# AUTISM SPECTRUM NEWS

SUMMER 2015

INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

VOL. 8 NO. 1

### **The Changing Landscape of Autism Education**

### Bridging the Gap Between Evidence-Based Practice in ASDs and the Classroom

By Jill Krata, PhD and Patrick R. Hof, MD The Seaver Autism Center Tissue Program Icahn School of Medicine at Mount Sinai

s the prevalence of autism spectrum disorders (ASDs) increases, more and more children and young adults are receiving services in public school settings. This has intensified the demand for effective educational and therapeutic services, and science is now providing evidence about which practices work best. Furthermore, current legislation (Individuals with Disabilities Education Improvement Act, 2004; No Child Left Behind, 2001) in general and special education mandates that all educators implement evidence-based educational programs.

Many interventions and treatments for students with ASD are often based on anecdotal reports, case studies, publication in non-referred journals, magazines, internet or other media outlets (Boutot & Myles,



2011). They are not based on empirical evidence to substantiate their effectiveness, thus precluding worthwhile interventions in the school setting (Hess, Morrier, Heflin & Ivey, 2008). Over the years, the field has made significant advances in research and practice, and today, a selection of strategies and interventions are available with best practice guidelines in place. Key words and phrases that educators should look for in the literature that indicate an evidenced-based practice (EBP) are: da-ta-based approaches, empirically validated treatments, and clinical practice guidelines (Perry & Weiss, 2007).

How do teachers and practitioners bridge this gap and implement more EBPs in the classroom? An administrator would rarely hand a procedural manual to a teacher and expect him or her to incorporate a particular strategy accurately. The literature in general and special education identifies teacher training, administrative support, time for planning, and a clear definition of roles, as the biggest barriers. The emerging science around implementation of EBPs, documents the need for a systems perspective for moving evidence-based practice into daily education practice for students with ASD.

see Classroom on page 26

### The Ever Changing Landscape of Higher Education: An Opportunity for Students on the Autism Spectrum

By Ernst VanBergeijk, PhD, MSW and Paul Cavanagh, PhD, MSW New York Institute of Technology Vocational Independence Program

hanges in the college-aged population in the United States are among the evolving opportunities for higher functioning individuals on the autism spectrum. According to the U.S. Census, from 2015-2065 we will see about a 2% drop in the percentage of 18-24 year olds. Two percent sounds like a small number, but in light of a population expected to exceed 400 million people during that time period, 2% will mean 8 million less college-aged students available to the over 7,600 Institutes of Higher Education (IHE) in order to make their enrollment. The colleges must fill seats in the classroom and beds in the dorms. This presents a unique opportunity for students on the autism spectrum to pursue higher education.

Thanks to early diagnosis, school districts using empirically based interventions, and a push for inclusion of students on the autism spectrum with general education peers, we are witnessing better outcomes for students. Now, many of these students are going onto college, vocational training programs, and post-secondary transition programs. Most colleges do not realize the sheer volume of students on the autism spectrum. However, students on the autism spectrum who are otherwise qualified to attend college are able to access reasonable accommodations under the Americans with Disabilities Act (ADA). Special education, as conceptualized in public education, does not exist in college. Colleges are feeling the impact as the demands for services and reasonable accommodations are changing and increasing with the influx of higher functioning individuals with autism spectrum disorders. College offices, tasked with assessing and providing reasonable accommodations to students with a disability, are seeing an increase in the distinct needs of students with an autism spectrum diagnosis, as opposed to students with a physical disability or other learning disabilities.

Increasingly, states, school districts and parents are realizing that IEP transition goals for work, college and independent living must include intermediate steps with specific targeted interventions. It is a quantum leap to go from a high school, in one building with bells demarking every class period, to college where a student must negotiate an entire campus and a variable schedule with no prompts from the institution. The change to a college environment is even more radical than the transition to the world of work and independent living. College schedules vary by the day of the week with, at times, large chunks of unstructured time. Recognizing these leaps, parents and school districts are drawing upon funding under Part B of the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 to fund transition services which can include either community based or college based transition programs.

To justify the expenditure to school boards or state offices of education advocates will, at times, cite the U.S. Department of Education's stance that Committees on Special Education have always had the power to use funding under Part B of IDEA to fund community based or college based transition services when appropriate.

"...as with all special education and related services, it is up to each child's IEP Team to determine the special education and related services that are needed to meet each child's unique needs in order for the child to receive FAPE (A Free Appropriate Public Education). Therefore, if a child's IEP Team determines that a child's needs can best be met through participation in transitional programs on college campuses or in community based settings, and includes such services on the child's IEP, funds provided under Part B of the Act may be used for this purpose." (Assistance to States for Education of Children with Disabilities,

see Opportunity on page 15

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### Using Evidence-Based Practices to Help Children with Autism Spectrum Disorders Improve Their Writing Skills

By Kristie Asaro-Saddler, PhD Assistant Professor of Special Education University at Albany

he use of evidence-based practices (EBPs) for children with autism spectrum disorders (ASD) has become an important topic. The field of ASD is rapidly growing and changing, and an increased number of people diagnosed with ASD has led to the demand to find effective interventions and treatments (Wong et al., 2014). It is important for these interventions to be researched and tested to determine if they will really be efficacious for individuals with ASD so that parents and practitioners do not waste their time trying ineffective or even harmful practices. Fortunately, several researchers and organizations have explored the effectiveness of various interventions to determine whether they should be considered EBPs for students with ASD. Among them are two organizations, the National Professional Development Center on ASD (NPDC; http://autismpdc.fpg.unc.edu/evidence-based-practices) and National Autism Center (NAC; and http://www.nationalautismcenter.org/national-standards-project/phase-2/), who conducted thorough reviews of the literature to determine the practices that have



Kristie Asaro-Saddler, PhD

been proven to be effective for individuals with ASD.

Are There EBPs Specifically for Academic Areas?

Most of the practices identified as EBPs have been in general areas to improve

overall functioning, specifically in behavioral and social areas. No known EBPs for students with ASD have been established in academic content area such as reading, writing, or mathematics. However, teachers and parents can easily implement EBPs into their academic supports.

One of the most important academic areas is writing. Writing is a predictor of academic success and is often the primary way schools assess a student's knowledge and growth (Graham, Harris, & Hebert, 2011; Graham & Perin, 2007). It is used for various purposes, including explaining, persuading, and relating a personal narrative (National Center for Education Statistics, 2012), and students are expected to use writing as a means to both communicate with others and to demonstrate their knowledge about the content areas (Common Core State Standards Initiative, 2014). Despite its importance, many students with ASD struggle with writing. It is therefore essential for parents and practitioners to help children with ASD improve their writing skills. The remainder of this article will focus on ways to implement EBPs into writing support.

> How Can We Utilize EBPs in Writing Instruction or Support?

There are several EBPs that can be im-

plemented in writing instruction. A selection of these practices that may be relevant to writing, taken from the NPDC (Wong et al., 2014) and NAC, will be described, and suggestions will be provided as to how they may be used to support writing. For information about how to implement other EBPs into writing, see Asaro-Saddler (2015) and Boucher and Oehler (2013).

Antecedent-based interventions – Identifying the factors that are impacting performance and changing them ahead of time by modifying the activity or the environment (Wong, 2014). Boucher and Oehler (2013) suggest preparing students with ASD for writing in a variety of ways, including sensory (e.g. reduce audio or visual distractions), motor (e.g. warming up the muscles in preparation for writing), and organization (e.g. using graphic organizers in the planning process). Preparing the students before presenting the writing task may help them better handle the situation before getting anxious or frustrated.

*Modeling* - Demonstrating a target behavior to the person learning the new skill, so that person can then imitate the model (NAC, 2015). This is a strategy that teachers often use in their classrooms to help

see Writing on page 30

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### **Blurred Lines: In Support of a (Broader) Interdisciplinary Model**

By Lucas Steuber, MA-T, MS SLP/CF CEO LanguageCraft

t's 6:00 PM on a Tuesday and Lindsey is taking her kids to swim practice. In the back seat they're talking excitedly about whatever the new game is while struggling to share an iPad, worn out from the day of school but excited for the evening ahead. Meanwhile, Lindsey is thinking about RSVPs for a birthday party and debating whether it's worth fighting traffic to the grocery store while the kids are at the pool. She's a little worried that the kids are getting too much screen time. Wondering if her son remembered to practice the guitar. Debating whether her daughter is too young for her first sleepover, which is coming up next weekend. Starting to make plans before the summer. What will she do when the school bus stops coming?

It's 6:00 PM on a Tuesday and Sue just dropped her son off at my clinic for speech therapy. She's exhausted after a long day of work followed by a meeting with the administrators at his school. He was restrained again today after grabbing the hair of a teacher in his self-contained classroom (although they don't call it that). Sue's frustrated, but she's seen a lot of growth in the past year; he can sit at the table for more than ten minutes for dinner. He can tie his shoes, although the bathroom is still a



Lucas Steuber, MA-T, MS SLP/CF

challenge. He has plenty of words now, although they never have anything to do with the rest of the conversation. She thinks her private occupational therapist and speech therapist are helping a lot, and she's considering seeing a behavior specialist. She wonders, though: Is she doing enough? How can she be more available for him, especially when she depends on her job for the insurance used for this appointment? What will happen in three years, when he turns 18? What will she do when the school bus stops coming?

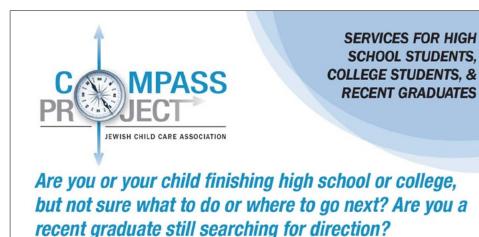
In the traditional model, "therapy" in some form is the extracurricular activity of the neurodiverse. There are soccer moms and karate dads, but then there are occupational therapy moms and speech therapy dads. There are kids who go learn how to swim in a pool, and kids who go learn how to swim through the foreign waters of participation in daily life. The same is true of cocurricular activities; specialists pull students from art and physical education before they pull from classes like science and math. There's a big question here that often lingers unasked: What, in the broadest sense, are we really trying to teach? Ostensibly, we are trying to provide instruction that affords children with Autism the ability to behave and communicate in the same "expected" fashion as their typically developing peers. One of many problems with that statement is the fact that we're doing so in the face of their vastly different experiences and perceptions of life.

Across all cultures, children – and humans as a whole – follow a generally similar developmental trajectory. There's birth, youth, adolescence, education, mating, aging, and more, not necessarily in that order. For every one of those milestones there are many of us who just hit a wall, either temporarily or permanently. For me it was college, where I finally had to confront an attention deficit that stopped me in my tracks. For children with Autism those walls can be taller and can take many forms. We invest a lot of energy into helping them get over those walls and back on the same path, but only rarely does it feel that we acknowledge there may be a *different* path, a route around the wall that affords a journey different but no less extraordinary.

As related health professionals, it's easy to get lost in a little hole with a little wall around it and limit our knowledge to that space. When we look across the battlefield we see other holes with other walls, some of them scorched from conflict. Behavior? Well, that's ABA (or is it SLP? Or OT? Or psychology?). Sensory problems with food? Well that's SLP (or is it OT? Or ENT?). Social communication? Well that's counseling (or is it SLP?). Sometimes it feels like we fight so much about the who, where, and how that we forget about the what and why. Is conformance with typical developmental expectations really the ultimate goal of therapy? When a square peg doesn't fit in a round hole, whose fault is that? The peg, the hole, or the person trying to jam it in?

To be clear, I'm not trying to undervalue the *who*, *where*, and *how*; many greater

see Model on page 23



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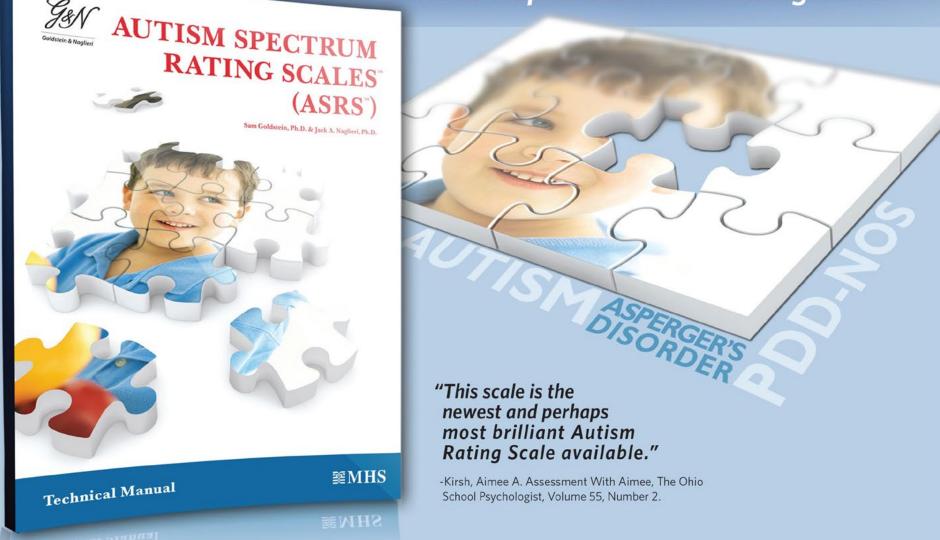
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### Addressing Behavior in the School Setting for Students with ASD

By Sheryl R. Frishman, Esq. Barger & Gaines

roblem and interfering behaviors are among the most challenging issues faced by school districts in their efforts to appropriately educate students with Autism Spectrum Disorder (ASD). These behaviors may be considered inappropriate, reduce instructional time, reduce the quality of instruction, alienate others, or may result in more restrictive placements.

The Individuals with Disabilities Act (IDEA) mandates that a school district provide all eligible students with a Free and Appropriate Public Education (FAPE), in an Individualized Education Program (IEP), provided in the Least Restrictive Environment (LRE). For a student with an IEP who has behaviors that impede his or her learning, or that of others, the IDEA, and the federal regulations promulgated thereunder, require a school district to use positive behavioral interventions and supports, or other strategies to address those problem behaviors.

Positive behavioral interventions should include a school district performing a Functional Behavior Assessment (FBA) in order to determine why a student is displaying difficult behaviors. By determining the purpose of the behaviors, a school district can then devise interventions to



Sheryl R. Frishman, Esq.

help a student display more acceptable behaviors that will meet his or her needs or desires. The FBA is conducted in order to understand the reason for the behavior, and to devise ways to prevent its occurrence in the future. An FBA is the process of gathering and analyzing information about a student's behaviors, and accompanying circumstances, in order to make a valid determination of the purpose or intent of those behaviors. An FBA should be considered as if it were any individualized evaluation of a student performed by the school district. This means it should be used to assist in determining whether a student is, or continues to be, a student with a disability in need of an IEP. In fact, the FBA process is frequently used to determine the nature and extent of the special education and related services that a student needs.

A comprehensive FBA should include a complete review of a student's entire school record and all available outside professional records. It should also include extensive and direct observation of a student in school (classroom, recreation and common areas), and community and home settings. In addition, it should include interviews with the student (if possible), his or her parents, siblings, teachers, other school personnel, community service providers, family members and friends, who know the student. Finally, it should include completed and analyzed rating scales, observed behavior charts and related assessment tools An FBA is a team effort and requires commitment and participation from all people who are part of a student's educational team. If a school district does not have the necessary personnel to do a comprehensive and complete FBA, they may contract out with appropriate providers to assist. Although a good FBA may take time to complete, if done correctly and comprehensively, it can be an extremely

valuable tool for helping to identify what happens before (the antecedent) and after a challenging behavior occurs. It also allows for the committee responsible for developing the IEP, to put in place comprehensive and positive strategies to support a student in learning new and appropriate behaviors.

Positive behavioral interventions also include the development of a Behavioral Intervention Plan (BIP). A BIP is a plan based on the results of the FBA. After collecting enough information in the FBA to identify the reason(s) or function(s) of a student's behavior, the committee on special education or behavior team, should develop a BIP. The plan should include positive strategies, program modifications, and the supplementary aids and supports required to address the behavior, as well as any staff supports or training that may be needed. Although, it is always the hope that these proactive strategies alone will decrease the problem behavior significantly, it is also essential that it be clear to all those involved, how the behavior should be handled when it does occur to ensure consistent consequences. The BIP should be made part of, or at the very least referenced in, a student's IEP.

