea that we have different types of conversations (or exchanges) with friends, customers, and coworkers.

In our program, we have implemented a two-part introductory plan. Key is the exposure of our students to a Dog Therapy Program. We are using this, however in a very unconventional way. Our students

are working 1:1 with therapy dog handlers who are training their animals for certification. The students are learning to be precise and defined in their actions and their speech (communication). The animals are loving and non-judgmental – such a brilliant combination! Our students are learning to use body language, keep someone's attention, and reward positive behavior. It has been an excellent outcome. Anecdotally, we have observed our students becoming more aware of personal space, gesturing and eye contact.

Secondarily, but equally as fundamental, our students are open to programs within local hospitals and nursing facilities where they are volunteering and truly giving to others. I don't believe this can be overstated.

The experience of giving rather than receiving is remarkable. The realization of someone's gratitude is expansive. Our students' self-worth and self-advocacy is growing. Our community partners, who offer their places of business as sites for learning experiences for our students, report that our students are respectful and able to handle direction.

When building a successful program, it is vital to create a home/school alliance. Goals must be congruent. Philosophy must be harmonious. IEPs need to be adequately addressed pertaining to objectives and settings. Remember to gear schoolwork towards career-oriented assignments. Work experience during a student's school years is crucial to getting and maintaining a position after leav-

ing school. The elusive soft skills are hard to describe but easy to see. Partner with your young adults to prepare them, as we did to learn to sort colors from shapes. Allow them to be aware of their own strengths and build on them. Expand the classroom into the community and build professional, positive, prepared and pliable individuals with the confidence to move forward.

*Vicki Ofmani, MEd, LDT-C, is Supervisor/SLE Coordinator at The Forum School, located in Waldwick, NJ. She is also a Member of the Board of Trustees for The Daniel Jordan Fiddle Foundation. For more information, please visit [www.theforumschool.com](http://www.theforumschool.com) or email [vicki.ofmani@theforumschool.com](mailto:vicki.ofmani@theforumschool.com).*

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**PEERS from page 15**

parenting stressors. Thus, a key aim of the present study was to further examine parenting stress prior to and following participation in the PEERS© program.

Data for the present study were collected from adolescents with ASD and parents participating in PEERS©. Group leaders for the present study received training in the PEERS© program and were certified PEERS© providers. Prior to and following participation in PEERS©, adolescents and their parents were asked to complete a series of questionnaires. Parents completed several measures assessing adolescent social skills, adolescent ASD symptoms, and parenting stress. The Social Skills Improvement System (SSIS; Gresham & Elliott, 2008) assesses adolescent social skills and interfering problem behaviors. The Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012) measures ASD symptoms, with subscales assessing social awareness, social cognition, social motivation, social communication, and restricted, repetitive behaviors. The Stress Index for Parents of Adolescents (SIPA; Sheras, Abidin, & Konold, 1998) assesses parenting stress. This particular measure was chosen because it provides separate scores for stress related to adolescent characteristics, parent characteristics, and characteristics of the parent-adolescent relationship. Adolescents completed the Test of Adolescent Social Skills Knowledge (TASSK; Laugeson & Frankel, 2010), a curriculum-based measure created to assess knowledge of the skills taught in PEERS©. Finally, both parents and adolescents reported the number of get-togethers adolescents had organized or been invited to over the past month.

Findings from the present study both replicated and extended past research on PEERS©. Paired-samples *t*-tests were used to assess differences in scores prior to and following participation. Adolescents achieved higher knowledge scores on the TASSK following the program ( $m = 21.70$ ,  $SD = 2.45$ ) than prior to participation ( $m = 12.00$ ,  $SD = 2.06$ ;  $t = 14.07$ ,  $p < .01$ ). This

