

# ON THE SPECTRUM



Proudly Supporting the Autism Community Since 1988

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## **ON THE SPECTRUM**

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## **Mission Statement**

Our mission is to provide information, education, support, awareness, and advocacy for those affected by Autism Spectrum Disorder. That includes family members, individuals on the autism spectrum, and the professionals who work alongside them.

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## **Ways to Donate to AHA**

Donate through our website (www.ahany.org), Amex's Just Give, the United Way, the Combined Federal Campaign (CFC), or mail a check or money order directly to AHA. Volunteers are always needed and appreciated. Call or email for further information. AHA is a 501(c)(3) not-for-profit organization; all donations are tax deductible.

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## **AHA Board Meeting Dates**

November 1 and December 6. All meetings in Amityville.

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## **The Importance of Scientific and Evidence-based Information**

The search for effective treatment of autism spectrum disorders (ASD) is made more difficult because each individual on the autism spectrum is unique. Myriad interventions are being offered, including a wide variety of medications, therapies, educational methodologies and nutritional approaches. While many of these methods reflect sound current practice, many of them do not. A parent's urgency to take action may be exploited by unsound practices that can be costly, time-consuming and physically demanding. Through our support programs, website, eNews and our publication, *On The Spectrum*, we make every effort to provide objective, up-to-date, reliable, evidence-based information, and we urge you to thoughtfully evaluate any proposed treatment.

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## Executive Director's Corner



Dear Members and Friends,

We are excited that all our summer work is coming to harvest. ROCK 'N' BOWL for Autism is on November 19th. And for our annual fall conference on Saturday, October 28<sup>th</sup> at Adelphi University we welcome back as keynotes the outstanding Brenda Smith Myles, and Drs. Kate Cody and Rebecca Sachs.

The AHA Team welcomes our newest staff member, Laura Majersky-Lopez. Laura has taken over our twice monthly eNews, monthly support reminders, and is our point person for ROCK 'N' BOWL. During the year our able team of Joan Hourihane, Samantha Diez, Leslie Feinberg, Bernice Polinsky and now Laura have responded to over 2000 referrals, logging and answering calls, working on conferences, support groups, a variety of events: everything overlaps. We are quite the team.

Two new TV shows relate to our autism community. One, called *Young Sheldon*, is about the Asperger character on *The Big Bang Theory* as a young child. The other show, called *The Good Doctor*, is about a medical resident with Asperger syndrome. I reflect on the last 23 years since my son Eric, after being misdiagnosed with a multitude of disorders up until he was finally diagnosed correctly with Asperger syndrome at age 25, and how completely isolated we had been up to that point. Sound familiar? Now, television viewers could be watching a comedy or a medical drama and possibly recognize their kiddo in the next room or a glimpse of that child they have been wondering about or hubby they have been perplexed about! Books, TV shows, plays and especially the first person accounts by individuals themselves on the spectrum, have marked the way we look, think, and react to autism. And we believe AHA has played a role in this increased public awareness and acceptance.

Eric struggled for many years. He had academic successes but with many rough patches along the way, including episodes of bullying and lack of friendships. For us the diagnosis brought clarity and a community. A community of family members for Chic and myself and friends for Eric. Resources for us all. AHA!

And as AHA continues on to today help us as we approach our 30<sup>th</sup> year by being that person others can learn from, reach out to and gain support from. Consider donating to AHA so that we can continue to help you and others. Your support is greatly appreciated.

Warmly,

## Who's Who

### Susan Deedy, Esq.



Susan Deedy has over 20 years of experience in the area of special education law. She earned her Bachelor of Arts degree from Fordham University and holds a Juris Doctorate from CUNY Law School at Queens College. Susan's law practice is dedicated to representing parents of children with disabilities to ensure that eligible students are provided with their legal right to a free and appropriate public education (FAPE).

Early in her career, Susan represented colleges and school districts. However, it did not take long for Susan to realize her passion is instead to serve students rather than school districts. In 2001, she established a law practice that, from the time of its inception, exclusively serves to protect students with disabilities as well as parents' rights under the IDEIA. Susan litigates cases at "Due Process" hearings, particularly to obtain awards ordering school districts to pay or reimburse parents' private school tuition costs. The majority of matters however are successfully negotiated and resolved without the need for litigation.