Positive behavioral interventions could also be addressed by the school district, through annual goals in the IEP, modifications in a student's program, support for

see Behavior on page 19

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### Tools for Transitions: Using Self-Management and Technology to Build Independence

#### By Dana Reinecke, PhD, BCBA-D Licensed Behavior Analyst Transitions

hifts from adolescence to adulthood, from high school to college or career, and from family home to independent living can be challenging for anyone. Many young adults struggle to manage their time appropriately and to make good choices that will help them to meet their long-term goals. Once past initial learning experiences, however, these young adults often adopt successful self-management strategies that help them to stay on target. Self-management, including noticing, monitoring, and influencing one's own behavior, can be as simple as setting an alarm clock to wake up on time for work, keeping a food journal to help in losing weight, or programming a smart phone reminder to make an important call. While most adults who negotiate their lives successfully are self-managing without even realizing it, some individuals have never learned these crucial skills and may find it difficult to move towards independence without them. Fortunately, a rich research literature suggests that individuals with disabilities can be taught to self-manage at many different levels, with success across academic settings (e.g., Coyle &



#### Dana Reinecke, PhD, BCBA-D

Cole, 2004; Olympia, Sheridan, Jenson, & Andrews, 1994), work settings (e.g., Christian & Poling, 1997), in home and social situations (e.g., Ninness, Fuerst, Rutherford, & Glenn, 1991), and for health-related concerns (e.g., Rauen, Sawin, Bartelt, Waring, Orr, & O'Connor, 2013).

Self-management begins with identify-

ing and monitoring one's actions. This skill, called self-monitoring, is often enough to lead to positive behavior change by itself (e.g., Ackerman and Shapiro, 1984; Mc-Dougall, 1995; Amato Zech, Hoff, & Doepke, 2006; Morrison, McDougall, Black, & King-Sears, 2014). Young adults can begin to tap into the power of self-monitoring by setting personal goals and determining what behavior change will lead to meeting those goals. For example, an incoming college student may set a semester-long goal of getting an A in his first class. This goal can be broken down into the behavior that will make that grade more likely: attending all sessions of the class, turning in all work on time, and studying for a minimum number of hours per week. He can then self-monitor each of these responses on a daily basis, providing feedback to himself and guidance towards doing what he needs to do to meet his goal. In the absence of self-monitoring, he might be less likely to notice when he is missing classes or not studying enough. There's also the very real sense of satisfaction that one can derive from noticing one's accomplishments, which are highlighted through self-monitoring. Our hypothetical student will feel great when he earns his A at the end of the semester, but he can also enjoy the feeling of accomplishment each time he records his class attendance, timely work submis-

sion, and hours studied each week.

The effectiveness of self-monitoring can be augmented by adding self-prompting strategies. Mechling, Gast, and Seid (2009) provided three high school students with ASD with personal digital assistants (PDAs) programmed with prompts for cooking activities. Although the prompts were not generated by the students themselves, they were able to access them as needed. The students improved their independent cooking skills, and they only used the prompts as needed. Self-prompting can be seen in action in nearly any setting or everyday activity. From the simplest string around the finger or post-it note on a computer monitor, to the most high-tech smart phone alert system, people self-prompt all the time. Learning to make use of this very typical, effective strategy is crucial for success in independence for individuals with disabilities.

Finally, self-management may also involve the self-delivery of consequences. Although not always necessary for success, sometimes the addition of positive reinforcement for a job well done can improve behavior change towards the individual's self-selected goals. Self-reinforcement need not be tangible; those of us who post accomplishments to social media and

see Transitions on page 20

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### **Beyond Academics: The Importance of Executive Functioning Skill Development**

By Katherine Cody, PsyD Licensed Psychologist Spectrum Services

hildren diagnosed with ASD are known to present with a range of executive functioning needs. While educators and special education teams work to implement accommodations, modifications and supports to provide students with ASD what they need to access their education and surrounding environment, much of the time students do not develop an understanding of how to create the tools for themselves. Recent research indicates that individuals with ASD exhibit an increase in executive functioning needs throughout development, with particular increase noted in challenges in flexibility, indicating the need for increased provision of direct instruction in these skills (Rosenthal, et al. 2013) These skills are critical to development of independent living skills, educational and occupational functioning as well as social functioning given that executive functions (EF) are responsible for the set of brain functions responsible for directing and controlling perceptions, thoughts, feelings, and behaviors. EF skills are required for people to effectively plan, execute, and follow through



#### Katherine Cody, PsyD

with tasks and solving of everyday problems. Most individuals diagnosed with ASD present with deficits in executive functioning.

Common skills needed for good executive functioning include:

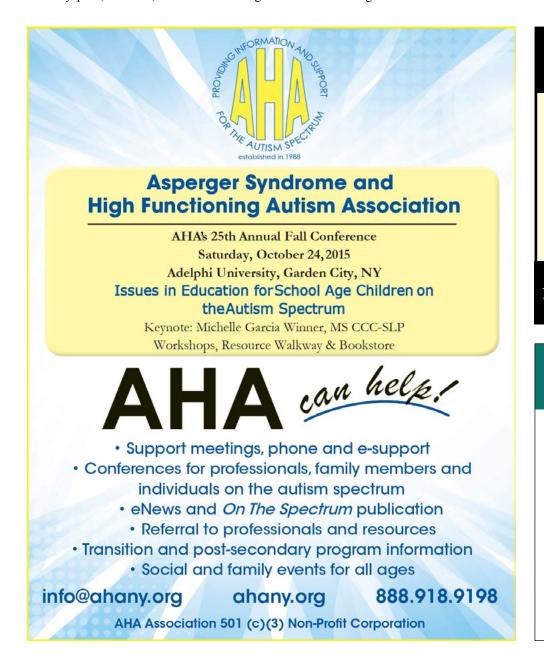
- Response Inhibition: The capacity to think before acting.
- Working Memory: The ability to remember information while performing other tasks.
- Emotional Control: Self-regulation of emotions to maintain behavioral control.
- Flexibility / Shift: The ability to revise plans and incorporate new information when needed.
- Sustained Attention: The capacity to continue attending to tasks despite distractors, fatigue, disinterest, etc.
- Task Initiation: The ability to start projects without significant procrastination or external supports.
- Planning / Prioritization: The ability to create a strategy or plan to achieve a specific goal.
- Organization: The ability to create and monitor systems to organize information or materials.
- Time Management: The ability to monitor the amount of time available for a task and to manage the

time keeping in mind limits and deadlines.

- Goal-directed Persistence: The ability to sustain effort directed toward a goal despite possible competing interests or activities.
- Metacognition: The ability to reflect and view one's self in a situation and observe one's own problem solving, self-monitoring, and self-evaluation.

In many schools, psychoeducational evaluations reveal areas of EF that would benefit from supports. In a student's Individualized Educational Plan (IEP) who has been identified as having these needs, there is likely to be a list of accommodations and modifications to support these needs; however, there are rarely goals associated with teaching students these skills. For example, a student who is identified as having difficulties with planning and organization might then have an accommodation of being provided tasks with the steps broken down or with deadlines for each step of an assignment. While this support is often crucial to a student's success, it does not necessarily teach the student how to use this strategy for him or

see Development on page 22



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### Two Case Studies of Success Using ABA to Increase Independence for Adults with Developmental Disabilities

#### By Amy Bukszpan, BCBA, Amanda Duva, MS, RBT, and Vivian Attanasio, BCBA Services for the UnderServed

had a doctor finally help me with my head, and now I feel so much better. I got glasses when I needed them. I couldn't have a job before because I was always in the hospital. Now I can get a job." These are the words of a 36-yearold woman transformed. A woman who 8 months ago had a future restricted by near daily episodes of challenging behaviors that included episodes of head-banging and physical aggression that would last upwards to six hours at a time. But today she speaks of the future, her plans for her future. These words of optimism, self-advocacy and self-determinism do not stand alone, but rather define the story of change and renewal for individuals living at an Intermediate Care Facility (ICF) provided by Services for the Underserved (SUS).

SUS is a New York City based nonprofit human services agency who provides a wide array of services to a spectrum of individuals and families with diverse challenges including individuals with intellectual/developmental disabilities. In August of 2014, SUS was awarded a Balancing Incentives Program Innovation Fund (BIP)



Nancy and Jeremy have both achieved greater independence over the last 8 months while living at the SUS ICF. Above is Nancy ready to leave on a date with her boyfriend and Jeremy outside his new IRA that he moved into in early June.

grant to improve quality care and management of individuals with developmental disabilities living in long-term residential settings. At the ICF, the grant provides funds for an analytical and systemic shift in administering services for adults with developmental disabilities; the application of the science of applied behavior (ABA), the benchmark in educating young children on the autism spectrum in the teaching of new skills and the decreasing of challenging behaviors. Each individual at the ICF received a full functional behavior assessment which then steered the development of an individualized service plan focused on increasing and decreasing behaviors based on the function, why an individual engaged in the behavior, rather than the topography, and what the behavior looked like. By analyzing and manipulating the motivating operations and the sustaining consequences of behaviors, behavior analysts and behavior technicians at the ICF have demonstrated success across many individuals at the residence.

Below are the stories of two individuals who currently reside at the ICF. Their stories highlight the success of the work accomplished under the BIP grant; that the application of the science of ABA to adults in a residential setting can lead to less restrictive living and a greater quality of life at any age.

Nancy is a 36 years old female who has resided in hospital and institutional placements since 2003. She has an extensive medical history as well as a long history of behavioral and psychiatric concerns dating from her first hospitalization at just 1.5 years old. Moreover, Nancy began a regiment of psychotropic medications as a toddler at 3 years old. Nancy carries multiple diagnosis and engages in severe challenging behaviors which include head banging, physical aggression, verbal aggression,

see Independence on page 31

### This is what success looks like...



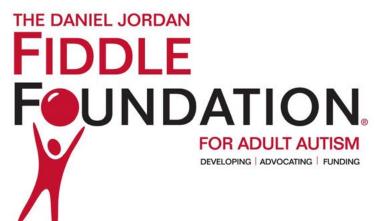
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### Supervision Training: Ensuring Quality at Every Level of an Organization

By Helena Maguire, MS, BCBA, Mary Jane Weiss, PhD, BCBA-D, and Frank L. Bird, MEd, BCBA Melmark

nterventions for learners with autism have become increasingly nuanced and complex over time. It is not easy for organizations and professionals to stay abreast of the changes in instructional technology. The identification of best practice techniques is a moving target; research continually changes and expands the range of techniques known to be effective. The identification of effective intervention is an ongoing and continually evolving process. All service delivery programs that provide state-of-the-art intervention have mechanisms in place to stay informed about changes in evidence-based practices. Similarly, they have extensive systems and curricula designed to train staff in the most current methodologies.

Much is known about what constitutes best practices in staff training (e.g., Mc-Clannahan & Krantz, 1993; Reid, O'Kane, & Macurik, 2011; Reid, Parsons, & Green, 2012). A number of studies have demonstrated that effective instruction results from training that is focused on implementation and not on information alone. Lecture-based presentations do not result in the ability to implement a technique. Instead, training must include a much more



Helena Maguire, MS, BCBA

specific focus on implementation. Staff members learn best when procedures are demonstrated and when the individuals are coached through the actual demonstration of such procedures. When trainers model the procedure and then provide coaching and feedback about the trainee's implementation, learning is most efficient.

What Works in Staff Training

In behavior analytic programs, training methods that include modeling, rehearsal, and feedback are termed Behavioral Skills



Mary Jane Weiss, PhD, BCBA-D

Training (BST). This has become the standard of intervention for ABA staff training programs. BST has been shown to be extremely effective in training a wide variety of skills to staff members (e.g., Sarakoff & Sturmey, 2004). It has also been shown to be an effective way to build skills in parents of individuals with disabilities (e.g., Miles & Wilder, 2009). Recipients benefit from the concrete demonstration of the technique and from the practice and coaching that are embedded into BST.

Supervision: The Art of the Science?



Frank L. Bird, MEd, BCBA

While staff training has been well researched, the other elements of supervision are less well understood. All ABA staff members require ongoing training and supervision to ensure the continual quality of the delivered intervention. The skill sets of supervisors are important to identify. In many human service organizations, supervisors are identified from the pool of implementers. Those with the most seniority and the best skills are considered for promotions to supervisory roles. Yet, the skills

see Training on page 27

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### ASD and the Local School District: How Parents Can Best Advocate for an Appropriate School Setting

#### By Irina Roller, Esq. President & Founder Law Offices of Irina Roller, PLLC

arents who have children with ASD can find themselves in a difficult situation when it comes to determining the right school setting for their child. As a special education attorney representing families in New York City, I have found that determining an appropriate school program and placement can be a daunting task for parents. Parents must make sure that they are equipped with accurate information, so that they can make an informed decision.

How can parents ensure that they obtain all the relevant information in order to make a well-informed decision?

In a perfect world, the local school district would provide parents with all of the information they need to make an informed decision. In fact, parents and the school personnel would work together to make sure that all the child's needs are met. Not only is this my personal version of utopia, but it is also the law. Unfortunately, parents can find themselves at the mercy of school officials who may not be equipped to provide them with all the information that they need to make an informed choice for their child.



Irina Roller, Esq.

Parents should go into the process of working with school personnel with an open-mind and a belief that their child's needs are a top priority. However, parents should not be naïve either. Students diagnosed with autism present a particular challenge to school districts. The spectrum of the disorder is very broad, as are the needs of each individual child. The type of program available is often not commensurate with the variety of needs that accompany a child with autism.

Simply put, your local school district may or may not have an appropriate program or placement to meet your child's unique needs, even when they have the best of intentions. It is up to parents to advocate for appropriate supports and services. In order to do so in a meaningful way, parents must understand the difference between a program recommendation and a placement. They are not synonymous. They represent two different and equally important aspects of the whole that makes up your child's education.

The program is the type of class and supports that your child will receive, which are spelled out in your child's Individualized Education Program (IEP). The IEP should have included specific details such as student to teacher ratio, management needs, service details regarding the frequency of services such as OT, PT, Speech, whether the student will need special education transportation, and many other details that should express all of a child's specific needs (academic, social, emotional and physical) and how they can be met so that the student is able to make meaningful progress at school. The *placement*, on the other hand, is the physical school building where your child will attend school and where the IEP/program will be implemented. The specific school where the program will be implemented is usually not indicated on the IEP.

Both of these components are crucial to determining whether or not your child's unique special education needs can truly be met.

There are many considerations that must go into determining the right program and placement for a child with ASD. The class size, the school size, the school's and teacher's ability to tailor curriculum and instruction to meet the child's needs, the availability of services such as speech therapy, occupational therapy or counseling, and many other factors that are specific to each individual case. Despite what parents are sometimes lead to believe, the child does not have to conform to what the school district has available. The school district must meet the child's needs.

In NYC, for example, there are major issues that arise because the process is fragmented in terms of program recommendation and the placement assigned. The team that discusses and ultimately decides what a child's program will be does not have any say regarding what school the child will be assigned to. This is particularly troubling

see Advocate on page 30

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### Social Interventions: The Importance of Considering Program Design and Instructional Methods

By Casey Schmalacker, BA Outreach Coordinator/Academic Coach New Frontiers in Learning

utism Spectrum Disorders (ASD) are categorized by deficits in social interaction and communication (Jordan & Powell, 1995). With scaffolded supports and structured practice in natural settings, individuals diagnosed with ASD can learn to build the critical skills necessary to engage meaningfully in society (Abele, 2009). Mastering these skills can increase access to social opportunities similar to their peers. When developing interventions, it is important to identify supports that contain research-based practices designed to support a diverse group of learners. By utilizing a Universal Design for Learning (UDL) approach to teaching social skills, educators can set up a learning environment conducive to not only individuals diagnosed with ASD, but also individuals with a broad range of social communication needs.

There have been several research studies focused on both environmental design and methods of instruction when teaching social skills to individuals with ASD. More specifically, studies have demonstrated the effectiveness of parent training and peer mentoring in individuals in all stag-



Casey Schmalacker, BA

es of development; whereas, studies on the benefits of educating in naturalistic environments has concentrated mostly on young children with ASD. "Given the positive findings using these techniques with young children, future research should explore their application to older individuals" (Reichow & Volkmar, 2009, p. 159).

This article discusses how social skill programs should be designed with UDL in

mind, while also utilizing researched-based methods for teaching skills to students with various social skill deficits. When identifying interventions that address social communication, effective programs utilize practices that can increase the generalization of social skills. Design and methodology are important to consider when selecting social skill interventions, and some areas to concentrate on include: 1) Universal Design for Learning; 2) Person Centered Planning; 3) Problem Solving Frameworks; 4) Natural Environments as a Classroom; 5) Parent Training; and 6) Peer Mentoring.

