Supporting Adolescents with Autism

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

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

Self-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 spectrum, 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 understanding 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...
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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 outpaced that of their typically developing siblings (Mazurek & Wenstrup, 2013). Specifically, youth with ASD spent 62% more time watching TV and playing video 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 are more vulnerable online. Researchers have found high levels of addictive video game use and Internet use among ASD youth (Mazurek & Wenstrup, 2013; MacMullin, Lunsky & 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 et al., 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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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 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 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

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.

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 apps, etc.

See Technology on page 34

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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).

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 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. Retrospective 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

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
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 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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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 circumstance. The 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—usually 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

Mental 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, 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 ambassadors 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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Providing a Safe Haven for Special Siblings

By Suzanne Muench, MSS, LCSW
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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 other 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 another, 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

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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 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 semesters 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 excitement of a college course.

Developing Person-Centered Websites

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

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Walking the Tightrope: Promoting Success in the Adolescent with ASD

By Shuli Sandler, PsyD
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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 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 gratifying 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
Parent and Adolescent Outcomes Following Participation in the PEERS© 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, Gauntman, 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©; Laugeson & Frankel, 2010) has garnered the largest evidence base (e.g., Laugeson et al., 2012; Schohl et al., 2014). The PEERS© 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 sessions 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© program and extend research on parent outcomes of participation in the program. Past research on PEERS© 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© 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©. 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© may have an impact on specific...
Promoting Student Independence and Successful Inclusion Through Systematic Use and Fading of Supports

By Amy Golden, MS, BCBA
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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 & Cooperberg, 2010; Twachtman-Cullen, 2000).

Paraprofessionals are routinely assigned to support students with autism spectrum disorders in the school environment (Giangreco, 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
Research 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 widespread 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 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, Karonen, 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 Spectrum.
By Mark Derewicz
UNC Health Care

Researchers Link Increased Infant Brain Fluid to Autism

MRI shows 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. Castelloe 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 Psychiatry*, 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.
I Know Why He Has Autism

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

By Tori Donahue
Berklee College of Music

Berklee 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 national, 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 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).

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

Rhoda Bernard will lead the Berklee Institute for Arts Education and Special Needs. “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-spectators-

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.boston-conservatory.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. To contact Dr. Bernard, email rbernard@berklee.edu or call (617) 912-9104.

References


Programs for Students on the Autism Spectrum

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References


Empowering Parents: Caregiver Support for Youth and Adolescents with ASD

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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 Mr. 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 one 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 experienced 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 (Mc-Cann, 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).

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Better Language Comprehension Through Brain Connectivity

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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 impinge on their ability to participate in 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.

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. Pre-1980, 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 reading difficulties are related to attentional issues. 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.
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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, & Rutter, 2000; Szatmari et al., 1989; Tantam, 1991; Greiert, 2016), with many reporting either living with their parents, or residing in supported residential settings (Greiert, 2016). Few described dating, having a significant other, or having intimate social experiences (Goode, Howlin, & Rutter, 1999; Howlin, Mawhood, & Rutter, 2000; Mawhood, Howlin, & Rutter, 2000; Szatmari et al., 1989; Tantam, 1991; Greiert, 2016), and almost half of the adult participants according to Goode, Howlin, and Rutter (1999) reported having no friends (Greiert, 2016).

Social scientists have identified four distinct features including social isolation (the relative absence of social relationships); 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 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.
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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 caregivers and 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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References


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

By Vicki Ofmani, MEd, LDT-C
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As we prepare our students for transitions from school to work, we have to shift our focus from 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 is 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 and work the same way others do is important. Putting their “best face” out-there should be a mantra. Others make judgment about us even if they don’t know us. We must be the root and planted firmly into 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.

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By Vicki Ofmani, MEd, LDT-C

Put things back where you found them. Clean up your own mess...Live a balanced life...If you think someone is tired, take over. If you think someone is hungry, get them something to eat...If you think someone is cold, give them your coat. If you think someone is sad, hug them...The list goes on. The point is to show kindness to others.

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, 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 application 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 support the new, 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 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.

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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 shulsandlerpsyd@gmail.com.

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.

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Early Start: Preparing Adolescents for the Transition Years

By Lois Trusler, BSW and Todd Harris, PhD
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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 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.

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 more motivated about interests as a lifetime, 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 at 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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References


behaviors such as aggression, self-injury, irritability, and hyperactivity, for example. 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 on-line 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 AD/HD: May 19th at New York Academy of Medicine and June 7th at Stony Brook University.

Continuum of Care and Capacity Building

The Centers of Excellence have been assessing current discharge practices, identifying 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 interconnect ed 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, e-mail rebeca.girard@ddiny.org or call 631-366-2947. This article was prepared by Rebecca 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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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 deemed 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.

After goals are identified, the IEP team should consider the services and strategies 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 from a grocery list they prepared.

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 deemed appropriate.

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- 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 adulthood have found that the single most important predictor of success is the mastery of self-care skills.”

Teaching self-care skills, including toileting/mealtime, 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 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, “Many children with autism do not experience the socialization that their peers do because they are not 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.

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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, recreation 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 post-secondary education 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). But research should extend beyond the Web. Judiciously, one to two sets of interviews with the student 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 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/).

Vanessa Pereira is Organizational Communications Coordinator and Stephen Kinnick is Director of Admissions, Mar-kees’, a success Development at Vista Life Innovations.

References


Please contact Lois with any questions or comments regarding this article at (610) 873 4933 or ltrusler@Devereux.org or visit www.devereux.org.

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count,

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 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.

To sample the extensive universe of personal technology, please visit The Arc’s Tech Toolbox™, an online database of personal technology options (https://toolbox.theatre). 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 jiankus@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 has presented on personal technology at state and national meetings of service providers, sharing insights and resources on helping people with UDD 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.

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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 scientific comprehension 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 or language) and to speak 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-activity-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 communicative 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 or call 800-300-1818.

References


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. 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 leaving 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 or email vicki.ofmani@theforumschool.com.
Enjoying stress prior to and following participation in the PEERS® program. Thus, a key aim of the present study was to examine the impacts of the PEERS® program on social isolation and withdrawal. 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, the 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 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 participation (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 sub-scale on the SPSA 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 90th percentile, on average. This indicates a clinically significant level of stress in this domain. Following the program, parent stress on the social isolation/wrathfulness and problem behavior scales fell within the 82nd 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 demonstrated 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.

Laura L. Corona, MA, is Graduate Assistant, Eric Davis, LMSW, is Training Program Coordinator, June Ann Worlock, PhD, is Senior Investigator, Sheras, L. Ronald, PhD, is Clinical Investigator, and Kristin V. Christodulu, PhD, is Director at the Center for Autism and Related Disabilities at the University at Albany. For more information about this research, contact laura.corona@albany.edu and visit http://www.albany.edu/autism/.

References


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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. Executing effective study 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 the strategy is effective 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-advocacy 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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References


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 capable students on the Autism spectrum now pursuing higher education and entering the workforce, 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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References


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Over the years Jordan slowly left the van and joined us at the grave site 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 hesitated; 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 high school. My husband would be so proud.

Leslie Wright-Brown, MS, RN-BC, is Manager, Department of Nursing Education and Research, at Saint Barnabas Medical Center in Livingston, NJ. To contact Leslie, please email bwrightbrown@gmail.com.

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While there are many benefits to integrating HFASD individuals with neurotypical counterparts, many remain socially excluded—particularly when conflict arises. Including helping them to self-advocate, and to be sensitive to individuals with ASD in integration, and teaching the HFASD student into postsecondary institutions.

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