Susan's mission is not only to fight individual cases, but to empower parents so they can be their child's best advocate. In Susan's "Parent Empowerment Program" (PEP), she provides trainings, workshops, and individual consultancy services to parents through professional practices and organizations that also serve children with disabilities. This program serves as a vehicle for professional practices and organizations to help children with ASD increase their visibility while also providing a distinguishable and valuable service to clients. Her PEP program teaches vital strategies, tools, tips, and legal ammunition so that parents can be strong and informed members of their child's CSE meeting where important educational programming takes place. Susan also trains attorneys for CLE credits in this specialized area of law. She serves as a committed Professional Advisory Board member for Asperger Syndrome and High Functioning Autism Association (AHA). Susan and her husband live in Wantagh and have four children.

## Back To School:

### Tips and Tricks for a Successful Transition into a New School Year

by Nicole Alicino, PhD, Postdoctoral Fellow



Returning to school can evoke a mixture of emotions for students and their parents. For some families the end of the summer and return to regular routines can leave parents and children pining for a longer summer vacation. Others are excited by the prospect of a new school year and eager to meet their teachers, buy school supplies, and reconnect with classmates. For students with ASD and their families, the return to school can present a unique set of challenges.

Why is it that transitioning back to school is so difficult for children and teens with ASD? ASD manifests with difficulties in three primary areas of functioning: social communication, social interactions, and restricted interests and repetitive behaviors. Transition into a new school year places demands on all these areas, often requiring supports to be implemented by parents and educators. Individuals with ASD also demonstrate challenges with areas of executive functioning. Research suggests that difficulties in at least one domain of executive functioning has been found in 90% of students with ASD. In particular, individuals with ASD often struggle with flexibility, and this contributes to their struggles with transitions and adapting to new routines. As such, supports pertaining to executive functioning difficulties, particularly inflexibility, can help facilitate a successful transition into the school year.

Parents play a critical role in helping children and adolescents prepare for the new school year and navigate the many challenges that are associated with new teachers, classrooms, expectations, and academic and social demands. At each stage of development, students with ASD face distinct challenges, and it is important that family members are aware of the strategies to prevent roadblocks that can stand in the way of a successful school year. While not an exhaustive list, below are some tips and tricks for supporting a successful transition into the new school year:

#### Elementary School Support Strategies:

1. Before the first day of school, meet your child's new teacher and, whenever possible, any support staff. Also try to meet the bus driver and do a "dry run."
2. Create a social story including a picture of your child's new teacher. Read the story repeatedly to familiarize

your child with their new teacher.

3. Establish and practice a "getting ready for school routine" multiple times before the first day. Visual supports – including checklists and visual schedules – can be helpful in supporting the establishment of this routine.
4. Create scripts for common problems experienced throughout a typical school day. Examples include how to tell an adult you need to go to the bathroom and what to do if you are feeling sick.
5. Write a 1-2 page document for your child's new teacher with information about sensory sensitivities, likes and interests, and allergies. You can ask your child for their input about what they want their teacher to know about them.

#### Middle School Support Strategies:

1. For some families, middle school can mean a new, often larger, school environment. Prepare your child by visiting the new building, obtaining maps and learning where classes are located. Identify the support staff to minimize struggles in the beginning of the school year.
2. Middle school is the first time many students will be expected to change classes, have a different teacher for each subject, and store their materials in a locker. This can place greater organizational demands on students and requires additional skills and support. Students can benefit from direct instruction of organization strategies, including written schedules and to-do lists. Additionally, many students like using apps that can support organizational skills.
3. Assignments often become more complex in middle school. Breaking down assignments into smaller chunks can help students with organizational demands, support the ability to self-monitor, and create a sense of accomplishment.
4. Middle school can be challenging for everyone: neurotypical students, students with ASD, and parents alike! One of the reasons middle school is notoriously hard is because of the complex social relationships that develop during this time. For students with ASD, the social hierarchies, emergence of romantic relationships, and onset of puberty can create an environment that feels confusing. Moreover, many students with ASD lack peer relationships that can help them un-

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# AHA Annual Spring Conference

## Meaningful Living on the Autism Spectrum: A Workshop Recap and Primer on ACT

by Alyson H. Skinner, PhD



At AHA's 2017 Spring Conference I had the privilege of presenting a breakout session with my colleagues Drs. Shana Nichols and Danielle Zito entitled "Learning to Live a Personally Meaningful Life: Acceptance and Commitment Therapy (ACT) for Individuals on the Autism Spectrum." Despite originating as a therapeutic intervention, the concepts and strategies encompassed by ACT are universally relevant. Since many ACT references may seem intimidating, between unfamiliar lingo and psychotherapeutic emphasis, let's start with the basics.