#### Universal Design for Learning

Utilizing universal design in social programs allows for the widest range of students to access and benefit from supports. The UDL approach concentrates on three cognitive areas that are important for individual learners. Specifically, UDL concentrates on: (1) the varying ways to represent information to the learner; (2) the ability of the learner to display the knowledge; and (3) the various ways to actively learn (Meyer, Rose, & Gordon, 2014; Rose, Meyer, Hitchcock, 2005). Since individuals with social communication deficits vary in their levels of interpersonal skills, programs need to accommodate individual needs. Taking a UDL approach discourages rigid guidelines and encourages flexibility around the needs of the learner.

Person centered planning is an approach that develops and supports learning environments that place the individual in the center of the planning process. This approach of supports allows for the individual's abilities and needs to inform the goals and design of the program (O'Brien & Lovett, 1992). Person centered planning calls for utilizing all resources that are available, as well as developing and creating new resources that are specific to the individual's needs. When addressing social concerns, a person centered planning approach can target behaviors that are specific to each individual in order to maximize learning.

#### Problem-Solving Frameworks

Utilizing problem-solving frameworks encourages individuals to develop systems that allow for overcoming obstacles in day to day life. Problem-solving frameworks are systems that outline a means to addressing problems in a sequential and scaffolded approach that can be applied across multiple situations (O'Connor, Stichter, 2011).

see Interventions on page 28



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Person Centered Planning

34 CFR parts 300 and 301, 2006, p. 46668). Some states such as Connecticut and Massachusetts have gone one step further to create "dual enrollment" and "Inclusive Concurrent Enrollment" programs, whereby the students take some college classes while still being enrolled in special education programs in their high schools. Typi-

cally the students will attend classes at the

local community college or state school. A third development, increasing the number of students with autism and other developmental disabilities in higher education, has been slow to gain traction. This is the adoption of the Comprehensive Transition and Post-secondary (CTP) program model. In 2008, Congress passed the Higher Education Opportunity Act, a reauthorization and significant revision, of the 1965 Higher Education Act. Title IV of the Higher Education Opportunity Act governs all forms of Federal Student Aid. Prior to 2008, in order to be eligible to complete the Free Application for Federal Student Aid students had to be enrolled in a degree bearing program full-time. Many academically bright students who are on the autism spectrum cannot handle the full-time load of 12-18 credits. It often has nothing to do with their academic ability. Rather, it has to do with deficits in their executive functioning, or their social and communication skills. Although all colleges have an office of disability services, the quality of support for students with autism varies widely. Often the staff in these offices have had little experience, or training, in the unique needs of students with an autism spectrum



Ernst O. VanBergeijk, PhD, MSW

diagnosis. With the passage of the Higher Education Opportunity Act, students with an intellectual disability (broadly defined, which can include autism) who are enrolled in a U.S. Department of Education approved CTP can receive certain forms of federal student aid (i.e. grants only) - even if they have not yet received their high school diploma or even if they are not pursuing a college degree full time. The added benefit for families is that the student with an intellectual disability, who is enrolled in a U.S. DOE approved CTP, now "counts" as a child in college under FAFSA. This can lower the Expected Family Contribu-

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Paul Cavanagh, PhD, MSW

tion for families with other children in college and can increase the amount of possible student aid to the family as a whole. The roll out of the Comprehensive Transition and Postsecondary Program model has been slow. Out of the over 7,600 Institutions of Higher Education with approved Title IV programs, only 34 colleges have received approval for CTPs by the U.S. Department of Education, or less than 1% of all institutes of higher education.

It is unclear why the adoption of this model has been slow. The only real requirements for the colleges in terms of the CTPs are that the CTPs must have a

curriculum and advising structure that address the needs of this population AND the institutions must ensure that the students with an intellectual disability are engaged in coursework and other activities with non-disabled peers at least 51% of the time over the life of the CTP. Perhaps, the administrative burden and application process has been a deterrent to many colleges.

Research into successful transitions for young adults with a variety of disabilities has now begun to emerge. Wehman et al. (2013) conducted the first clinical trial of vocational training as an intervention with transition-aged young adults on the autism spectrum. Participants were randomly assigned to vocational training in a hospital setting versus a control group referred to as "business as usual," meaning the participant received services through the local school district and the state office of vocational and rehabilitative services. Participants in the vocational training condition had an employment rate of 87.5% after completion of the study as compared to the "business as usual condition" where only 6% of those participants were employed. Furthermore, Lounds Taylor, Smith and Malick (2014), found that greater vocational independence and engagement were related to subsequent reductions in autism symptoms, and maladaptive behaviors. They also found increased improvements in activities of daily living. The prevailing wisdom had been that one needed to teach social and independent living skills prior to vocational training to achieve good outcomes for individuals on the spectrum.

see Opportunity on page 17

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### **Gaining Momentum in a Post-Secondary Education Inclusion Program with Innovative Supports**

#### By Hope Goldfard, MS **AHRC** New York City and James Lawler, DPS **Pace University**

ollege inclusion programs are continuing to develop for an increasing inflow of graduating high school students with developmental and intellectual disabilities (Paiewonsky, et. al., 2010). At AHRC New York City, higher functioning students on the spectrum are engaging in learning and sociality in a special education program, at the Seidenberg School of Computer Science and Information Systems of Pace University, offering special supports and technologies. The program is improving employment opportunities for further inclusion of the students into society.

#### Engaging in College Experiences

The emphasis is on students with disabilities on the spectrum who have individualized education plans (IEPs) and an aptitude and a passionate interest in college experiences.

The essence of the program is for the students to be in courses and experiences in the Seidenberg School, and if desired in the curriculum of liberal arts in the Dyson



#### Hope Goldfard, MS

School of Arts and Sciences, and in extra-curricular experiences in the university. with other students without disabilities.

The courses are at elementary and intermediate levels and may be generalized or specialized subjects, such as Intermediate Computer Technology or Multimedia User Interface Design and Programming with



#### **James Lawler, DPS**

Web Technology in the Seidenberg School, and even Communication and Popular Culture in the Dyson School. "The focus of the program, in eclectically mixing information systems and liberal arts, is on learning and on sociality that facilitate holistic opportunities in life planning skills," according to Ms. Goldfard, AHRC New York

City. The full inclusion of the students in interactions with instructors and other students without disabilities is a highlight of the program.

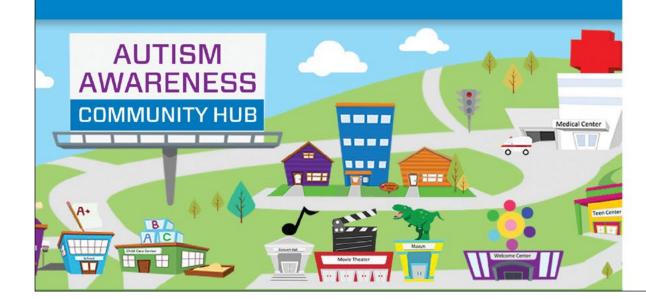
The courses and the experiences match person-centered plans (Holburn, Gordon, & Vietze, 2007) prepared for the students by counselors of AHRC New York City, a community partner of the university since 2007. The plans are prepared with the families of the students and the students themselves, with the plans corresponding to potential vocation visions. Free from disruptive disorders, the students are referred to the Seidenberg School by AHRC, based on eligibility from the New York State Office for People with Developmental Disabilities (OPWDD).

Funded initially by grants of AHRC in a pilot period, and by Pell grants of the United States Department of Education eventually, 12 higher functioning students on the spectrum have completed 14 courses cumulatively in the schools with other students. They have engaged in 96 events of extra-curricular programs of recreation and sociality with other students. They have been graded at an average A- level since 2013. The number of students is incrementally integrated into the schools at 3 students in a semester. The numbers are

see Momentum on page 29

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#### **Opportunity from page 15**

The Lounds Taylor, Smith and Mailick results indicate that providing well-structured opportunities for employment and community engagement can result in improvements in activities of daily living. Research by Moore & Schelling (2015) points to the importance of post-secondary transition programs. According to Moore & Schelling, 9 out of 10 students with an intellectual disability who participated in a postsecondary program were employed within two years of the study. However, when they compared their results to that of National Longitudinal Study 2, only about 51% of the students with intellectual disabilities were employed within the same two year period. These preliminary results suggest that post-secondary transition programs like CTPs are effective in helping students with autism and other kinds of disabilities transition to the world of work and independence. Research by Klinger (as cited in Diament, 2015) presented at International Meeting for Autism Research earlier this year, suggests that mastery of self-care skills are a better predictor of post-secondary transition success than intellectual disability. Individuals with the highest self-care skills were better able to maintain employment, utilized employment support services less often, and worked more hours, regardless of symptom severity or intellectual ability. This further affirms our assertion that merely providing access to, and support in the area of, academic credit bearing coursework is insufficient for students on the autism spectrum. A transition program curriculum must contain aspects of independent living and self-care skills.

The latest development in the ever changing landscape of higher education comes in the form of federal legislation. The Workforce Innovation Opportunity Act (2014) now requires state offices of vocational and rehabilitative services to allocate at least 15% of their budgets to transition aged youth. Further, the Act allows these agencies to be more flexible in what they are able to fund. Prior to the passage of this act, vocational rehabilitation agencies were reluctant to fund aspects of a person with a disability attending college unless it was directly linked to an employment outcome. Also, these agencies were very reluctant to fund programs that dealt with the "soft skills" of employment which were deemed as "pre-vocational" and yet essential to successful transition to the world of work and independent living for young adults on the autism spectrum. This new act may

provide a wider variety of supports for individuals with an intellectual disability transitioning to the world of work.

Drs. VanBergeijk and Cavanagh are the Associate Dean and Assistant Dean of New York Institute of Technology Vocational Independence Program (respectively), which is a U.S. Department of Education approved Comprehensive Transition and Post-secondary (CTP) program. The duo also administer the Introduction to Independence (I to I) Program which is a 7 week summer bridge program for students ages 16 and up. For more information, please visit www.nyit.edu/vip.

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Workforce Innovation and Opportunity Act of 2014, Pub. L. No. 113-128, 29 USC 3101.





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

By Carrie Cariello

### Who Should Take the Blame for Autism?

ast week, I saw yet another article that claimed to solve the mystery of autism. This time, it was gestational diabetes in the mother. It's always something, isn't it? Either autism is because of advanced paternal or maternal age, or the dot-com era, or people who eat gluten. the article pointed to the the manufacturers who make Roundup.

(I'm not even sure what Roundup is. I'll be right back...Oh, it's weed killer you use for gardening. No wonder I didn't know what it was.)

I know it's all in the name of research and ultimately it's super-important stuff, but the subtext of these headlines feel, well, a little vengeful. They feel like accusations.

I'm not trying to argue that we shouldn't investigate the heck out of autism spectrum disorder. We most certainly should. We should research what's causing it, fund the programs for it and do what it takes for people on the spectrum to lead full, productive, happy, meaningful lives.

But this undercurrent of blame hurts—a lot. It hurts to think a choice I did or didn't make contributed to my son's condition. It



Jack and Cody

makes me feel hopeless.

Even though I know—I *know*—there's nothing I could have done differently, I still pause when I read things like this. I hover over them for the tiniest second before I click on to something else.

And still I refer to the mini-checklist in my mind: nope, I didn't have gestational diabetes. My husband Joe was not even thirty when Jack was born. Neither one of us are particularly savvy when it comes to technology, and I have never grown so much as a tomato on my own, so I never used Roundup.

On Mother's Day in 2004, I gave birth to a 9-pound, 3-ounce baby boy named Jack (1 of 5 children). This boy was wired differently from the very beginning, and because of that we suspect genetics played a heavy role. That is our autism story, and I'm sticking to it.

But we all have our own stories to tell our own pathway down the bumpy spectrum road. And each one is authentic and true and raw and sometimes, hilarious. Each one is simultaneously heartbreaking and heartwarming.

So how can science pin down a single cause, when autism hardly has a single story? Blame.

You know how with a kaleidoscope you can look inside and see a thousand colors and patterns all at once? And then if you turn the dial a little bit, the colors and shapes move, and everything looks completely different? I think autism is like a kaleidoscope. It is ever-changing and always shifting. It looks different to everyone.

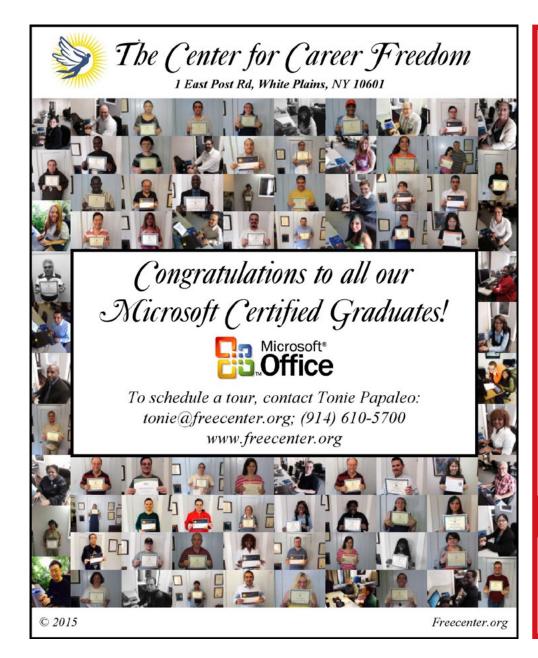
And I think blame is a lot like a kaleidoscope, too. We can consider it from one angle, and feel pain and embarrassment and shame, or we can turn the dial just a smidge and know hope.

Because of his grandmother, Jack eats pears.

Because of his father, Joe, he understands prayer.

Because of his teachers, he wears his glasses all day long and only takes them off to sleep at night.

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Carrie Cariello EXPLORING THE COLORFUL WORLD OF AUTISM



"What Color is Monday?"

"Someone I'm with Has Autism" Now Available!

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### **Exploring How Parents Choose ASD Treatments**

By Heidi Hillman, PhD, BCBA-D Associate Professor Quincy University

oday, 1 in every 50 children is diagnosed with an Autism Spectrum Disorder (CDC, 2013). There are hundreds of treatments, ranging from behavioral and educational therapies to traditional and complementary alternative therapies to downright dangerous therapies (e.g., Leskovec, Rowles, & Findling, 2008; Meyers & Johnson, 2007). However, many of these treatments are not empirically supported (e.g., Kasari, 2002). Few conditions other than ASD have been plagued with fad therapies that waste valuable time, money, and are possibly dangerous (e.g., Foxx, 2008). Given the chronic symptoms associated with ASD, and the plethora of therapies, it is important for parents to make informed choices regarding treatment.

Several studies discuss the therapies parents choose (e.g., Goin-Kochel et al., 2007; Green et al., 2006; Hebert & Koulouglioti, 2010) but few studies focus on the decision making process of parents selecting therapies. In order to provide effective guidance to parents when choosing therapies, it is important to understand how parents make therapy decisions. How do parents navigate through all the treatments and find the effective ones? Why do parents choose the



Heidi Hillman, PhD, BCBA-D

therapies they do? Where do parents turn to for information about treatments? Does severity of the child's autism symptoms affect choice of treatments?

This study explores how parents choose ASD treatments, and what factors are important. The author of this paper developed a survey asking parents with at least one

child with ASD about the number of therapies they tried, what therapies they are currently using, where they go to for information about autism therapies, what is important when choosing a therapy, what does evidence-based mean, and to rate the severity of their child's autistic symptoms using a scale. The survey was turned into an online survey, using Survey Monkey®. Using an online support group directory (autismspeaks.org) to find support groups for families of children with ASD, 166 were found in Illinois and 66 were found in Missouri. The search was limited to Illinois and Missouri because the author wanted to learn more about how parents in this region decided on autism therapies since she provides applied behavior analysis (ABA) services to families in this region. However, these results could potentially generalize to a wider group of parents. Out of the 232 support groups found, six support groups were removed because they focused on adults, resulting in 225 support groups. Email invitations to participate in the survey were sent to the contact person listed for each support group. As a result 620 parents completed the survey; 92% of the respondents were mothers and 8% were fathers.

All parents reported using at least one type of therapy, 61% of parents reported using two or three therapies at the same time, followed by 39% using four or more therapies at the same time. When asked to

list the therapies they tried or are currently using, parents reported (listed in order of frequency): standard therapy (speech therapy, music therapy), medications, vitamin supplements (B12, melatonin, magnesium, and vitamin C), elimination diets (gluten-free, casein-free and removal of veast). complementary alternative therapies (massage therapy, chiropractic), ABA therapy, relationship based treatments (social skills therapy, Floor time, attachment therapy), physiological therapies (sensory integration, physical therapy, occupational therapy), detoxification (chelation), equine therapy, aquatic therapy, and special education. An interesting note, parents who rated their child's autistic symptoms as more severe also reported using four or more therapies. This tells us that the greater the severity of symptoms, the more therapies may be in use, a possible attempt by parents to quickly find an effective therapy.