indicates that adolescents successfully learned many of the social rules presented during the course of the program. In addition, adolescents reported organizing more get-togethers during the course of the program ( $m = 2.33$ ,  $SD = 1.58$ ) than prior to their participation ( $m = 0.56$ ,  $SD = 1.01$ ;  $t = 2.6$ ,  $p = .03$ ). Parents reported higher rates of adolescent social skills on the SSIS following the program ( $m = 90.33$ ,  $SD = 8.03$ ) than prior to participation ( $m = 79.44$ ,  $SD = 14.01$ ;  $t = 3.19$ ,  $p = .01$ ). Similarly, problem behaviors were reportedly lower following the program ( $m = 21.00$ ,  $SD = 8.57$ ) than prior to attendance ( $m = 28.89$ ,  $SD = 10.18$ ;  $t = -5.60$ ,  $p < .01$ ). In addition, parents reported adolescent ASD symptoms to be lower following the program ( $m = 64.00$ ,  $SD = 7.26$ ) than prior to participation ( $m = 73.00$ ,  $SD = 10.01$ ;  $t = -3.67$ ,  $p < .01$ ). Prior to the program, scores on the SRS-2 fell in the moderate range, which indicates the presence of clinically significant social deficits that interfere with everyday interactions (Constantino & Gruber, 2012). Following the program, scores on the SRS-2 fell within the mild range, indicating mild to moderate interference of ASD symptoms in social interactions.

Finally, consistent with previous research, overall parenting stress was not significantly different following the program ( $m = 168.00$ ,  $SD = 33.31$ ) than prior to parents' participation ( $m = 194.00$ ,  $SD = 26.90$ ;  $t = -1.96$ ,  $p = .09$ ). However, parents did report significantly less stress specifically associated with adolescent characteristics following the program ( $m = 81.00$ ,  $SD = 6.96$ ) than prior to participating ( $m = 91.89$ ,  $SD = 17.13$ ;  $t = -2.25$ ,  $p = .05$ ). In particular, parents reported change in their stress levels related to adolescent social isolation and withdrawal. The subscale on the SIPA assessing social isolation and withdrawal measures parent concerns regarding adolescent social skills deficits, interpersonal development, and social responsiveness. Prior to beginning the PEERS© program, parent stress related to social isolation and withdrawal fell in the 90<sup>th</sup> percentile, on average. This indicates a clinically significant level of stress in this

domain. Following the program, parent stress on the social isolation/withdrawal domain was in the 82<sup>nd</sup> percentile, on average, which falls within normal limits.

The results of the present study provide further evidence in support of the PEERS© program. Providing an evidence-based, manualized social skills curriculum to adolescents with ASD and their families has a variety of benefits. As previous research has documented, adolescents gain knowledge about appropriate social behavior, increase contact with peers outside of the program, and demonstrate increased social responsiveness. The present study provides additional evidence that the benefits of the PEERS© program extend to parents. Participating in PEERS© may alleviate some of the stress parents experience specifically related to adolescent social and interpersonal skills. Future research may continue to examine the impacts of the PEERS© program, with a particular goal of documenting lasting effects of the program.

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**Self-Advocacy from page 8**

- Communicating any confusion on the support offered and asking more questions when confused
- Communicating if certain follow up steps seem difficult to manage without further support

**Executive Functioning Skills:** Even when students have a plan of action to address current and future problems, the implementation of these plans can be difficult. Executive functioning skills and systems are important to ensure that plans are executed effectively. Creating clear plans can support individuals through the initiation and follow through process. Skills include:

- Ensuring a follow up plan is scaffolded in order to establish a platform for success
- Clearly mapping out next steps for follow up

- Checking in to make sure strategies are working and adjust when they are not

**Self-Monitoring and Generalization:** Once complete, it is important for individuals to reflect on whether or not their attempts at solving a problem were effective. If they were not, individuals must remember to utilize a different strategy in the future or alter the strategy to try and address the problem. If the strategy was helpful, individuals need to be aware of why it helped so that they can generalize that strategy to similar situations in the future. This includes:

- Understanding how support can be used in novel situations
- Assessing effectiveness of strategies
- Remembering successful strategies for future use
- The teaching and modeling of self-ad-

vocacy for individuals diagnosed with ASD should be incorporated as an essential piece of the learning and development process during adolescence. These skills should be developed well before individuals reach the postsecondary or employment environments. Strong self-advocacy skills lead to greater confidence and success in young adulthood and beyond. Self-advocacy takes time to develop; therefore, in order to understand the intricacies of how it is utilized, adolescence is a critical period for its development.