### What is ACT?

Acceptance and Commitment Therapy, better known as ACT (and pronounced like the word), is a third-wave cognitive behavioral therapy approach. First introduced by Steven C. Hayes, PhD in the 1980s, ongoing empirical research has demonstrated its usefulness for addressing a range of concerns including anxiety, depression, trauma, substance abuse, and interpersonal conflict. Recent studies examining application of ACT for difficulties associated with Autism Spectrum Disorder (ASD) have produced promising findings, which is unsurprising considering its foundational concepts. Rigidity and resistance to change comprise hallmarks of ASD, rendering ACT's central aim of increasing flexibility naturally relevant to individuals on the autism spectrum.

The Association for Contextual Behavioral Science describes ACT as "applying mindfulness and acceptance processes, and commitment and behavior change processes, to the creation of psychological flexibility." Contrary to natural inclination and other cognitive behavioral approaches, it is not designed to extinguish – or even necessarily reduce – the distress that typically precipitates treatment. Instead, in the words of expert Russ Harris, "the goal of ACT is to create a rich and meaningful life through mindful action, while accepting the pain that inevitably goes with it." After all, the most pleasurable emotions (for example, joy and love) are inherently attached to the most difficult (such as pain and loss). ACT postulates that efforts to "get rid" of difficult emotions are not only ineffective, but actually underlie much of our own suffering.

### How does ACT work?

Although symptom reduction is not considered a

primary goal, it is often a by-product of working within ACT framework. Tendency to avoid or fight against unpleasant thoughts, emotions, and experiences (coined "experiential avoidance") exacerbates discomfort that might be otherwise tolerable. Six core concepts comprise the basis of the ACT model:

- **Acceptance** is fostered through acknowledging internal and external experiences without attempting to change them. Embracing our range of experiences does not mean we must necessarily endorse or enjoy them; rather, we become empowered by disengaging from an unwinnable inner battle.
- **Cognitive diffusion** entails recognizing thoughts as simply words and images produced by our own brains. We challenge the illusion that thoughts, in and of themselves, are threatening or all-powerful by simply noticing them curiously and nonjudgmentally (or imagining our favorite cartoon character dictating them!).
- **Contact with the present moment** requires physical and psychological attunement to the here-and-now. Even just pausing momentarily to "check in" with each of our senses might interrupt a spiral of destructive thoughts.
- **The observing self, or self as context**, represents a process of distinguishing our core being from ever-changing thoughts, feelings, and experiences. Mindfulness exercises and metaphors enable our awareness of this "flow" without intrinsic attachment to it.
- **Values** are identified and used as a reference for gauging congruence between our behavior and the central principles we hold. What do we want to accomplish from a big-picture perspective? How do we hope to be regarded or remembered? What impact would we like to make during our lifetime?
- **Committed action**, last but far from least, involves examining inconsistencies between our values and day-to-day priorities. How much time and energy do we actually devote to the most meaningful aspects of our lives? By setting concrete goals directly aligned with our personal values, we inform decisions and behave according to what matters most to us, regardless of difficulty or discomfort.

### Where can I learn more about ACT?

Those wishing to delve further into ACT, whether for

*Spring Conference Recap, cont'd on page 6*

*Spring Conference Recap, cont'd from page 5*  
personal application or therapeutic intervention, may be interested in exploring the following resources.

**Books:**

- *The Happiness Trap: How to Stop Struggling and Start Living: A Guide to ACT* by Russ Harris
- *Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy* by Steven C. Hayes, PhD
- *Things Might Go Terribly, Horribly Wrong: A Guide to Life Liberated from Anxiety* by Kelly G. Wilson, PhD and Troy DuFrene

**Websites:**

- ACT Mindfully – [www.actmindfully.com.au](http://www.actmindfully.com.au)
- Association for Contextual Behavioral Science – [www.contextualscience.org](http://www.contextualscience.org)
- Learning ACT – [www.learningact.com](http://www.learningact.com)

**YouTube Channel:**

- Acceptance & Commitment Therapy by Dr. Russ Harris

Alyson H. Skinner, PhD, is a Licensed Psychologist who works with individuals, families, and multidisciplinary professionals in private practice and community-based settings. Dr. Skinner specializes in comprehensive evaluation, consultation, and evidence-based treatment for complex and co-occurring neurodevelopmental and mental health conditions.