In regards to where parents go for information about therapies, an overwhelming 72% parents reported they went online first and then talked with family and support group friends, followed by 18% parents reporting they talk with family and support group friends first. Only 10% said they went to their physician or autism therapy provider for information about therapies. Being that the population surveyed is parents who are in support groups, it should

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#### Behavior from page 8

his or her teachers, and any related services necessary to achieve those behavioral goals. For example, if a student needs a BIP to improve learning and socialization, the BIP should be included in the IEP and aligned with the goals in the IEP.

Successfully dealing with behaviors in students with ASD requires collaboration among a variety of professionals. For example, a speech-language pathologist and special education teacher may work together towards improved communication skills for a student with ASD. Of the utmost importance, is the involvement of the family of the student with ASD in order for any behavioral intervention to be successful. The pervasive nature of ASD and difficulties generalizing from school to home and community environments make parents and other family members essential partners in the successful eradication or reduction of difficult behaviors. While parents should not be expected to provide educational programming, regular communication regarding a student's educational program and progress is essential. The degree of a family's collaborative involvement will vary from family to family, and it is important for a school district to consider the range of obligations and demands faced by parents. School districts should also demonstrate an awareness and respect for the culture, language, values and parenting styles of the families of students with ASD and provide parent training, if appropriate.

The IDEA and the federal regulations promulgated thereunder, also require that an eligible student with ASD not be removed from the general education environ-

ment to receive instruction, unless his or her educational needs cannot be met with supplemental aids and services in a general education setting. A student with an IEP is entitled to receive an education in the Least Restrictive Environment (LRE). This usually means in a setting with the most opportunity possible to learn along-side their peers without disabilities. The IEP is required to address interfering behaviors, so that the student can receive an education in the LRE. If the Committee on Special Education approves a setting as appropriate, it cannot then change a student's placement because of difficult behaviors, unless the district has attempted to appropriately address the behavioral needs. Before determining that a student would be so disruptive, that he or she would significantly impair the education of the other students, the district must consider the full range of supplementary aids and services that could be provided to the student in their current educational placement to accommodate his or her unique needs. Each IEP should also contain a statement of the program modifications or supports that school personnel will need so a student can be involved, and progress in, the general curriculum, can participate in extracurricular and nonacademic activities, and be educated alongside their peers without disabilities.

Nevertheless, a school district is also responsible for keeping students and staff safe, while protecting the rights of individual students. If any student is acting in a way that is dangerous to others or to the student him or herself, it is the school district's first job and obligation to deal with the danger and keep students and staff safe. Special education law cannot interfere with school safety. An eligible student with ASD can receive the same consequences or discipline as other students. The only one exception to this rule is when there is a long-term exclusion or suspension from education. The specific rights and rules concerning discipline for special education students is beyond the scope of this particular article.

Balancing the LRE requirement with the requirement that a school district provide an eligible student with FAPE is an ongoing and required dance for school personnel, Committees on Special Education, the student, and their family. The eligible student with ASD is assumed to be best educated within the general education environment alongside their peers without disabilities, unless there are very specific and clear reasons justifying a more restrictive and specialized environment. For the student with difficult behaviors, modifications to the general education curriculum in the regular educational setting may be required, and is a priority. For a student that has interfering behaviors, conducting FBAs and developing and modifying BIPs is required by law prior to moving students to a more restrictive educational setting. Problem and interfering behaviors are among the most challenging issues faced by school districts in their efforts to appropriately educate students with ASD. Using FBAs and BIPs and aligning them with an ASD student's goals in the IEP, will help to eliminate or reduce interfering behaviors, and will assist the student, the school district, and their family have a more positive, meaningful, and collaborative educational experience.

This article should not be considered legal advice. Please consult with an attorney before relying on any information contained herein.

Sheryl has worked almost exclusively with people with disabilities and their families for over 18 years. She is an expert in the area of special education, disability and special needs law and is a sought after speaker for professional and family organizations in the areas of special education law, life planning, and not-forprofit board governance for agencies that work with people with disabilities. She has also authored numerous articles on these topics. In addition to Sheryl's legal work, she is a zealous advocate for the needs, acceptance, and integration of people with disabilities in the community. Sheryl is involved and active in many organizations in the disability community including taking leadership roles in many of them and has been instrumental in developing and implementing programs in New York State for people with disabilities and their families. Sheryl is currently a Board member of the Arc of the United States. She is the past President Arc Westchester and served on the Board of Governors of NYSARC Inc. for six years. Currently, Sheryl serves as the President of the Board of Directors of Ferncliff Manor, a residential school in Yonkers for children with severe disabilities. Sheryl has been the recipient of many awards and honors for her work in the special needs community. Sheryl is a graduate of Union College and received her law degree from The Benjamin N. Cardozo School of Law School of Yeshiva University. Her eldest son, Aaron, has Autism, and is her inspiration.

For more information, you may contact Sheryl at sheryl@bargergaines.com or visit www.bargergaines.com.

### The ASD Nest Middle/High School Model for Inclusive Education

Aaron Lanou, MSEd Director of Professional Development ASD Nest Support Project NYU Steinhardt

his fall in New York City, over 1,000 students with ASD will be educated in fully inclusive classrooms in public schools all across the city. They will be learning and brainstorming and problem-solving alongside more than 3,500 of their general education peers. Of these thousand students, 300 are middle and high school students on the autism spectrum.

These students are part of the New York City Department of Education's ASD Nest program. Launched in 2003 at one school in Brooklyn, The ASD Nest program is now in 35 public schools across the five boroughs of New York City. The program was developed by researchers, including Dr. Shirley Cohen of Hunter College and Dorothy Siegel of NYU, and district leaders, led by then Superintendent Carmen Fariña. It was created in response to the growing need for effective school support for the growing population of students with ASD who are able to do grade-level work (Koenig, Feldman, Siegel, Cohen, & Bleiweiss, 2014). The program continues to be supported by New York University's ASD Nest Support Project, under the Principal Investigator, Dr. Kristie Patten Koenig and



#### Aaron Lanou, MSEd

Project Director Dorothy Siegel. Without appropriate supports, these students struggle in typical school environments, due in part to misunderstood behavioral differences, social challenges, and unique academic needs (Sansosti & Sansosti, 2013). ASD Nest program schools aim to cor

ASD Nest program schools aim to correct this problem. For teachers and therapists working in ASD Nest schools, this process begins by recognizing that students with ASD have ways of thinking about and responding to the world around them that are different than others. Their job is then to understand how these *differences in thinking* impact students, and then to support them when those differences become *challenges*.

To accomplish this, every ASD Nest school employs distinct practices that stem from three core elements of the ASD Nest model. Below are ten of the practices:

#### Structural & Collaborative Elements

- 1. Reduced class sizes: Nest classes have fewer students than typical inclusion classrooms to create environments in which students with ASD are comfortable
- 2. Training & professional development: All staff receive graduate-level pre-service training in autism and benefit from ongoing in-service workshops to maintain knowledge of promising practices in the field
- 3. Interdisciplinary team meetings: Teachers and related service providers collaborate weekly to discuss student challenges and develop cohesive support plans
- 4. *Home-school collaboration:* Staff communicate regularly with families about school events and to share successful strategies

Instructional Elements

- 5. *Co-taught classrooms:* A special educator and general educator team-teach every Nest class, allowing for maximal differentiation to support diverse learners
- 6. *Class-wide practices:* Teachers provide whole-class visual supports, priming, and organizational strategies for executive functioning weaknesses
- 7. *Therapeutic supports:* Speech therapists deliver a specialized social-therapeutic intervention and occupational therapists assist in organizing calming classroom environments, and social and sensory supports are woven throughout the students' school day
- 8. A positive behavior approach: Nest schools utilize school- and class-wide positive behavior supports, offering clear behavioral expectations and re-inforcing expected behavior

#### **Philosophical Elements**

9. Focus on strengths: Nest teams incorporate students' special interests and leverage students' strengths to alleviate their challenges

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enjoy seeing the "likes" roll in can attest to the power of recruited social reinforcement. For some, periodic splurges that are related to behavior change can make it easier to make shorter-term sacrifices. Consider an individual who wants to improve healthy eating and exercise. A natural reinforcement plan that provides a meaningful consequence for behavior change might be to buy some new clothes when a certain weight level is reached. This provides motivation and incentive for the individual for those times when the healthy lifestyle is harder to maintain, as well as a well-deserved sense of accomplishment when the goal is reached.

The best thing about self-management is that it can be absolutely free, and completely independent of assistance from others. Self-monitoring, prompting, and reinforcement can be accomplished in whatever ways are most appealing and productive for the individual. Although high-tech solutions are in no way necessary for effective self-management, the ubiquity of technology can make self-management even easier and more appealing to anyone. Multitudes of apps are available on mobile technology to support self-monitoring, self-prompting, and self-reinforcement across a variety of life situations. Recent research provides support for the use of both specifically-designed and publicly-available technology for self-management for individuals with disabilities (e.g, Mechling & Savidge, 2011; Cihak, Fahrenkrog, Ayres, & Smith, 2010; Blood, 2011).

Self-management is associated with greater independence and maintenance of behavior change, because control of procedures is given to the individual rather than relying on others. All aspects of self-management are readily and freely available to those who know how to use them. The key is ensuring that individuals are ready to self-manage as they enter transitions to more independent life circumstances. As in any transition situation, it's important to start to plan for necessary skills well in advance of the life change, and self-management is no different. Effective self-management strategies can be generalized and utilized throughout the lifespan, and effective self-management repertoire will serve anyone well in meeting and exceeding their personal goals.

To learn more about Transitions, an apprenticeship to assist young adults with Autism and other learning differences with success in college and careers, visit www. transitionsusa.org, e-mail info@transitionsusa.org or call (518) 775-5384.

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### Accommodating Executive Function Deficits is Important for School Success

#### By Yvona Fast, MLS Author and Advocate

Individuals on the spectrum often need special modifications at school. Because everyone is unique, all teachers should have a written document explaining a little about how the student learns best and outlining agreed upon adaptations. There are many lists of possible accommodations for students on the autism spectrum, but they must be tailored to each child. So much depends on each individual's abilities and what areas they find challenging. For most children, however, one key to success is an accepting and supportive environment.

Many people on the spectrum have problems with executive functions. These are the abilities that allow planning and prioritizing. These mental processes help us make decisions and monitor behavior. One common analogy is that executive function does for the brain what a conductor does for an orchestra.

When executive functions are limited, one major area of deficit is organization. These are the skills needed to organize one's thoughts, tasks, things, and time. The deficit can make it difficult to organize work, plan and manage projects, brainstorm feasible solutions to solve a problem, initiate tasks, and follow multi-step instructions.



**Yvona Fast, MLS** 

Fortunately, there are ways to compensate deficiencies in executive functioning. The first step in attacking this problem is to simplify. Reduce the number of things the child needs to keep track of until he is more capable of keeping track. For example, an extra set of textbooks for home helps because the student doesn't need to remember to bring them back and forth. Rigid structure and routine, technical organizing tools and freedom from distractions can help the child stay focused on the task at hand. Different colored folders make it easier to keep track of things. A planner or electronic organizer can help the student stick to deadlines. Smart phones and other gadgets can be set to offer reminders.

Work with the school staff to ensure she has a routine from the moment she hits the door in the morning and that they coach her throughout the day. Make sure there is a place for everything, and it always stays the same. At home, have a dedicated homework site as well as a set time to work on assignments. Have a specific, labeled shelf for school and library books that travel back and forth, and another labeled shelf for commonly needed materials. Have labeled, color-coded hooks for the school backpack and coat. A list of classmates for each class enables the child to phone someone to clarify assignments when necessary.

Use email to eliminate losing papers. Homework can be submitted at night by email; if the student forgets to bring the paper copy to school, the teacher already has it. All notices, permission slips etc., can also be emailed to the parent, who will email or fax them back as needed. As the child grows, he can take responsibility by emailing or phoning assignments to himself or to his parents, though at first, he may need prompting from an aide or teacher. That way it is still his responsibility to get the assignments home - just a different way of doing it. Allow him to submit completed papers and exercises via email to the teacher. (He is still responsible for completing and submitting the work - but he is using a different system that minimizes his organizational challenges.)

The problem here is not simply that the child forgets; she is unable to organize herself to remember. The Special Education (SPED) team must first help her develop systems and then continue to coach and prompt until she gets on top of it.

A coach or tutor can work with the student to develop strategies for organization, time management and study skills. This is often an aide or other person trained to work with special needs students. The coach can help the child discover which strategies work best for her, and will be invaluable with term papers and major research projects. These are important life skills that these children are unable to pick up on their own; they must be taught and reinforced. That is why a coach is necessary.

One thing the coach can do is review with the student at the end of the day what is supposed to go home, and make sure he has it. The parent should do the same before the child leaves home for school. Often it is necessary to both show and tell. For example: "Here is your lunch money, it is in the left pocket of your pants." The

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coach can also supervise a weekly locker cleanout. This is critical to keep the child from getting overwhelmed and losing things.

For large projects, this student will need help breaking complex tasks into their individual parts. Be sure the steps are written down and spelled out, so she can refer to them the next time. If a child needs help beginning a large task, help her think of one thing she could do to begin. Don't worry whether it should be the first step, middle step, or last step. Hopefully, just doing something will help break the logjam. Some other organizational tools:

- Checklists
- Ongoing check-ins to refocus and/or redirect attention as needed
- Written version of verbal instructions (i.e., list of steps)
- Make sure everything is labeled with the child's name. Engraved metal pet tags work well for this.
- Repeat, rephrase and clarify directions and information to ensure understanding
- Restate instructions to check for understanding
- Repetition, reinforcement and re-teaching of skills being taught

- Information/directions must be broken down into smaller segments
- <u>Class notes</u>: Assigned note taking buddies for class notes and assignments, or a note taker assigned in each class. Some teachers make enough copies of the note taker's notes for everyone to pick up from a basket, while others might hand them only to students with LDs (learning disabilities) or to those who were absent.

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

Student Strategies for Effective Time Management

- *Build routine* into your school day. Follow a plan or schedule. This will help you deal with interruptions, avoid distractions, and control the tendency to put things off.
- *Write a daily schedule* at the beginning of each day. Create and use "To Do" lists, and prioritize them. Decide what must be done first, what's urgent, and what can wait.

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- *Use your planner* not only to record tasks, but also include the details and task instructions. This notebook should be organized with headings, e.g. details of task, additional points to remember, deadlines etc.
- Schedule a time to work on each task, and write it in your daily planner. Be realistic. Allow more time than is needed for any project. Include time for distractions. A good rule of thumb is to pad the amount of time you think it will take you to complete a task by at least half. If you think a project will take an hour, block an hour and a half.
- Set realistic deadlines, and then work backwards, creating smaller deadlines. A computer outline can help with this.
- *Be flexible*. Remember that the schedule is only a blueprint. At the end of the day, look over what you've accomplished. If something isn't finished, don't get frustrated; simply move unfinished business to the next day.
- Use calendars. A monthly vs. a weekly calendar helps some people be more cognizant of the big picture. If things tend to sneak up on you, you may need to see more at one time and then switch to one day at a time mode.
- Organizing software and electronic organizers are useful for program-

ming repeating events. Things that take place at the same time can be programmed once to repeat at the same day and time each week, reducing the likelihood they will be forgotten.

- A multi-alarm programmable wristwatch or smartphone is another useful time management tool.
- *Record all project deadlines* on the calendar or electronic organizer. Break long-term projects into intermediate deadlines and enter these in the planner or calendar.
- Break large jobs into smaller chunks. Learn how to "chunk" work into meaningful units and time.
- Set smaller clearly defined goals that you can achieve in a reasonable amount of time. Don't try to tackle a large project all at once.
- Set clocks and watches a few minutes ahead.
- *Don't procrastinate*. Do it now, not later.

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

### **Tips on Advocating for Your Child's Education**

By Maria Suchy-Kozak Education Advocate Student Advocacy, Inc.

ASD diagnosis. Now what? In addition to all your other roles, you are now your child's Education Advocate. Because of the wide spectrum of what autism can look like, a diagnosis doesn't always happen during the early years.

You could get there early when your toddler begins to lose the language he/she had already acquired. Then again, maybe your child had a variety of seemingly unrelated issues like attention deficit hyperactivity disorder, sensory integration issues, delayed language development, obsessive compulsive disorder, intestinal or diet issues, just to name a few, and slowly, someone thought to look deeper and now your child is school age.

If your child's issues are affecting his education, you have the right under the Federal Special Education Law, IDEIA (Individuals with Disabilities Education Improvement Act of 2004, commonly referred to as IDEA, as it was called prior to 2004), to have your child fully evaluated by the school district to determine if there is a disability and if the disability is impacting your child's ability to be educated.