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**Goal Setting from page 17**

spectrum (Carr et al. 2014b). Amongst the broader population, upon whom the data set was based, self-monitoring was included in two thirds of the studies. Several of these studies noted that the participants valued establishing goals independently and self-monitoring their progress. Feedback was described in almost half of the interventions, with original author reports suggesting that feedback information contributed significantly to achieving positive outcomes in intervention.

Carr et al. (2014b) argued that goal setting training may be important to include in treatment packages that aim to develop independence for students with ASD, and that development of effective goal setting techniques may be a vital skill for high functioning students who wish to pursue higher education. Additionally, as capability in goal setting appears to be developed over time, it was noted that training for generalization across tasks and settings and monitoring maintenance over time is of particular importance. While the data from the goal setting review is drawn from a variety of learner profiles (given the absence of research published with students with ASD), the original research reports have suggested that goal setting skills are teachable.

With increasing numbers of highly capa-

ble students on the Autism spectrum now pursuing higher education and entering the work force, teaching self-management to adolescents is of utmost significance. Including goal setting in self-management support packages, and devoting adequate time to attain mastery of these skills is of critical importance to assist students, teachers, clinicians, and family members wishing to develop independence in this population. Additional information on goal-setting and the implications for students with ASD may be found in the published review (Carr et al., 2014b).

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**Grief from page 24**

featuring Tony Atwood, Temple Grandin and seven more experts. I read it that night, while Jordan went to websites the psychologist recommended. "My God," I thought. "This is Jordan since age three!" Jordan was relieved. "I always knew I was different. Now I know I am not alone. I am an Aspie!" The psychologist referred us to a Cognitive Behavioral Therapy Group where Jordan received counseling from grades 9 to 12.

Over the years Jordan slowly left the van and joined us at the gravesite on her Dad's birthday and all major holidays. At times, she reminds me to get to the cemetery "to see Dad." She still does not say a lot. Six months ago when she pondered asking for permission for a lip piercing, she told me "last night I dreamt about Dad talking to me about getting another piercing. He told me don't do it. So I don't want it." She smiled. When I did asked if she wanted to reflect and share her memories of her dad's illness and death for this article, she hes-

itated; I gave her permission to say "no," and she responded, "Okay, not today."

Thinking back, I now understand how Jordan could verbalize needing a "break" when my husband was hospitalized. Not having an Autism Spectrum Disorder (ASD) diagnosis at the time, I simply recognized and acknowledged the stress she was under. If I had responded with the cliché, "So Jordan, tell me how you really feel," she probably would have responded "Mom, I just told you." Whether on the spectrum or neurotypical, no one is

prepared for the untimely death of a husband and father. I believe on some level, everyone's "unique abilities" equip you to travel this journey with a loved one. Jordan is now 21 years old and is graduating from college. The twins are juniors in high school. My husband would be so proud.

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**Empowering from page 26**

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**Sexuality from page 25**

While there are many benefits to integrating HFASD individuals with neurotypical counterparts, many remain socially excluded due to their eccentricities and thus, there is no assurance that skills learned can be organically applied and generalized across people, places, and situations.

**Reframing Autism**

Research continues to pathologize and disempower individuals with ASD by magnifying biologically based behaviors as problematic and in need of management (Gougeon, 2010). Hellemans et al., (2007) suggests that 29 percent of individuals with autism exhibit severe sexually problematic behaviors (Hellemans et al., 2007; Gougeon, 2010). Some of the atypical behaviors noted in the Hellemans et al., (2007) sampling included paraphilia, which one individual exhibited towards young girls (Hellemans et al., 2007; Gougeon, 2010). Other actions deemed as "problematic autistic behaviors" included public masturbation, and attraction to particularities including breasts, lips, eyes, and legs (Hellemans et al., 2007; Gougeon, 2010). With exception to paraphilia, the behaviors expressed as overt and problematic all fell within "normal" range when comparing similar behaviors exhibited by neuro-typicals (Love, 2004; Gougeon, 2010). In fact, many people regardless of disability and sexual orientation are attracted to the physical attributes of another including one's eyes, legs, hair, and even scent (Gougeon, 2010). However, for those demonstrating poor social acuity, impulse control, and self-expression navigating society's "hidden curriculum" becomes overwhelming and problematic. Some may be unjustly targeted due to the peculiarities associated with their diagnostic profile.