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## From the Trenches: The Key to College in Two Words: "Self-Advocacy"

by Lisa Feit



How do you help your child on the spectrum prepare for the huge transition from high school to college? The answer is simply 2 words: self-advocacy.

My Aspie son recently tried a pre-college program. In the first week, he got sick and had to handle the health center,

fought for accommodations that were supposed to be in place but were not, and learned that assignments are not always posted when promised. Through all my son's angst, I found myself on the outside, observing. My role as Mom was to coach my son to manage the challenges by himself. Since all college students are treated as adults, this means your child, not you, must seek support. Here are five things that helped my son to prepare for college that I would recommend for you:

- Take your child to every IEP or 504 meeting, every team meeting and every meeting with his teachers. Let him talk. He needs to be able to explain his disability, fight for his accommodations and ask for support without your help.
- Teach your child to manage expectations. Life is not fair. One of the best things my son learned from taking a difficult college course in high school was his own limitations and his need for accommodations.
- Start college discussions early. Meet with the support program directors at each college. Our kids learn differently and there are many different levels of support.
- Help your child choose a college with the best support program for your child's needs. This may not necessarily be the school which has the best program for his major.
- Teach your child that accepting help is as important as asking for help. This is a difficult thing for our bright kids on the spectrum to understand.

The day your child begins high school is also the day you begin to transition your child to college. Allow your child to make mistakes and to become his own advocate when things go wrong. There will always be bumps in the road, but if your child can ask for and accept help, your child can succeed in college and in life!

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Lisa Feit is a happily married stay at home mom with 2 sons. Her older son is diagnosed with Asperger's and Lisa self-identifies as an Aspie. Lisa is a retired attorney and holds a BA in Psychology. She has spent the past 18 years dedicating her time to advocacy for her children and sharing her experiences to help others advocate for their children. Lisa is a co-facilitator of an AHA parent support group.

## Impaired Theory of Mind

by Rebecca Sachs, PhD



I stand at only 5 feet. I don't typically recognize this fact in my daily life minus the occasional blocked view at a movie theater. But, then there are these striking moments when my short stature becomes far more obvious and I get to see the world as most others do. I find that I am suddenly eye-to-eye with the person I'm hugging goodbye or even get to look down at a friend in conversation when standing on the stairs two steps above. It's disorienting at first to experience the higher-than-usual vantage point. And there also comes the realization that this is how others must typically experience me – looking down – versus the way I see them – looking up.

However, this is not a story about short therapists, but rather about the experience of being a psychologist to individuals on the autism spectrum, and of many of my patients who experience obsessive-compulsive disorder (OCD) as well. To be a psychologist with a “neurotypical” brain spending numerous hours in conversation with my patients is a fascinating professional space to inhabit, but also one in which I can sometimes feel like an imposter.

I can't help but doubt myself since I am unable to fully immerse in their experience. I am limited – limited in my knowledge of autism and OCD, limited as a therapist, and limited in my understanding of the human experience. One patient who often struggled with relationships described to me that he would relate to others by referring to his favorite books and movies, but wished he didn't always have to. In his words, “I feel like I am always reading a script.” As a therapist without autism or OCD, I too can feel like I am reading a script, lacking the genuine understanding of my patients' points of view. Some therapists I know who work in the “OCD world” came to the profession based on their own experiences of coping with obsessions and resisting compulsions. There are many times when I sit in my office with a particularly difficult case that I envy the “advantages” of my colleagues' personal perspectives.

Many of the individuals who temporarily occupy my therapy space arrive with questions. Some are adults who have heard a piece on public radio, read a recent book on autism, have a loved one who has suggested the possibility of being autistic, or had another professional finally put a label to decades of experience. Others are children and teens who have embraced the label of “autistic” since receiving early intervention services, but now come to me

confused by their OCD and bombarded with questions: Am I dirty? Will something bad happen to me? Did I do something wrong? Is my teacher mad at me? Will I have enough time? Why don't I feel just right?