Maria Suchy-Kozak

#### Rule #1: Parents Need to Be Educated Consumers

It will be up to you to know and understand what your and your child's rights are under the Federal Special Education Law, IDEIA. You will need to learn how to speak the language. If you are unsure about your ability to do this or simply don't have the time, then you will need to find a qualified Education Advocate to guide you. You should not expect the School District to educate you as this is not their responsibility. The more you avail yourself of responsible organizations and agencies that provide education advocacy services and the more proficient you become in the language of special education, the stronger you will be in helping to craft a good school experience for your child. Student Advocacy's free publication, 101 Answers: Getting Help at School for Your Child with a Disability can help (http://www.studentad-vocacy.net/wp-content/uploads/2010/11/STU122 Book English Web.pdf).

#### Rule #2: Good Does Not Mean Best

The first thing to learn about IDEIA is that your child is entitled to appropriate services. That does not mean best. And while services that are "based on peer-reviewed research" are the ones you should expect, you do not get to dictate which ones you want. And here in is the dilemma you (and many other parents) might face. You will hear about all sorts of therapies and ideas through your network of contacts, but school districts don't have to provide them. Parents should work with their school districts to understand what can be provided and learn to advocate for research-based services.

Rule #3: Quality Evaluations

While your child is entitled to an eval-

uation, at no cost to you, the sad reality is there is a huge disparity in the quality of the evaluations.

If your school district was the first to identify autism in your child, then congratulations on receiving some potentially beneficial information in the evaluation. However, if your child has a multitude of issues as mentioned earlier and no one at the school has thought to do a screening for autism, your advocacy skills will need to be honed further. How can anyone plan a quality program for an autistic child if no one has thought to consider the possibility of autism? There are a variety of ways to go about this depending on your resources. You could get a private evaluation from a competent professional who specializes in this field and who has experience in writing reports for educational planning. Or, if you don't agree with the school district's evaluation you could exercise your rights under IDEA and request an independent evaluation. Either way, the goal is to obtain quality information about who your child is as a learner and some good strategies on how to help him/her learn.

Rule #4: Identify

Make sure that you understand the documents and letters you receive from the School District. Understand the different

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herself when the support is not present. So, let us fast forward to college when the same student is assigned with a term paper; after years of having tasks broken down for him, he does not know how to approach what appears to be a large assignment in an organized manner to meet the deadline at hand. If in high school or middle school, an accompanying IEP goal had been developed targeting the student's understanding of how to break down complex tasks and the student had been provided with direct instruction in how to develop an organized plan for large projects and assignments, then the student is more likely to be independently successful in other settings in which those supports are not present.

Additionally, building one set of skills does not develop another and IEP goals are likely needed across domains of EF. Supports for students with ASD and accompanying EF deficits should focus upon the following steps:

1) Provision of accommodations linked with identified areas of need. Example: Provision of directions in small, distinct steps for students with attentional difficulties, planning/organization needs or time management challenges.

2) Provision of modifications linked with identified areas of need. Example: Modifying worksheets with less information on a page to support attention.

3) Provision of goals targeting development of compensatory skills and strategies linked with identified areas of need. Example: Teaching a student how to develop and use a checklist by looking at the steps needed to complete a task, performing each step on the checklist and completing the list in sequential order (for students with planning/organizational and time management needs).

When providing students with direct instruction in EF strategies, instruction should utilize their known areas of strength. For example, many individuals with ASD present with strength in the area of visual processing and reasoning. As such, instruction in these strategies should be comprised of both auditory and visual instruction as well as instruction for the student in how to generate the visual support for himself. Instruction in compensatory skills should be delivered in a manner in which the student understands how and why these skills will assist him to be more independent in completing a variety of tasks. It is important that as a part of this process the student is learning about his own strengths and needs to know how to effectively manage challenges as well as to advocate for assistance when needed. For example, if a student understands that he exhibits difficulty with working memory and creating a checklist will help him to successfully complete his assignments, he is more likely to engage in acquisition of this skills than if it is presented as yet another task for him to do (Ozonoff & Schetter, 2007; Guare, Dawson & Guare, 2013).

In addition to the direct instruction of EF strategies, provision of parent training in ways of supporting their child at home is crucial to establishing lasting success and generalization of skills. When parents are taught how to support their child using the same strategies as used at school, students are more likely to recognize the strategies and comprehend how to develop them for themselves. For example, if working memory is identified as an area of difficulty for a student and checklists are implemented at school to facilitate accurate task completion daily, checklists should be used at home to facilitate accurate chore completion or completion of an after-school schedule. Not only is generalization of the strategy more likely to occur if it is used across settings, but the students are likely to learn compensatory skills with greater speed if they are occurring in multiple environments.

The key to facilitating student success and future independence is to step beyond provision of accommodations and modifications and to teach students how to develop compensatory skills for themselves so they are prepared to enter a world that does not always provide these supports to them.

For additional information Spectrum Services or Dr. Cody's practice, visit: www.spectrumservicesnyc.com or contact Dr. Cody directly at KatherineCodyPsyD(a)gmail.com or (917) 512-7751.

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### The Vital Need for Support and "Me Time" for Parents of a Child with Autism

By Lucina Clarke, MSEd Executive Director My Time Inc.

aising a child diagnosed with an Autism Spectrum Disorder is a journey. It requires a lot of support. There will be challenges but many wonderful rewards. It can be a difficult process but when you have the right people around you, it is a road well-travelled.

As I write this article. I feel a sense of joy, hope, peace and love. Helping to support parents caring for a child with autism is my passion. What is parent support? It is when a group of parents come together to share their concerns, joys, fears, excitements, challenges and love for their child on the autism spectrum. The word "support" has many definitions. In this sense of parent support as it relates to parents supporting each other in groups, it can be defined as: "Lean on me, don't judge me, be there for me, embrace me, allow me to cry and please listen to me." Also, it means that during those times when you feel like the world is on your shoulders or everything is crumbling down, with a positive support group, you will know you are not alone.

What parent support is *not* is complaints, negativity, judgments, critiques, hopelessness and feeling alone. On the contrary, parent support is positivity in



Lucina Clarke, MSEd

the most caring, empathetic and dynamic form. It is not clinical therapy. Rather, it is therapy for the mind, body and soul. In my opinion, every parent should have the right to belong to or be a part of a group that provides that special judgement-free place to share and connect.

In a survey of 219 parents of children with autism, Sharpley, et al. (1997) found that more than 80% of parents reported sometimes being "stretched beyond their limits," with mothers reporting higher stress levels than fathers. The authors commented that the three most stressful factors of being a parent of a child with autism are "(a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviors by society and, often, by other family members; and (c) the very low levels of social support received by parents." Subjective parental pain and consequent stress went unobserved (Johnson, 2013).

Mothers, you must take some time out of your hectic schedule for some "me time" in life! Too often, as a woman you feel and think you are a superhero that can do it all, raise the child and take care of the family while failing to take care of yourself. It is important to step back and think about when you last set aside time to take care of yourself to manage the stress of everyday life. When you take some "me time" to care for yourself, it is like having a delicious piece of chocolate melting in your mouth - the sensation of relaxing and focusing on yourself is quite intoxicating! Challenge yourself to bring out your fabulousness. Love yourself enough to be alone and take that quiet moment just for you.

Fathers, while often overlooked, also need support. Seeking out help and support is not a feminine thing, it is a real thing. You too have concerns about your child and how to best support his unique needs. It is alright to cry and feel helpless but you must translate these feelings of despair into motivation for seeking out support. Find a group that embraces your emotional yet exterior macho side. It's out there - believe me I see it. When you and your partner are getting this vital support, your home and surroundings are calmer, more relaxed and more conducive to providing support to each other. Get to know other men who have a child with Autism. Be proud to speak of your child. Boast, embrace and shine in the moment. Connecting with other fathers will show you that you are not alone.

Sigan Harley, a University of Wisconsin-Madison researcher, conducted a study that showed more than 30 percent of fathers of grown children with autism experience symptoms of depression so severe that they warrant clinical attention. Harley states, "Fathers of adolescents and young adults with autism are really faring the worst" (Diament, 2011). This statement confirms my observation of the fathers I have served who attended the support group. Most of the fathers have a difficult time expressing their fears, concerns or even acceptance of a child with Autism. It seems difficult for them to speak about the disability and some of them may not voice their opinions. I realized that with the fathers, they too have to be reminded that they are not alone and need support. I will always remember the words of one of the parents, "I was flying blind until I started attending this

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#### Model from page 6

minds than mine have worked to find those answers, and evidence-based practice is an ethical obligation of any health professional. What I'm saying is that we also have an ethical obligation to think outside of that space, primarily because the current model just isn't working. Insurance funding for children with Autism does not - for the most part - provide access to the holistic, interdisciplinary therapeutic model that families want and need. Now we are in an environment where insurance billing has become a source of conflict between professions, when really it should be an opportunity for us to invite more people in. If we can't get reimbursed for the frequency of therapeutic visits we feel is appropriate, then let's find experiences and instruction that can complement our services without requiring the same rigorous practices (and their concomitant cost). If our goal as professionals is the growth and happiness of the children we serve, then it really shouldn't matter who facilitates it, provided we can ensure it is done ethically, responsibly, and in a way supported by the science.

I asked Lindsey what she wanted her kids to learn at swim lessons, and she said

self-discipline; bodily awareness; teamwork, friendship, and social intelligence; perseverance in the face of hardship; flexibility in the face of failure. I asked Sue what she wanted her son to learn in therapy, and her answer was almost word for word the same. I wonder whose program will be more successful, given that the swim instructor automatically has access to something I don't: An instructional context that's aligned with social and developmental expectations. If swimming with same-age peers is a better program for learning social skills and flexibility, professional scuffles about scope of practice will become moot as every child with autism is pulled out of therapy and enrolled at the YMCA. In my experience, the only people who actually care what letters I have after my name are the insurance companies. Are those letters a gateway to entry, or are they a cage?

A few months ago I met with an Autism researcher at a medical university who shared with me some fascinating facts about his past working with rodents. For years he injected mice with various toxins and environmental agents in an effort to create Autism, and he finally "succeeded" – at least insomuch as he created antisocial mice with sensory preferences. Then he changed the size of the cages where the mice were held, and everything disappeared. He couldn't reproduce his results. He said that his research and career was held in a "cognitive jail imposed by size eight shoes," referring to the experimental restrictions imposed by the industry-standard size of rodent cages. If that fundamental convention was wrong, then what did that mean for all the assumptions based on it? An intellectual house of cards built by a century of researchers comes crumbling down because of a few square inches of shoebox.

I worry about the professional cages we've built for ourselves. Some are so large and flexible that I can't make out the horizons, and some are so small and rigid that they barely seem to contain anything at all. To what extent are we jailed by the conventions of our practice? Meanwhile, while we argue in the ivory tower about who gets to do the things that work, there are other people setting up shop outside selling predatory hocus pocus that *doesn't* work. Professionals in our field have lost the public trust because we let the snake oil brokers hold the microphone for too long. Let's take a different path back to the stage. Let's shake off the cognitive jail, assume everything we know is wrong, and worry about parceling out the who, where, and how when we're confident we've

nailed down the *what* and the *why*. Let's build a constellation of evidence-based support as varied and unique as the children that we serve, and let's do it together; there's no one-size-fits-all approach to therapy, and there's something bizarrely paradoxical about being rigid in service of a population that ostensibly needs to learn flexibility.

It's 7:00 PM on a Tuesday and Lindsey is back at the pool picking up her kids. I finish working with Sue's son and walk back into the lobby (the last question he asks me: "Are names still words, even if they're weird?"). As she's checking out, my office manager tells Sue she has seven visits left this year. "What do I do after that?" she asks. I pause and think of my friend Lindsey.

"Have you thought about swim lessons?"

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### **Accommodations After High School: What Now?**

#### By Hallie Ertman, BS Resource Manager Madison House Autism Foundation

Ust getting into college, let alone succeeding there, is stressful for many students and their families. When a student is on the autism spectrum the whole process can seem unmanageable. What do you do when you have what it takes to succeed in higher education, but you struggle with things like time management, organization, changes in routine, or the social aspect of your environment? How do you figure out what you need to do your best in school, and how do you get it?

There are over 4,000 colleges and universities in the United States, and many of them have excellent supports and even dedicated programs for students with disabilities. It takes both planning and effort, but many students on the spectrum can and do earn college degrees; including those who have struggled in the classroom.

One of the first steps is determining the right level of support. Offering the highest level are the special disability programs, which can be either internal or external to a school. These are often transitional, particularly the external programs, but some take students all the way through a degree. Virtually all such programs offer supports outside the academic realm, such as social skills training or support with daily living



Hallie Ertman, BS

skills. The more common, and generally less expensive, model is individualized support. This means being accepted into the school through the typical process, applying for specific supports or accommodations, and then usually advocating on your own behalf to see that your supports are received on a class-by-class basis. Housing accommodations and non-academic supports exist, but they may be harder to get.

When a student knows approximately what level of support is appropriate, the next step is figuring out exactly what accommodations are needed and what shape they will have to take. Examine the IEP closely, if there is one, but also consider the differences between high school and college. Think about the new challenges that college brings and what extra supports could smooth the way. A high school day is one continuous block for most students, but this is not true in college. Will managing a daily schedule for class, homework, and study time require extra help?

Some of the most common supports in higher education are uncommon or irrelevant in high school. Preferential seating, for example, might not have been needed when students had assigned seats. Being allowed to use a calculator, have a laptop in class, and to leave the classroom for self-regulation breaks may all be new potential accommodations. Access to speechto-text software or assistive devices, note takers, alternate exam formats, extended deadlines, tutoring, altered assignments, tape recorders, and access to instructor notes are less likely to be new, but they may become important to students who didn't require them at lower grade levels.

With this groundwork laid, you can evaluate specific schools and programs. In examining your choices, it's not sufficient to know that certain accommodations are offered. Not all institutions implement them the same way. Tutors, for example, can be professional or peer. You need to know how many are available, what kind of training they get, whether or not they are certified, how much experience they have, and whether they are available for every subject or class.

To determine if a school is implementing something poorly or in a way that just won't work for you, think about what each service really means and why it's needed. Consider a student who receives extra time on tests. Why? Does it have to do with concentration, verbal processing, both, or neither? If concentration is a factor, will he need the entire test time to be uninterrupted? Does he also need a distraction-free area? If he hasn't needed a separate testing area in high school, is it possible he will in college, when classes are in large lecture halls with hundreds of other students? Some schools offer extra time on tests by creating a dedicated, distraction free test area outside the classroom. At others, all students take the test together in one lecture hall and the majority of students are released when their time is up, which creates noise and other distractions for the students who receive extra time. In the least effective cases, all students receive the same amount of test time in the classroom, and when that time is up, those receiving

see What Now on page 28

#### Blame from page 18

Blame them.

Because of my daughter Rose, Joe and I knew for sure that the sneaky anxiety snake was indeed whispering in his ear once again.

After eating breakfast together one morning, Rose waited until her brother went upstairs for his sneakers before she touched my arm and said softly, "Mom, something isn't right with Jack."

It was a few weeks after Easter, and she was still wearing the pink rabbit earrings that the Easter Bunny left in her basket. It was her very first pair of dangly earrings.

How can a 7-year-old girl wearing her first pair of dangly earrings so aptly describe her big brother's anxiety?

"He just isn't himself."

Because of our 12-year-old son Joey, Jack runs track on Wednesdays. See, Jack hates sports. He really hates

anything right now that doesn't have to do with YouTube videos and Oreos and baking cakes. So we signed him up for the Special Olympics track team. And he threw the biggest fit you've ever seen until Joey agreed to do it with him.

And during the first practice, Joey took off down the track, his neon yellow sneaker flashing. He looked back over his shoulder at his brother, and then slowed just enough for Jack to catch up. Jack jumped on his back, laughing.

If Jack believes he is fast—that he can run like the wind and feel the cool breeze of a New Hampshire spring in his face well, that's all Joey's fault.

Blame him.

Because of our dog Wolfie, he knows

that sense of comfort or discomfort - this

how it feels to cry into the furry neck of a patient, waiting puppy.

Because of 6-year-old son Henry, he knows how to shout to be heard.

Then there is Cody. Sweet, adorable, green-eyed Cody - the boy in Jack's class who told another boy to leave Jack alone and stop calling him names.

I blame Cody for being brave and honest and kind. I blame him for being one of Jack's very first friends.

Then there's Jack himself; the owner, the landlord, the keeper of the spectrum key. He never asked for this diagnosis. He never asked for a cure or for headlines or blame.

And he is so much more than science.

He is a fifth-grader who longs to belong. He is a brother and a son, a track-runner

and a cupcake-baker. Like a kaleidoscope, he is colorful and

beautiful and perplexing.