Parents, educators, and community partners can help reframe public perception by promoting education and awareness. Gougeon (2010) defines reframing as a necessary shift in thinking in which a peculiarity is better defined as a skill deficit, thereby illuminating the relevant social barriers and stigma associated with autism, while alleviating the identified deficits with appropriate strategies and skills. Reframing should address "counterfeit deviance" - which is defined as behaviors that appear divergent upon initial observation but can be attributed to factors other than aberrant sexual arousal (Hingsburger, Griffiths, & Quinsey, 1991) - by re-conceptualizing these behaviors as being symptomatic of a social communication disorder (Gougeon, 2010).

Therefore, preparing HFASD students for campus living is essential. Providers and families should meet with all relevant parties to familiarize them with the diagnostic features of autism. Behaviors asso-

ciated with ASD are often misinterpreted, and without clarification could impact an individual's ability to receive fair and equitable treatment when confronted by campus police and administrators. The Individual Education Plan (IEP) should follow the student into postsecondary institutions. The IEP ensures that all reasonable accommodations will be met in accordance with their respective academic institution. Conversely, the social supports that were once embedded throughout high school are no longer maintained in college. For many HFASD students, the Disability Resource Center (DRC) becomes their lifeline for accessing the necessary resources to promote academic success. However, the DRC is not the most ideal location for social engagement and student community. Furthermore, the DRC is restricted from assisting HFASD students with other relevant campus supports including student housing and financial aid just to name a few. Although research suggests social ties can benefit ones overall health and well-being, social ties can also undermine health and may vary across social groups (Umberson & Montez, 2010). The social and sexual deficits that present in autism may inhibit them from fully integrating into their communities as social and sexual beings manifesting in depression, anxiety, low self-esteem, isolation and other mental health issues (Aylott, 2000; Ozonoff et al, 2005; Gougeon, 2010). Therefore, it is critical to identify resources that encourage positive social ties and promote personal health habits (Umberson & Montez, 2010).

Campuses should consider establishing best practices that can expand beyond the DRC to ensure that every HFASD student can successfully transition to campus life. Recommendations include connecting ASD students with a student mentor, counseling supports, and related groups so that they can develop social ties. Moreover, university residence life offices should accommodate ASD students as many have specific sensory, social, and emotional needs that dorm-life can trigger. Because many individuals with ASD have lead restrictive lives, having a roommate and being asked to cohabitate with someone other than a family member can create extreme anxiety. Dormitory resident assistants need to be sensitive to individuals with ASD including helping them to self-advocate, and communicate on behalf of themselves - especially when conflict arises.

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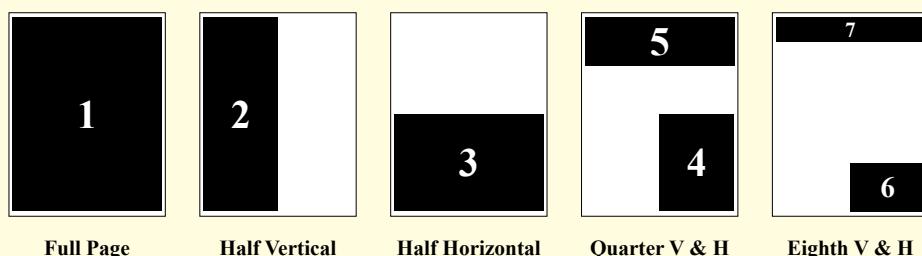
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