No matter why they come to me with questions, I try to provide answers. In the moment, I avoid questioning myself. Instead, I use metaphors and stories and rely on my expertise to try and convey in real terms what “compulsions,” “reassurance and accommodation,” “social-communication deficits,” “rigid thinking and behaving,” “sensory sensitivities,” and “executive dysfunction” mean.

I compare their autism and OCD to my shortness. “You have a tricky brain,” I say. “Just like I have a tricky body.” My tricky body is also great sometimes, like on airplanes or other tight spaces, I explain, just like the huge advantages their distinctive way of processing and expressing information can be in certain situations.

I talk about new ways to live the life they want. I let them know that I arrange my pots and pans on the low shelf because of my “tricky body.” If my environment can't be changed to accommodate my shortness, I use resources like a step stool or ladder. When accommodations and resources have failed me and I simply cannot reach the light bulb on a high ceiling, I use the ultimate strategy and ask for help.

These stories seem to help, but there is still a gulf in our relationship. The largest distance between them and me is the often-looming self-concept that many share: they hate that they are different and at times difficult. When they express that they “need” accommodations, resources, or help, their frustration can be palpable. Or, worse yet, the despair they describe of being rejected and denied help over the years can hang thick, like stale air in my office. As one patient described, “I could never really ask for help because it was usually denied. After a while I just stopped.”

I struggle in these moments with how to respond. Intellectually, I know my patients are often more rejected and bullied than others in this world. I also know that they can have an altered perspective of social interactions, perhaps skewing them to see situations more negatively than in actuality or in more absolutist terms than reflecting the nuances of life. I observe their language – “always,” “never,” “everyone,” and “no one” – and the sense of impossibility that results. I wish I could step inside their minds at that

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# The TEACCH Autism Program: First Families, Then Assessment and Program Design

by C. Faith Kappenberg, PhD, LCSW



THE UNIVERSITY OF NORTH CAROLINA  
**TEACCH**  
Autism Program  
*Services Across the Lifespan*

“For people with autism, the best predictor of quality of life is employment, and for children with autism, the best predictor for future employment is attaining independent living skills.” Those words of Dr. Laura Klinger, Executive Director of the TEACCH Autism Program at The University of North Carolina (UNC), guided my recent return to train at TEACCH after twelve years. I have incorporated TEACCH principles and strategies into behavior support, teaching daily living skills, parent counseling, and in professional development workshops ever since my first TEACCH trainings at UNC in 2000, 2003, and 2005. After these many years, I am pleased to share information in this article about how the TEACCH principles and program components are as effective as ever for parents, professionals and, most of all, for children and adults with autism on any level of the spectrum.

In 1965, Dr. Eric Schopler and North Carolina parents created TEACCH, the acronym for Treatment and Education of Autistic and related Communication Handicapped Children. In 1972, North Carolina funded TEACCH, which became the first state-wide program of autism services in the U.S., achieving the highest rate of employment for people with autism of any state. One of the pillars of TEACCH that was as prominent and meaningful over the past fifty years as it is today, was Schopler’s commitment to grounding TEACCH in the principle that parents/families are co-therapists and co-teachers. He, as much as any professional I ever met, understood that “family engagement” and “parent-school collaboration” are not euphemisms, but values and practices that all professionals must be guided by and live by every minute. This grew out of first-hand experiences as a social work graduate student that were so formative for Dr. Schopler that they became the foundation for the TEACCH approach known as Structured TEACCHing.

As a social work student, Eric Schopler was assigned to the infamous Orthogenic School in Chicago run for decades by the equally infamous Bruno Bettelheim. Bettelheim promoted the then-common belief that

parents, particularly “refrigerator mothers,” caused autism due to their inability to love their child. Schopler witnessed Bettelheim’s so-called treatment of children with autism by isolating them from their parents and most of the staff with a treatment of climbing on stone statues. Schopler remained horrified by this, and went on to obtain a PhD in psychology and to direct research on the stress of parents of children with psychosis, which at that time included autism and autistic psychopathy, a term for Asperger syndrome that unfortunately lingers today. Years later, Eric Schopler and TEACCH dedicated themselves to validating the traumas and duress that the Bettelheim parents and their children had endured, by producing a documentary and honoring them.