• Visit the group

- As you visit the group, you will get a sense of the dynamics
- Ask yourself these questions: Do I feel comfortable? Am I able to feel that I can share without being judged?

Finally, find a support group that educates, supports, empowers, uplifts and enlightens each of you. As my husband and co-founder of My Time Inc., Wayne Clarke stated, "Parent support is not a new phenomenon but My Time Inc. is bringing a new and dynamic perspective to it."

For more information about My Time Inc., please visit www.mytimeinc.org or Sometimes, he makes my eyes hurt. Sometimes, he makes my head hurt and other times, my heart.

As the world of science continues to tackle the difficult job of figuring out where autism comes from, I'm going to continue turning the kaleidoscope in my hands so I can learn the patterns and colors and mystery right in front of my very eves.

I'm going to celebrate the people-and puppies-responsible for Jack's progress, his joy, his confidence and safety.

"Hey. That is my friend. Don't talk to him that way."

"What Color Is Monday?" is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: www.WhatColorIsMonday.com and Facebook.com/WhatColorIsMonday.

#### Me Time from page 23

parent support group. The blinders are being removed. I can be a better parent and be more supportive with my wife in raising our son on the autism spectrum." When you hear words like this, it affirms the critical role that support groups play for parents.

Parent support groups vary. As a parent, you will have a sense of which group fits your unique needs. Life is about choices. We tend to make choices based on how we feel, other people's input and based on societal views. My advice to you when picking a support group is to always go with your instinct. Trust that gut feeling, that butterfly sensation in your stomach,

is a given gift to us that we rarely utilize. Support in all manner must feel good. Positivity reigns over the negativity. The aura or dynamics in the group should give you positive energy and should show respect to all and for all.

Parents, you deserve having "me time" or a time to relax. You have to rejuvenate yourself as you raise your child on the autism spectrum to live a functional and social life in the community. Be well, stay strong and think positive.

Here are some tips when looking for a support group:

Get in contact with the support group facilitator

email Lucina@mytime.org.

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10. Commitment to true inclusion: Students with ASD are recognized as full contributing members to their class and school communities

These elements together create learning environments where students on the autism spectrum are understood, respected, and supported.

#### Changing Needs in Adolescence

The ASD Nest program began as an elementary school model. This model has been described in great detail in *The ASD Nest Model: A Framework for Inclusive Education for Higher Functioning Children With Autism Spectrum Disorders* (Cohen & Hough, 2013). As students in the ASD Nest program aged up, the program began to enter middle schools across New York City. This is in line with a growing trend in this country: an increasing number of students with ASD in inclusive classrooms (USDOE, 2010).

Secondary students with ASD continue to require supports to be successful in their classes, get along with their peers, and smoothly navigate through each school day (Fleury et al, 2014). And while many of the core supports in middle and high school can remain the same from elementary school, the ASD Nest program identified a need to update the model for secondary schools. There are significant scheduling differences between elementary and middle/high school, and the social and academic needs of students with ASD change as they become adolescents. Both these structural and developmental differences change the way students in middle and high school get support. No longer is one pair of teachers responsible for an individual student all day; instead a student interacts with up to 12 adults across a school day. A student cubby can house and organize all of a fifth-graders materials; in middle school, students need to navigate lockers, textbooks, and desks in five different classrooms

#### The Middle School/High School Nest Essentials

Over three years, a dedicated group of middle and high school teachers from ASD Nest schools worked with Aaron Lanou, the Nest's Director of Professional Development to develop the guiding document for Nest middle and high schools. Built on the same core elements—Structural & Collaborative, Instructional, and Philosophical—described above, the *Middle School/ High School Nest Essentials* (Lanou, 2015) define the model's "instructional elements," specially designed for secondary teachers.

The *Nest Essentials* are broken down into the following categories, intended for all teachers working with this population in a given school, to create a coordinated system of support across classes and teaching teams. While being written for use in ASD Nest schools, these "essentials" can be incorporated into any inclusive secondary classroom.

Organization of the Classroom Environment - The starting point for classroom strategies is the room itself. Because students with ASD can become distracted or overwhelmed by their environment, classrooms need to be arranged and organized in such a way as to avoid visual and auditory distractions (Fisher, Godwin, & Seltman, 2014). Generally, classrooms should be neat and organized, without visible clutter that could serve as a visual distraction. Adjustments should be made to address students' sensory needs, such as using alternative lighting. Overhead fluorescent lighting can be experienced as distracting or even painful; standing lamps or natural light are good alternatives.

*Classroom Structures & Routines* - Because students with ASD benefit from structure and predictability, teachers need to create and teach common classroom routines (Myles & Simpson, 2001). For example, entering and exiting routines should be established and directly taught to students. In addition, an agenda and homework area should be designated and displayed in the same location every class session for easy reference. All routines need to be explicitly taught, practiced, and reinforced throughout the school year, and a visual poster should be displayed as continual reference.

Self-Regulation Routine - Students with ASD can become overwhelmed and struggle to regulate their behavior in ways expected of students in inclusive classrooms. Therefore, classrooms should have a break routine for allowing students to remove themselves from a stressful situation (Mvles, & Southwick, 2005). The break area, located either in a designated area of the classroom or a separate nearby room, is not a time-out area. Rather it is a place for students to elect to go to calm themselves and ready themselves to return to instruction. Break areas should be quiet, comfortable and can contain calming books and activities. Again, the break routine should be taught and practiced to help students develop self-regulation.

Social Supports - Because students with ASD may misunderstand aspects of social relationships and social expectations, classroom structures, instruction, and activities should be planned to support students' social challenges. Before beginning group work, for example, every group member's role should be defined and explained concretely. Teachers can use roles—such as recorder, researcher, and reporter—to clarify expectations. Support should also be given during class activities that may tap in to social challenges, such as finding a partner and accepting feedback from peers.

*Instructional Strategies* - Classroom instruction needs to be delivered to match the learning style of students on the autism spectrum. Their academic performance can be impacted by social challenges and impairments in executive functioning (Whitcomb, 2015). Accordingly, supports should be created to make the curriculum accessible. Copying from the board should be limited, and note-taking supports, such as graphic organizers and guided notes, should be provided. Complex tasks need to be broken down into clear sub-steps, and a visual of the steps should be provided. Finally, visual timers can be used to show how long activities last and to prepare students for transitions.

The benefit of implementing practices like those described is that they support not only students with ASwwwD, but all students in inclusive environments.

#### Putting it All Together

The *Nest Essentials* classroom strategies are a core feature of the ASD Nest Middle/High School Model, but they are only a piece of the overall support structure. The ten practices described earlier are all necessary to create a supportive learning environment, and the process must begin with a deep desire to see inclusion as a "way of doing business in schools" (Kluth, 2013, p. 15). For a school or district to effectively implement this kind integrated system of supports, logistical and attitudinal buy-in is necessary from all stakeholders:

- As school leaders, administrators need to be knowledgeable about inclusion of students with special needs, and commit to the training and support for their staff to support this population.
- Teachers and therapists working with adolescents with ASD need to be flexible, creative, and collaborative, and commit to understanding student differences.
- Families, both of those of the students on the autism spectrum and of the general education population, need to understand the model and its benefits.

Laying the Groundwork for Future Success

This fall, three particularly incredible students are beginning their freshman year of college. Without the ASD Nest program, there is a strong chance these students would never have made it to this milestone. These three young men were three of the first students in the ASD Nest pilot in 2003. Through the academic and social strategies provided, and the structural commitment to supporting the adults who worked with them, these students thrived. They developed the skills and competence to prepare them for successful college careers and meaningful and fulfilling adult lives.

School systems around the country and the world—can create supportive school environments for adolescent students on the autism spectrum. By providing classroom supports within a system of structural supports, schools can help students with ASD can achieve their full human potential.

Aaron Lanou, MSEd, is Director of Professional Development at the ASD Nest Support Project at New York University's Steinhardt School of Culture, Education and Human Development. For further information about the ASD Nest program please visit http://steinhardt.nyu.edu/asdnest or contact us at asdnest.web@nyu.edu.

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#### Classroom from page 1

Before these practices can move into the classroom, we need to agree on a working definition of an evidence-based intervention. Professionals' and caregivers' reliance on untested methods and strategies with limited evidence has resulted in unrealistic and unreasonable expectations for students, while hindering the potential progress of students with ASDs. It is important for teachers, administrators and school personnel to be knowledgeable about evidence-based approaches to adequately address the needs of students with autism. To help accomplish this, the National Professional Development Center on Autism Spectrum Disorders (NPDC), collaboration among three universities — the University of North Carolina at Chapel Hill, the Waisman Center at the University of Wisconsin at Madison, and the MIND Institute, University of California-Davis - has established a set of standards for a practice or intervention to be considered evidence-based. The NPDC determines if an intervention is effective through a process of peer-reviewed research in scientific journals and must meet the following criteria:

(1) Either a randomized or quasi-experimental design where two high quality experimental or quasi-experimental group design studies are conducted by at least two different researchers **OR** 

(2) A single-subject design where five high-quality single studies were conducted by three different investigators who have a total of at least 20 participants **OR** 

(3) A combination of evidence, meaning one high-quality randomized or quasi-experimental group design and at least three high-quality single subject design studies conducted by three different investigators (http://autismpdc.fpg.unc.edu/what-criteria-determined-if-intervention-was-effective).

When considering interventions and strategies in the classroom setting, we are focusing on individual instructional practices used to teach specific education targets, skills, or concepts to children with ASDs. They are ideally based on explicit teacher behaviors that can be described and measured and typically involve multiple steps (Odom, Collet-Klingenberg, Rogers & Hatton, 2010). The NPDC has identified 27 evidence-based practices, reflected in Table 1. (http://autismpdc.fpg.unc.edu/evidence-based-practices).

While best practices in autism are more complete and accessible today, educators still face the challenge of accurately replicating the strategies in the classroom. It is imperative, not only for the field of special education, but also for those educators responsible to have firsthand knowledge of these practices to help minimize the gap between research and practice. Teachers have the advantage of directly being able to identify each student's specific needs and goals; when they have knowledge of how to implement EBPs in the classroom they are better equipped to match the strategies to the individual needs of each student (Simpson, 2005). It is also equally important to collaborate with educational professionals, as well as the student's family to identify additional pertinent goals and objectives along with the student's individual preferences and motivators.

These identified EBPs are not final, the



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literature in ASD is active, with new research studies focused on interventions being published monthly (Odom, Collet-Klingenberg, Rogers & Hatton, 2010). Since the literature seldom describes the implementation in enough detail for a teacher to bring to the classroom, the NPDC has constructed step-by-step guidelines and corresponding checklists to guide teachers in their use of these methods in schools. These checklists are assembled in web-based modules, developed by the NPDC in collaboration with the staff at the Ohio Center for Autism and Low Incidence Disabilities and the Autism Intervention Modules website (http://www.autisminternetmodules.org). In addition to the implementation guidelines, the modules also contain information on the evidence-base for each practice, procedural details of the EBP, descriptions of how to collect data for the particular practice, case examples, picture examples, video examples and additional resources, such as data, sheets, materials (Odom, Collet-Klingenberg, Rogers & Hatton, 2010).

Teachers have little support when selecting strategies and are left to their own devices when determining which practice is best. This often leaves them to make decisions based on variables unrelated to the scientific basis for particular strategies (Hess, Morrier, Heflin & Ivey, 2008). A third of the interventions teachers reported using in the classroom had limited support from a research standpoint, suggesting a disconnection between the accepted best practice and what is going on in the classroom. A way teachers and practitioners can bridge the gap between research and practice is by effectively promoting EBP in their schools by utilizing the NPDC webbased modules. This helps practitioners grow knowledgeable about EBPs and how to implement them with fidelity. More guidance on best practices for teaching students with ASD is needed. Public and private school leaders should also receive training. Academic leaders, involved in curriculum selection, teacher recruitment, employment and evaluation, are in positions to ensure that teachers use the most effective strategies to teach students with autism and avoid strategies with limited scientific evidence. The work of the NPDC is one resource using research to develop step-by-step guidelines, implementation checklists and web-based modules for edu-



Patrick R. Hof, MD

cators and other practitioners.

To move the research on effective interventions for students with autism into the classroom requires a systematic process for identifying and describing EBPs. The NPDC is supporting this effort. The broader range of literature featuring more EBPs bodes well for the scientific field as well as for improving outcomes for children and youth with an ASD and their families. Teacher preparation programs need to ensure that future educators have the tools to accurately evaluate research to help them identify EBPs, know how to implement that practice and keep informed of the latest research. School systems must encourage professional development and support for implementing evidence-based strategies into daily practice. Through practical instruction, as well as opportunities for professional conferences, workshops, and systematic reviews of research, educators will be better able to meet the diverse and challenging needs of students with ASD. Moving from science to practice continues to be a clear challenge. However, it is a critical next step for the field.

Jill Krata, PhD, is Program Coordinator of Autism BrainNet at the Icahn School of Medicine at Mount Sinai. Dr. Krata has over 15 years of clinical and academic experience in working with individuals with autism spectrum disorders, intellectual disabilities, and various genetic disorders such as Williams and Fragile X syndromes. Dr. Krata holds a doctorate degree in intellectual disabilities and autism from Teachers College, Columbia University and master's degrees in clinical psychology, counseling psychology and special education. Dr. Krata previously worked at the YAI Network in a variety of clinical and managerial positions in the residential and clinical and family services departments, including the Center for Specialty Therapy, Premier HealthCare and most recently, as the Manager of Clinical Services at the Autism Center. Currently, Dr. Krata is the Program Coordinator of the Autism BrainNet regional node at the Icahn School of Medicine at Mount Sinai. Dr. Krata is affiliated with various professional organizations, including the American Association on Intellectual and Developmental Disabilities (AAIDD), The National Association for the Dually Diagnosed (NADD), The Council for Exceptional Children (CEC) and the Division on Autism and Developmental Disabilities of the CEC, and The Williams Syndrome Association (WSA).

Dr. Hof graduated from the School of Medicine of the University of Geneva, Switzerland, and now is the Irving and Dorothy Regenstreif Research Professor of Neuroscience and the Vice-Chair of the Fishberg Department of Neuroscience at the Icahn School of Medicine at Mount Sinai in New York. He also leads the Kastor Neurobiology of Aging Laboratories in the Friedman Brain Institute. Dr. Hof became, as of 2012, Editor-in-Chief of the Journal of Comparative Neurology, which was founded by C.L. Herrick in 1891 and is the oldest journal of neuroscience in existence. His laboratory has extensive expertise in the pathology of neuropsychiatric disorders and has established an international reputation in quantitative approaches to neuroanatomy and studies of brain evolution. Dr. Hof's research is directed towards the study of selective neuronal vulnerability in dementing illnesses and aging using classical neuropathologic as well as modern quantitative morphologic methods to determine the cellular features that render the human brain uniquely vulnerable to degenerative disorders, in particular Alzheimer's disease and frontotemporal dementia. Dr. Hof recent research demonstrated using a combination of electrophysiology,

#### see Classroom on page 29

Table 1. Identified Evidence-Based Practices (Practices in boldface type were identified as new in 2014)

Antecendent-Based Intervention	Naturalistic Intervention	Self-Management	
Cognitive Behavioral Intervention	Parent-Implemented Intervention	Social Narratives	
Differential Reinforcement of Alternative, Incompatible, or Other Behavior	Peer-Mediated Instruction and Intervention	Social Skills Training	
Discrete Trial Teaching	Picture Exchange Communication System (PECS)	Structured Play Group	
Exercise	Pivotal Response Training	Task Analysis	
Extinction	Prompting	Technology-Aided Instruction and Intervention	
Functional Behavior Assessment	Reinforcement	Time Delay	
Functional Communication Training	Response Interruption/Redirection	Video Modeling	
Modeling	Scripting	Visual Support	

#### Tips from page 22

parts of an IEP (Individualized Education Program) document. Always fully understand the nature/purpose/title/agenda of any meeting that is scheduled. The rules for a Committee on Special Education meeting (CSE) are prescribed by law and are different from a team meeting. You can only be prepared to fully participate at a meeting for your child if you know what the meeting is being called and the purpose of such a meeting. If you are not sure about the purpose of a meeting, call the person who sent the letter and ask before the meeting.

#### Rule #5: Put It in Writing

Always take notes. Be an active listener as this is your opportunity to hear what everyone is saying about your child. There isn't much time so best to save your personal stories for a less formal venue. Confirm your understanding on what is being agreed to at any meeting you attend. If it's a CSE meeting and an IEP is being developed, make sure you understand what will be written into the IEP about your child's strengths and weaknesses. Ask to see a draft at the meeting. Contribute to what is written about your child so that it sounds like the kind of learner your child is. His/her educational needs must be apparent to any teacher that reads the IEP.

Sum up your understanding of what transpired at the meeting and the agreements reached and send it to the school district. A new IEP must always be sent to you after each CSE meeting. When you receive the IEP make sure it matches your expectations and agreements reached. Mistakes do happen. Call and follow up with a letter immediately should you discover one.

#### Rule #6: You Are Not Done Yet

There will be an IEP written and avail-

able by the first day of school. That is the law. You will receive it when it has been finalized and ultimately approved by the School Board. Don't assume all your child's teachers have read it by the first day of school. If there are issues that need to be communicated to the teacher, do so in a personal letter that introduces who your child is. Providing a copy of the IEP with the letter won't hurt and might even be appreciated. Be proactive in your involvement with the school and parent committees, if you can, as this is the best way to meet other parents, share information, get to know the staff and know firsthand what is happening in your child's school. Teachers are busy people too.

#### Rule #7: Don't Panic

Nothing is working. If you are lucky, this may never happen to you, but chances are at some point you will go through a range of emotions because of something the school did or did not do and it looks like the worst school year ever. And since you have a child with ASD, time is of the essence and the clock is ticking relentlessly while you see the signs of regression creeping up. The thing to remember is that this should never be viewed as a do or die situation. Rather, it needs to be looked at as another opportunity to hone your advocacy skills. For the reality is you are raising an ASD child to become an adult with ASD who needs to learn to be the BEST that he/she can be, to be as independent as possible and contribute to the world we live in in a positive way. There will be many obstacles along the way but there will also be many wonderful people you will meet in that journey and opportunities you never dreamt possible. At least this has been my experience having raised two ASD boys, now in their early 20's.

For more information, please visit www.StudentAdvocacy.net.

#### Training from page 12

needed in supervision often do not overlap significantly with the skills needed for implementation and direct service delivery. While those skills may be necessary for effective supervision, they may not be sufficient. What makes for an effective supervisor? How should individuals be helped to assume a supervisory role? What are the skills needed for effectiveness in this role?

Supervision allows for the provision of specific feedback to hone skills. Detailed and concrete feedback must be delivered to correct errors, increase efficiency, and ensure that instructional opportunities are maximized. Supervision also allows for the assessment of the integrity of the instructional procedures. Is the instruction being delivered as planned? Are all elements of the intervention in place? Are there important aspects of instruction that are not evident?

Supervisors also build professionalism skills - helping to train the next generation of trainers, supervisors, and administrators. Supervisors can shape the professionalism of supervisees by providing guidelines and feedback on interactional style, on the protection of confidentiality, on the management of conflicts and differences of opinion, and on building consensus within a team.

#### Melmark's Supervisor Training Program

At Melmark New England, Helena Maguire has spent 20 years developing a systematized and evidence-based way to build skills of new supervisors. The program is rooted in the theory and techniques of ABA. It is organized into an 11 session training program focused on core, essential skills for supervisors. Topics covered include: Motivation and Staff Supervision, Pinpointing Work Performance, Monitoring Staff Performance, Staff Training, Communication and Listening, Performance Feedback: Procedural Integrity, Performance Evaluations, Diagnostic Feedback Role Plays, The Discipline Process, and Creating an Effective Team.

An organizational behavior management approach is used (e.g., Reid & Parsons, 2000). Supervisors are taught to use the principles and procedures of Applied Behavior Analysis to improve the skills of staff. Participants at Melmark's Andover, Massachusetts and Berwyn, Pennsylvania sites are taught to pinpoint needed skills, train staff in those skills, and monitor their performance.

Within the training, emphasis is placed on efficiency and effectiveness. Supervisors are trained to delegate and to follow-up on those delegations. They are taught to provide objective and specific positive and corrective feedback in the context of a supportive and nurturing supervision relationship. Consistency and fairness in approach are emphasized.

As part of their supervision training, trainees take on a supervisory project. This project is designed to help build skills in goal setting, staff motivation, delivering feedback, and assessing the success of an implemented program. Participants in the training might take on a staff compliance challenge such as the collection of data on self-help skills. They might target a cultural issue such as positive interactions between staff, and develop an "applause" bulletin board for increasing staff members' statements of appreciation and positive feedback to one another.

The project itself offers an opportunity for learning project management skills. The following summary of crucial tasks outlines the strategy for getting a long-term project done. It also builds the skills needed for such projects - problem identification, hypothesis generation, data collection and analysis, the creation of recommendations, and the ability to present such information in a public presentation.

- 1. Identify a problem.
  - Identify the behavior with an operational definition you are looking to either increase or decrease (Dependent Variable).
- 3. Collect some descriptive information as to when this behavior occurs and does not occur.
  - Collect baseline data on this behavior. Specify what data system you used in written form.

- 5. Summarize this information as to the hypothesis of some potential functions.
- 6. Develop a written specific intervention (Independent Variable) that you have selected to employ to change behavior in the desired direction.
- 7. Collect data until you see stable responding.
- 8. Draw conclusions in writing as to the efficacy of your selected treatment, via PowerPoint.
- 9. Propose recommendations for the continued use of your treatment. Develop a PowerPoint presentation to demonstrate your project.
- 10. Present final presentation (brief PowerPoint with data).

The combination of this project, along with the targeted training in the scope of supervision skills helps to develop the initial skill set essential for success. This novel program takes time to implement, but is efficient in the long-term. Many problems are avoided as the individuals have a strong foundation in an OBM approach to organizational systems development and a behavior analytic approach to staff management.

#### Summary

Every quality program worries about transitions in leadership. Legacy plans are common themes for executive directors and other high-level administrators. Transitions in leadership at lower and middle levels of management are often not given the same attention. Yet, inadequate preparation of supervisors can reduce their effectiveness.

Investing in the next leaders requires that organizations develop training programs that target this crucial group. Melmark has developed an innovative program to build the skill sets of supervisors, to ensure that training is continual, that professionalism is monitored, and that all members of the organization are comprehensively mentored in instructional techniques, collegial interactions, and stateof-the-art interventions. Helena Maguire, MS, BCBA, is Senior Director of School Services at Melmark New England. Mary Jane Weiss, PhD, BC-BA-D, is Executive Director of Research at Melmark. Frank L. Bird, MEd, BCBA, is Chief Clinical Officer of Melmark, Inc.

The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. We provide evidence-based educational, vocational, clinical, residential, healthcare and rehabilitative services, personally designed for each individual in a safe environment of warmth, care and respect. For more information, please visit www.melmark.org and www.melmarkne.org.

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#### What Now from page 24

extra time are escorted elsewhere to finish the test.

The best way to find out how an accommodation works in reality is to spend time at a school's Disability Services Office (DSO) or its equivalent. The DSO employees will be able to explain the services and accommodations available, give you advice on describing the accommodations to professors, and should also be able to describe how various supports are implemented. Don't be afraid to press for details. This office may even be able to connect you with current students on the spectrum who are willing to talk about their experiences.

Required classes also vary between schools, both for majors and the general education requirements. If an individual has significant trouble with a specific type of class, then it may be worth looking for a school where that subject won't be needed. Some schools may not require the problematic class; others may be willing to negotiate or waive requirements. If you think you'll need to have some requirements waived, look for schools that have an established process for documenting and granting such requests.

Evaluating a school's class structure can be a way to address students' needs though good fit, rather than actual accommodations. Some students on the autism spectrum will have an especially hard time with huge classes and crowded lecture halls. Not only does it mean dealing with more people, it may also be harder to self-advocate when there are more students making demands on a professor's time. Others may have a harder time with small classes that place more emphasis on group work, discussion, or other social interaction. There is no single 'right' class structure for individuals on the spectrum; it's just one more thing to think about when choosing a school.

When visiting a campus, ask about average class size within departments. Ask about specific courses. Ask to peek into classes in action. Most students will have to take some classes that don't suit them well, but different schools emphasize different teaching methods and there is considerable flexibility in this area. Aim to have as many classes as possible geared to the individual's learning style.

Perhaps the greatest change between high school and college, for most students, is the need to make housing choices for the first time. Some will choose to live at home to create a longer transition between high school and full independence, which has the added benefit of saving money, but many will live on campus.

A single room in student housing is a good option for many individuals on the spectrum. This offers the social environment of a college campus with a private place for needed retreats. Not being assigned a roommate, who is usually a stranger, alleviates some of the most difficult aspects of the college transition. Some self-advocates strongly recommend a single room, but others caution that it can allow some students to miss meals or classes unnoticed. Single rooms are also almost guaranteed to cost more: very few schools offer the upgrade to a single room as an accommodation for students with autism or any other intellectual or developmental disabilities. This is an area where competing needs will likely have to be weighed against one another very, very carefully. The guiding principle must always be the needs of a specific individual

The final major area of consideration is

not an accommodation per se, but rather a matter of fit. There is a huge variety of design and layout among college campuses. When visiting schools, evaluate as many areas as possible for lighting, spaciousness, and other issues of sensory-friendliness. Most guided tours don't include every building and may focus on the newest and most updated structures, so ask where a specific student would be living or taking classes.

Wherever possible, try to see things at different times of day. Tours are often conducted during times when they will be least disruptive to, and least disrupted by, current students, but a prospective student with sensory concerns needs to know what campus spaces will feel like during a typical day. The best way to find good, quiet places for decompressing and alone time is to see how the library, dining hall, computer labs, and other common areas are used throughout the day during an active semester.

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#### Interventions from page 14

This approach can be used to minimize stressful social situations by identifying, analyzing, and responding to various problems that individuals may encounter. Individuals who have difficulty learning these problem solving skills through daily interactions can find direct instruction on how to manage conflict in problem solving opportunities to be helpful in future social situations. "The key is to start with concrete, hands-on projects that have meaning for the child, then slowly move into abstract problem-solving involving thoughts and creativity, in academics and social situations"(Grandin, 2008, np).

#### Naturalistic Environments

The use of the natural environment for educating individuals with regards to social skills has demonstrated great benefits in younger children; whereas, the research supporting the use in adolescents and adults is much more sparse (Reichow, Volkmar, 2009). Naturalistic environments can provide the opportunity for generalization of social skills. Learning occurs in an environment where individuals will master skills in an authentic setting. The natural environment allows for students of varying abilities to learn and apply wide ranging skills that are targeted based on person centered planning (Renzaglia et. al, 2003). Examples of skills being taught in a naturalistic setting can range from street crossing and navigation planning to negotiate more complex social interactions. The natural environment also provides opportunities for generalization by pinpointing meaningful skills needed to be successful in everyday interactions (Renzaglia, Karvonen, Drasgow, Stoxen, 2003).

#### Parent Training

Parents and caregivers play an integral role in helping children to develop appro-

priate social communication skills. When social skill interventions are being implemented, it is important to involve parents in the development and execution of the interventions. Individuals diagnosed with ASD have demonstrated higher levels of generalization when parents are properly trained in the strategies being utilized (Hemmeter & Kaiser, 1994). Parent involvement in the intervention process allows for individuals to continue practicing social skills outside of the intervention setting. The intervention process should continue even when the individual is not meeting with professionals, creating a setting where the individual can practice and utilize systems outside of the intervention setting.

#### Peer Mentoring

The National Standards Report (2009) from the National Autism Center has stated that peer-mediated interventions are an established intervention treatment for individuals diagnosed with ASD (National Autism Center, 2009). Peer mentors provide individuals with ASD a point-person who can help decipher what are appropriate and inappropriate behaviors in social settings. These individuals take on the role of a mentor rather than a professional, creating a different dynamic between mentor and mentee. By navigating the world together, individuals with ASD can learn and practice social skills in a natural social context, one that does not involve adults, professionals, or teachers (Zhang & Wheeler, 2011). Following the framework of inclusion, peer mentors can help students learn appropriate behaviors in realistic contexts with realistic models. Peer mentoring has also effectively reduced inappropriate social behaviors including unresponsiveness, changing conversation topics and inappropriate talking (Chung et al., 2007). Reichow and Volkmar note that, "interventions that train peers to deliver treatment has much support and should be considered a recommended practice for all individuals with autism" (Reichow, Volkmar, 2009, p. 160).

When selecting social intervention approaches, it is important to be aware of the design and methods being used. Each learner is different, requiring varying supports. Interventions utilizing the six factors above benefit a larger portion of the population in need of social skills development while also increasing the chances of generalization. Understanding the importance of these factors when choosing the right social skills program is critical in order to find programs most appropriate for each individual learner.

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limited but are the norm in programs for this population (Hart, Grigal, & Weir, 2010).

Facilitating Learning with Program Supports and Technologies

Especially exciting about the program are the supports and technologies offered to the students.

#### Mentorships

Each student is helped by a mentor, who is an existing or former student without disabilities. The function of the mentor is to help the student with disabilities on the spectrum with the assignments in the courses and the interactions with instructors and the other students. Funded by AHRC, the mentor is involved several hours before, during and after a course session with the student bi-weekly. The mentor is further involved in the events of recreation, sociality and sports with the student. Socialization is indicated to be often of higher interest to students on the spectrum (Papay, & Bambara, 2011). The mentor is important to the student on the spectrum in experiencing life in a big university.

#### **E-Portfolio Supports**

Each of the students is given a documentation e-portfolio facility. The e-portfolios are facilitating a journey of learning. The e-portfolios are furnished with "digital learning objects":

- *Blogs* expressing how they are learning in the courses;
- *Journals* reflecting on what they are learning in the course disciplines; and
- *Projects* showing what they were learning in the semesters.

The e-portfolios are electronic resumes of the students, reflecting increased learning as they progress in the semesters. The portfolios are even evidence of potential occupational skills. These e-portfolios are important in the personal pride of the students.

#### Micro-Blogging Supports

Each student is supported by easy-to-

mathematical modeling, and high-resolution cellular imaging, that pyramidal neurons are affected in a regional and layer-specific manner in the primate cerebral cortex with substantial alterations in dendritic spines and dendrite integrity, that are reflected by disturbances in the biophysical properties of these neurons. His research also extends to study patients suffering from psychiatric illnesses, such as autism spectrum disorders and schizophrenia. Dr. Hof also contributed considerably to our understanding of the structure of the mammalian brain and has identified, in select mammalian species, specific neuronal types in parts of the cerebral cortex known to be involved in social awareness, judgment, and attention, that can be considered as markers of adaptive

access micro-blogging internet sites, such as BlogSpot, Tumblr and Twitter, which are enabling further interactions with instructors, mentors and other students on projects in the semesters. The sites are expanding friendship, individualized networking and information sharing. Importantly they are increasing full inclusion of the students in new learning spaces at the university.

Mobile Computing Supports

Each student is further supported by personalized iPad tablets. Funded by AHRC, the applications (apps) on the tools are for facilitating learning and socialization:

- *Everyday Skills* facilitating interactions with instructors and other students;
- *It's My Future* facilitating self-advocacy and vocational skills;
- *Next Dollar Up* helping in money management with bookstore and cafeteria staff;
- *Snipbase* helping in preparing "to do" project semester tasks with interactive text; and
- *TouchChat HD AAC* helping in providing increased motor and speech skills when with other students.

Other technologies include *Alexicom AAC* speech tools and *WatchMinder: Vibrating Watch and Reminder System* and *Activity Tracker* wearables. These mobile computing tools are important in managing personal progress in the semesters, and, interestingly, the students are already proficient in the tools.

#### Networking Spaces

Finally, the students are supported by "exemplars" or the other students on the spectrum. They meet on program progress, or problems, at "lunch and learns" bi-weekly. They meet in remedial seminars with other students without disabilities monthly. When not in courses in the spring and fall semesters, they are involved in seminars in the summer, such as a STEM Collaboratory of creative critical thinking and problem solving on state-ofthe-art technological topics, joining a mix of student teams. These networking spaces are important in more socialization of the students.

"It is important to note that these supports and tools did not require increased internal resources of the school or the university, as the incremental but limited number of the students was manageable in existing infrastructural and instructional resources, such as in an office of disability services and in policies on standards of universal design for learning and transition," according to Dr. Lawler, organizer of the program in the Seidenberg School.

#### Improving Employment Opportunities for Inclusion Students

The program, in individualized plans for employment (IEPs) prepared by AHRC New York City, is molding the students on the spectrum for employment opportunities, as other programs are in the country (Heasley, 2015). Though the initial intent of the program was to integrate merely more qualified students on the spectrum into the life of the university, the supports and tools furnish a foundation for the students to be more independent, motivated and prepared for life opportunities. "The program is noted by the [organizational] staff and the students to be offering pronounced skills," according to Ms. Goldfard. The students have marketed their strengths through the e-portfolio resumes that they prepared in the semesters. Since 2007 most of the students have moved into meaningful positions as semi-professionals in organizations, such as Brooklyn Roasting Company, Cooke Center and SANYS (Self Advocacy Association of New York State), participating more in society.