Over the years, TEACCH expanded to be the first and only source of autism programming/support in many U.S. school districts and countries. In the 1970s, TEACCH was endorsed by the NY State Health Dept. as an evidence-based approach for preschoolers with autism and communication disabilities. In 2003, the landmark book, *Educating Children with Autism*, was regarded as the gold standard for educational evaluation of programs for autism. TEACCH was one of the programs to be cited as a model program that met the National Research Council’s rigorous criteria. In 2005, when I was at TEACCH to train and participate in Dr. Schopler’s 40th anniversary, I recall asking Dr. Catherine Lord, co-editor, if the National Research Council would publish a badly needed series of similar books of best practices guides for middle and high school. She explained that when completing this book in the midst of a changing presidential administration, it was all that they could do to get it published.

Through the decades, and today, families, researchers, educators, and therapists continue to face these ubiquitous challenges to institute and expand best practices in schools and community settings. Of note, among her extensive credentials as a renowned researcher and academician, Dr. Lord completed a clinical internship at TEACCH. While TEACCH may not be as familiar to many as other evidence-based methods of positive behavior support and training, TEACCH has the advantage of having stood the test of over 50 years of research, and remains a client-friendly, practical approach that complements and blends with other approaches, including discrete trial and other forms of behavior analysis. It is designed to teach and

support a child or adult in the classroom as well as in natural settings at home, recreation, community, pre-vocational, and employment settings.

Back in 2000-2005, when I attended the week-long TEACCH trainings, these were times when, even more than now, we were searching for family- and teacher-friendly evidence-based approaches that could effectively combine teaching communication, self-regulation, organization, and activities of daily living – no simple achievement then and now. Today, we live in an era where social emotional learning (SEL) is emphasized for all young children as the essential foundation for lifelong problem solving. Parents worry that their children with learning disabilities keep falling behind. Teachers feel taxed with pressure to shepherd delayed learners and diverse learners along. Since its creation, Structured TEACCHing (ST) has specifically addressed these demands by designing learning, play, and independent activity systems that allow a child or adult with autism to process, organize and problem solve information at their own pace. The key element of assessing each individual is identifying their unique learning styles. As an example of person focus, ST trains us to assess “learning styles” as opposed to deficits and challenging behaviors. ST practitioners understand that people with autism are susceptible to confusion, stress, and dysregulation. Dr. Klinger described ST as an Antecedent System. They find that the large percentage of what teachers and parents would report to be challenging behaviors are eliminated when the activity and system for using it are designed to match the child’s or adult’s learning style. In other words, by implementing ST, we can prevent and address the pitfalls that would otherwise cause and reinforce repetitive behaviors, rigid adherence, isolating, dysregulation, overstimulation, sensory overload, etc. When needed, they draw on Functional Behavior Assessment, Pivotal Response, PBIS, and other forms of behavior analysis.

TEACCH does not replace speech therapy and discrete trial. Rather, professionals and families can integrate its assessment and organizing systems with other approaches for a preschooler, school-age children, teen, or adult with ASD, as well as for children and adults with related executive functioning needs. TEACCH fits under the broad umbrella of evidence based approaches for applied behavior analysis that require assessment, data collection, progress monitoring, reassessment, and research.

Having previously trained at TEACCH with Adolescents,

Level Two, and Invitational topics, my recent trip was for TEACCH Early Childhood Training with 4, 5, 6, and 7 year olds who were verbal and nonverbal. True to form, as trainees, we experienced a parallel process of Structured TEACCHing ourselves, using a physical environment and curriculum that were intentionally structured for sequential, visual, and experiential practice of all the elements that we learned. An array of visual materials and containers were available as we worked in small groups, observed the students, and assessed each child’s learning styles. Next, we were given specific tasks to create a new activity or expand on a child’s skill using a familiar activity. We implemented the activity with the child, and then we were asked to reassess, restructure where needed, and retry the activity.

For people less acquainted with Structured TEACCHing and the research that supports it, questions sometimes arise about overreliance on visual schedules, lack of flexibility, and applications in inclusive settings. Actually, hallmarks of ST are teaching transition, flexibility, generalization, and independence. This is achieved by building these elements into a child’s or adult’s daily program in all assessments, tasks, activity/work systems, and schedules. Knowing what to do, where to do it, when an activity is finished, and knowing what to do next, are always made visually and spatially explicit. Regardless of level of functioning, amount of language a person possesses, and delays in processing and attention, people with autism receive clear permanent information that enables them to complete meaningful tasks and meaningful transitions.

One of the benefits of TEACCH has been to bring back a multitude of photos of the tasks (activity systems), work areas, schedules, and visuals that they create. Recently, when I showed my photos to a group of teachers, they were amazed at how efficiently very small spaces and everyday materials were used to organize areas and tasks for teaching, independent work, and a relaxation station. After all, everyone can benefit from a relaxation station. For more information with articles by TEACCH practitioners and about training, consult [www.TEACCH.com](http://www.TEACCH.com).

Dr. Kappenberg is a long-time member of AHA and serves on our Professional Advisory Board. She is a co-founder of Westbrook Preparatory School and served as their Clinical Director. Currently, she directs the Long Island Early Childhood Direction Center at the Center for Community Inclusion, LIU-Post at [Faith.Kappenberg@liu.edu](mailto:Faith.Kappenberg@liu.edu). Her offices for psychotherapy and consultation are in St. James and Glen Cove at [Kappenberg@aol.com](mailto:Kappenberg@aol.com).

## Autistic Adults and other Stakeholders Engaged Together (AASET) – Engaging Autistic Individuals as Primary Stakeholders in Seeking Solutions

by Stephen Shore, EdD



Autistic adults have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD, but we know very little about why these differences are occurring and how to improve outcomes.

In order to address this issue, the Patient Centered Outcomes Research Institute (PCORI, which is a U.S. institute that funds research on medical topics) has awarded a group called the Autistic Adults and other Stakeholders Engaged Together (AASET), a grant of \$250,000. AASET has been formed to identify the most pressing health issues for individuals with autism, to prioritize the specific positive health and healthcare outcomes desired by autistic adults, and to identify potential evidence-based interventions from the perspective of autistic adults. What makes this project unique is that it calls for individuals on the autism spectrum to be meaningfully involved at every step.

Under the terms of the grant, the objectives of AASET are to: a) establish a Community Council of autistic adults and other stakeholders to inform and guide “Patient Centered Outcomes Research/Comparative Effectiveness Research” (PCOR/CER) studies to improve health and healthcare delivery; b) plan and implement two national conferences which will support the work of the CC through priority and agenda setting of interventions and outcomes; and c) draft an engagement plan to include a governance structure for the CC, a written process and metric for evaluating engagement, and meaningful discussion of ethical involvement from a human-subjects protection perspective.

Teal Benavides of the Augusta University Research Institute is the project leader, in collaboration with Stephen Shore and Anita Lesko as co-leads, and Alex Plank as social media coordinator. The project team includes Dena Gassner and other self-advocates who are on the autism spectrum.

On July 11, 2017, AASET assembled its Community

Council, a team of thirty people, most on the autism spectrum, to meet in Milwaukee, to discuss our priorities and create an agenda. Following the meeting, the Community Council reviewed infographics focusing on areas of need; findings included the need for better mental health services and greater understanding of the co-morbid conditions that commonly occur with autism. Perhaps most interesting, especially since the large majority of the Community Council is made up of people on the autism spectrum, was the suggestion for increased supports for successful social interaction. (So much for the myth that those with autism eschew social interaction!) What we discussed was that reluctance to engage in social interaction may stem from the fact that, for many with autism and often from an early age, attempts at social interaction often turn out negatively. Therefore, many people on the autism spectrum just give up on what becomes an aversive activity.

### Current Accomplishments and Proposed Outcomes

Now that we have worked to build a common agenda with autistic self-advocates and their families, we look forward to further processing the results of our July 11th meeting in Milwaukee, followed by increasing engagement with the larger stakeholder community. We hope to involve organizational sponsors such as AHANY, the Gersh Academy, Boston Higashi School, Autism Speaks, Autism Society, and many others.

The three main outcomes we anticipate from completing this project are:

1. The development of an informed, invested **Community Council**. This national group of 20 autistic adults and their family members will be relied upon to contribute to future PCOR/CER studies. This independent body is necessary to ensure that autistic adults have their own organization, which can partner with researchers.
2. **Prioritization of health and healthcare outcomes and desired interventions** as solicited through community engagement. Research among individuals with autism has not traditionally involved them in making the decisions about what research questions and approaches should be asked.
3. Establishment of an **Engagement Plan**, with the following:
  - A.A *governance structure* to describe the formal

relationship of the Community Council to the research team and other stakeholders, as well as detail the responsibilities of this group as the project continues.