Overall, the initiative is benefiting the students with increased learning and socialization that is enabling opportunities in society. The initiative is planned as a certificate-for-credit non-degree program of 12 courses of 36 credits to be completed by the student in 3 years. The program is modeled on the national Think College! Post-Secondary Education Options, in order to be eligible for Pell grants, and is recommended by the authors to institutions interested in pursuing a full inclusion program sponsored by a non-profit organization and a post-secondary university.

This initiative of partnership of Pace

University with AHRC New York City has been locally recognized with the *AHRC New York City Community Partner Award* and nationally recognized with the *Jefferson Award Bronze Medal for Community Service*, awards for projects that enhance the quality of life in the community.

For disability advocacy institutions, and also educational institutions, interested in the methods of program supports and technologies for post-secondary programs, they may contact Professor James Lawler at lawlerj@aol.com.

Hope Goldfard, MS, is a Community Support Specialist at AHRC New York City, and James Lawler, DPS, is Professor of Disability Studies and Information Technologies at Pace University. AHRC New York City is a chapter of NYSARC, Inc. and ARC, national organization for helping individuals with developmental and intellectual disabilities; and Pace University is a leading institution of higher learning in New York City and Westchester County of New York State.

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mechanisms and functions in response to particular ecological pressures. He is an Associate Director of the Alzheimer's Disease Research Center at Mount Sinai and he receives major funding from the NIA and NIMH. He has been recently funded by Autism Speaks, the Seaver Foundation, and the Simons Foundation for his work on the neuropathology of autism and from the James S. McDonnell Foundation for his studies of brain evolution. Since 2014 he is the Director of the Seaver Autism Center Tissue Program, the Mount Sinai regional node of Autism BrainNet (http://www.autismbrainnet.com).

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about the Autism BrainNet, visit www.AutismBrainNet.org or www.TakesBrains.org.

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#### Writing from page 4

students acquire a new skill. Teachers and parents can actually sit with a child and write in front of him or her, explaining their thought process and why they are doing what they do. Adults should be sure to make overt the processes that they do not normally think about: how to take a thought and turn it into words, how to look for errors to correct, and what to do when they get stuck. Then, parents and teachers can provide the finished piece as a model for the child to follow along with or refer back to when they complete their own work. Modeling can also include video modeling, in which a person (may include the child with ASD himself) is pre-recorded engaging appropriately in the desired behavior (NAC, 2015), and the video is then used as a model to imitate. Parents may consider recording the child successfully engaging in the writing process, and then playing the video again as necessary to begin the process or keep the child going as they work through the task.

Parent-implemented intervention – Parents act as therapist or receive training through a structured parent training program to implement interventions in their home and/ or community (NAC, 2015). While there are likely no structured support groups to teach writing to children with ASD, parents can work with schools or local tutoring centers to learn the best-practices in writing instruction. Parents can meet with their child's teacher to find out how they teach writing in their classroom, and what they can do to implement those practices at home.

*Prompting* - Any assistance (verbal, gestural, or physical) given to help a learner acquire a new skill (Wong et al., 2014). There are many ways that a parent or practitioner can prompt a writer. Simple verbal prompts might be provided by asking a writer to add another word, or prompting their thinking about what to write next (e.g. "What else can we say about the haunted house?"). Physical prompts can be provided in the form of hand-over hand support if necessary to formulate letters or hold the pencil correctly (Boucher & Oehler, 2013).

Reinforcement - An event, activity, or other circumstance occurring after a learner engages in a desired behavior that leads to the increased occurrence of the behavior in the future (Wong et al., 2014). Parents and teachers can use reinforcement in various ways to support writing. Depending on the needs of the student, reinforcement can occur as a preferred activity or tangible item provided after an essav is completed or after a single letter or word is written. Some students might like to use technology, another EBP for children with ASD (Wong et al. 2014); therefore, allowing the child to type instead of writing with a pencil might be reinforcing for those who like keyboarding. For others, being allowed to draw a picture once the story is completed might be rewarding.

Task analysis - Breaking a skill into smaller, more manageable tasks to teach one at a time (Wong et al., 2014). Writing is a complex task that requires a person to plan, draft, revise and edit in order to produce a complete piece. Sometimes the process can be overwhelming and writers will shut down because of the demands of the task. A parent or teacher can task analyze a writing assignment to help the writer be more successful. For example, writing the letter "T" can be broken down into the following eight steps: locate the top left part of the space; place your pencil there; draw a line (about the size of your eraser) to the right; take your pencil off the page; locate the center of the line you drew; place your pencil there; draw a line straight down until vou reach the bottom of the space; and take your pencil off the page. If combining reinforcement with task analysis, you can reinforce at the completion of each step, or when the entire letter is written, depending on the needs of the child. Task analyses

can be conducted for more complex writing tasks as well. If the child has to write a biography about a famous sports star, for instance, the parents can help by breaking down the task: picking a star one day, researching their topic another day, completing a graphic organizer the next day, transferring their notes to an essay the next day, revising it for content the next day, and finally editing it on the last day.

#### A Few Things to Keep in Mind

It is important to remember that each person, with ASD or without, is different. Although these EBPs have been identified as effective for a majority of students with ASD, they may not work for every learner. Therefore, parents and practitioners must be sure to review each practice and consider the specific strengths, needs, and interests of their own children/students before implementing a practice. As indicated earlier, practices may be combined (e.g. task analysis with reinforcement) to see if there are increased benefits. In addition, parents and practitioners may need to try an intervention several times before it starts to demonstrate effectiveness; therefore, they should be patient and not give up prematurely. Be sure to monitor the effects of the intervention, however, and withdraw it if it does not seem efficacious over time.

#### Conclusion

Although there are no evidence-based practices specifically for writing instruction, parents, teachers and other practitioners can integrate general EBPs into their writing instruction and support. The suggestions offered in this article may help lead to improvements in the written products of students with ASD.

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#### Advocate from page 13

when it comes to students with ASD, whose needs can be very complex. Sometimes the program and the placement can appear OK on paper but may not work for a child in practice.

The school district must find a way to meet the unique special education needs of your child. If they cannot, then parents have the right to find an appropriate private school and sue the school district for tuition funding or reimbursement by filing a due process complaint.

The landmark federal law known as the Individuals with Disabilities Education Act (IDEA) states that all children with disabilities must be educated in the least restrictive environment (LRE). The purpose of this law is to guarantee that children with disabilities are not removed from a regular classroom or isolated from non-disabled peers when there is the ability to educate them in a mainstream setting with support. LRE decisions should be thoughtfully made based upon your child's unique learning needs.

At due process hearings for tuition funding of a special education private school, there is no argument I hear more often than that the student is not being exposed to "typical" or "non-disabled" peers. For some students, that may be what they need at that point in time in order to be successful in school. Parents are not bound to find a private school that offers the LRE, just one where their child's needs are being met.

While parents should advocate for their child to be in the LRE to the extent possible, the appropriateness of a program and placement should be the leading factor. It is important for parents to remember that special education schools in NYC and many other places in the US are a far cry from the segregated institutional settings that the IDEA meant to extinguish.

While some children with ASD can be successfully educated in a mainstream

setting if given the appropriate services and support, there are many children who would not benefit from a mainstream setting, and are best served in a special education setting that specialized in meeting the unique needs of a certain population of students. Realistically, the success of any child will depend on the school, teachers and school environment.

What makes private special education schools successful at meeting the needs of a particular population of students is the fact that they can specialize. And what's wrong with specializing? We go to specialists for every other need we have. Children with ASD deserve to feel safe, understood, nurtured, and see that they similar to their peers. Sometimes that can only be accomplished in a special education school for a particular student.

While there are arguments to be made for both settings, the real question that parents should ask is: What is appropriate for my child at this time? Parents must remember that children and their needs change, and choosing one type of school setting does not bind them to it forever. The law requires school districts to review a child's IEP at least once per year for this very reason.

I encourage parents and school districts to keep an open mind about all the possibilities and to make program and placement decisions in a coordinated way, based on the individual needs of each child, as Congress intended.

The Law Offices of Irina Roller, PLLC is based in New York City and is dedicated exclusively to the representation of children with special needs. We represent families who seek tuition reimbursement and funding, assistance with CSE meetings to develop IEPs, and disciplinary actions. To contact our firm, please email info@ NYCSpecialEducation.com. Also visit our website at http://www.NYCSpecialEducation.com or follow us on Twitter @IrinaRollerLaw.

#### Independence from page 11

and attempts to eat inedible objects. Past interventions to decrease challenging behaviors included being enclosed in a padded and locked time-out room, removal of personal items, and as needed medication injections. Nancy's life did not extend past the ICF stone walls, and there was little hope in changing that.

At SUS, behavioral interventions do not include the previously used treatment protocols, such as a time-out room or as needed medications. The science of Applied Behavior Analysis guide intervention protocols to decrease challenging behaviors and increase adaptive responses. When Nancy first transitioned to our care, she complained of constant headaches and pain all over her body. She was engaging in up to 800 incidents of head banging per day and up to 500 incidents of physical aggression per day. A Functional Behavior Assessment conducted to first identify the function of the challenging behaviors. Once the function of the behaviors were identified, seeking attention, a behavioral intervention based on positive reinforcement and extinction was put in to place. By providing Nancy with ongoing, high quality attention which included allowing her to go out into the community, an immediate decrease in target behaviors began to take place. Additionally, a new person with her eyes on an unfolding future began to take form. Despite this, the physical complaints of headaches and pain failed to decrease and remained puzzling and extremely concerning to the team.

The team continued to investigate Nancy's complaints of pain it was recommended that Nancy's consider a surgery that would place a shunt to relieve cerebral-spinal fluid and relieve pressure from the pseudo-tumor that may be causing her headaches and dizziness. Following the surgery, Nancy's made incredible improvements, decreasing the number of behavioral incidents by half. These decreased incidents are unprecedented in her medical history and would not have been possible without the coordination and dedication of the primary physician, and medical and behavioral team working together.

Although Nancy still engages in challenging behaviors, the tremendous decrease in daily episodes has opened up many more opportunities in her daily life. By reinforcing appropriate behaviors by providing her with high quality attention, providing access to preferred items and people, and acknowledging her medical complaints through treatment and reinforcement for accepting treatment, the team has developed positive approaches to decreasing Nancy's challenging behaviors without resorting to punishment procedures.

Nancy hopes to live on her own, or with her boyfriend one day. This summer, due to the BIP grant's initiative to move individuals to less restrictive settings, she will be taking the first step towards this goal. Nancy will be moving out of the SUS ICF and into an Individualized Residential Alternative, or IRA. At the IRA, Nancy will live in an apartment in the community where she, and other peers from the SUS ICF, will learn to cook, and care for themselves and their new home outside the brick walls of an institution. This is a momentous step for Nancy, but like any other woman in her 30s, if you ask her what she is most excited about, she says, "to decorate my new home, with a pink bedroom.'

Jeremy, another individual who has benefitted from his transition to SUS, remembers his life in 1980's New York City. He often talks about his family, his girlfriends, and the mistakes he has made along the way. He reflects on how he came to live at the state developmental center but also speaks about his plans for the future.

A 56 year old male who resides at the same ICF as Nancy, Jeremy had been living in a state developmental center for approximately 28 years prior to his transition to SUS. He communicates verbally and is able to maintain conversations on a variety of topics with staff and peers. While at the Developmental Center, Jeremy had lived in a locked-down unit and had little freedom to his day. But since transitioning with SUS, Jeremy has lived on an unlocked unit, goes on community outings frequently, and will be moving into a 2 bedroom apartment later this spring.

Since Jeremy's transition to SUS in October 2014, he has expressed an interest in purchasing DJ equipment and returning to his old "DJ roots." He enjoys chatting with staff and peers about his favorite topic, wanting to become a DJ and old school rap and hip-hop. With assistance from the aforementioned BIP grant, SUS provided DJ classes on site so that Jeremy could familiarize himself with new technology and usher him into the 21st century. Jeremy remarked that he was surprised to see how the equipment had changed so much over the years. A few months later, SUS introduced more modern equipment to Jeremy such as iPods and iPads with small speakers and even assisted Jeremy in learning to use a computer to send and receive emails, access social media, and locate past friends and family. By utilizing Jeremy's preferences and motivations (DJ equipment and lessons), behavior analysts working with Jeremy have documented an overall increase in appropriate socializations and compliance with staff and peers as well as a universal decrease to zero instances of any challenging behaviors.

In February of 2015, Jeremy was introduced to another individual living in an SUS IRA who was in need of a roommate. They "clicked" immediately, and instantly began making arrangements to visit with each other. They are now going to be roommates. This spring, Jeremy will be the first individual from his cohort at the ICF to make the move to less restrictive housing by moving to an IRA in the Bronx, NY. When he visited his new apartment, Jeremy said, "These rooms are pretty nice and I have a kitchen to cook in!" He then motioned to his roommate, "Don't forget to turn the stove off and lock the doors." Furthermore, this summer, Jeremy will begin working with The Urban Farm in NYC. He will receive hands on training and classroom teaching for 9 weeks focusing on horticulture, agriculture, and food services. Afterwards, Jeremy will have the opportunity to choose one specific field to apprentice in, and a job coach will assist him in taking his hands on training and applying it to real life work.

Jeremy is excited for his bright and promising future. He talks about earning his GED and learning to read, but above all, he is excited to live a more independent life. Nancy talks about getting a dog in her new apartment, getting a job, and one day living with her boyfriend. Both Nancy and Jeremy still have long, personalized journeys ahead of them. But through the science of ABA, by knowing what motivates each one of them to engage in a specific appropriate or inappropriate behavior, and how to respond based on function to those behaviors, behavior analysts can continue to teach, and support both of them, as they move to greater independence.

To find out more about Service for the UnderServed or the Balancing Incentives Program Innovation Fund go to http://sus. org/ or http://www.health.ny.gov/health\_ care/medicaid/redesign/balancing\_incentive program.htm.

#### Exploring from page 19

not be surprising that many look to their fellow support group peers for information. However, not one parent reported looking at data or reading research about the various therapies, and only a handful of respondents reported they read books—either digital or paperback—discussing ASD or therapies.

When asked what was important when choosing therapies, the most popular comments were: they wanted the most effective treatment with the least amount of time since dealing with a child with autism is exhausting; reduction of symptoms in least amount of time; amount of time it takes for treatment: ability to fit into our busy day: affordability; removal of foods that could potentially be causing symptoms because others say their kids' symptoms decreased; trying popular therapies being discussed in my circle such as moms groups or autism support groups. One mom reported she is so desperate to help her son she tries any therapy that sounds effective and safe. When asked specifically have they used ABA therapy, 47% of the parents said they are currently using ABA therapy while 33% said they did not have access to ABA therapy, 20% said yes but stopped because it was too time intensive, and 5% said no.

We can hypothesize the surveyed parents want their children to lead fulfilling lives

and will try multiple therapies to attain that goal. However, in their effort to help their children parents may fall victim to try unsafe, ineffective treatments that are non-evidence-based and costly both in money and time. In best practice, before starting any therapy parents need to question whether there is scientific evidence supporting the therapy. It is concerning that none of the surveyed parents reported using scientific evidence when choosing therapies. In fact the most important factor was time and effort of therapy implementation, not evidence of effectiveness. Parents' lack of using scientific evidence may be caused from disconnects between published research on ASD treatments and parents locating the research. First, most research is published in journals or presented at conferences that many parents do not have access to. Second, the scientific arena uses language such as evidence based when research supports a therapy, whereas the parents surveyed understood evidence based as meaning nothing more than the therapy works. Third, since there are so many treatments for autism-including complementary and alternative methods-it would be time consuming for parents to read the scientific literature on all the treatments.

From this study we can glean several things. First, parents need further guidance in locating and understanding the research and research on ASD therapies needs to be

disseminated outside of research arenas. Second, since ASD is a collection of symptoms and not all children with the disorder display the same symptoms, one type of therapy does not fit all families. Third, parents' primary concern is time efficiency, and some parents perceive ABA as too time consuming even though ABA is an effective therapy. However, in a search for effective therapy parents will simultaneously use multiple therapies, which is very time consuming. It is imperative practitioners show parents that over the long run ABA may be less time consuming because of its demonstrated effectiveness. Fourth, parents' most popular way in finding information about therapies was the Internet however depending on where the parents are searching the Internet is not always a reliable source of information.

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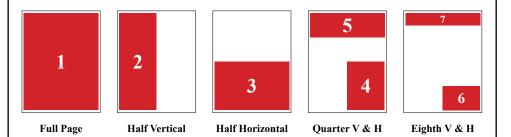
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