B. A *report for the ethical involvement and financial compensation* of self-advocates and family members in future PCOR/CER studies.

C. A *process and metric* which should be used to ensure that autistic adult and family member engagement is occurring.

Planned for October of 2018, our second and final conference will solidify our work with recommendations to PCORI so that we can begin addressing the medical needs of individuals on the autism spectrum.

Much thanks to PCORI, Teal Benevides, Anita Lesko, and all involved in making better health care for autistic individuals a reality!

Stephen Shore, EdD, teaches in the Ruth S. Ammon School of Education at Adelphi University. He presents and consults internationally on educational and social inclusion. Dr. Shore's books are translated into many languages. He is a member of the AHA professional advisory board.

**Research Update**

## News and Updates from the Stony Brook SCTL

by Matthew D. Lerner, PhD



The Stony Brook Social Competence & Treatment Lab (SCTL) continues to provide cutting-edge, evidence-based services and research for individuals with Autism Spectrum Disorder (ASD). Here are some brief but exciting new developments:

### Employment & ASD

One of the greatest areas of need for adults with ASD is effective, meaningful, gainful employment. We recognize the need for policy guidelines to support fulfilling, sustainable job opportunities for people on the spectrum. As such, in collaboration with the Autism Science Foundation, and with the sponsorship of the International Society for Autism Research, we are conducting a national survey to guide employment policy and opportunities. This survey represents the U.S. arm of an international collaborative project. We could use your help! If you are a) an individual with ASD who is least 18 years old, b) a parent of an individual with ASD, c) a Clinicians/Service Provider who works with individuals with ASD, d) an employer who employs at least one individual with ASD,

and/or e) a researcher working in the field of ASD, we welcome your input at [lernerlab.com/employmentsurvey](http://lernerlab.com/employmentsurvey).

### Computer Games & Treatment Opportunities

We continue to conduct several exciting studies examining ways to understand and treat social challenges. In a number of studies (sponsored by the Simons Foundation, the Brain & Behavior Research Foundation, and the National Institute of Mental Health), we continue to use computer-based "games" to help understand how children (ages 4-18) understand different aspects of the social world, and to see how different profiles of understanding relate to "real world" social strengths and challenges.

We are also proud to continue to provide evidence-based interventions to the Long Island community! We recently completed our study of Socio-dramatic Affective Relational Intervention (SDARI), the approach we developed to capitalize on specialized games and activities to improve social connections. However, thanks to support from Autism Speaks, we now provide SDARI as a service through the Stony Brook Autism Clinic! Likewise, there are some exciting new developments in terms of fun, engaging intervention studies that we plan to announce soon.

Next, we have developed a smartphone app to help people track their social interactions. This has helped us understand differences in patterns of social interaction and find ways to improve the quality of those interactions in a simple, non-invasive way! We are still looking for adults with ASD to help try out this app as part of a study, so please feel free to reach out if you are interested!

If you're interested in any of these opportunities, want to learn more, or just want to say hi, please contact us at [lernerlab.com](http://lernerlab.com), [lernerlab@stonybrook.edu](mailto:lernerlab@stonybrook.edu), or 631-632-7857

Dr. Lerner is an Assistant Professor of Psychology, Psychiatry & Pediatrics at Stony Brook University, where he directs the Social Competence & Treatment Lab (SCTL). His research focuses on understanding emergence and "real world" implications of social problems in children and adolescents (especially those with ASD), as well as development, evaluation and dissemination of novel, evidence-based approaches for ameliorating those problems.

### AHA Family Bowling

Port Jeff Bowl, Sundays, 12:30 pm - 2:00 pm

October 15, November 12, December 10

RSVP: Joe Kraker at 516-382-0492

[ahany.org/events/family-bowling](http://ahany.org/events/family-bowling)

**Destination: Normandy, France**

by Dena Gassner, PhD candidate



In 1991, the doctors said about my son PK's autism diagnosis, "I'm very sorry to tell you." They didn't say, "everyone grows" or "we don't know." They projected a dismal future and no hope for our precious boy with the halo of golden curls. They told us he would "never..." – fill in the blanks – we know all the nevers.

PK had many challenges throughout his school years, yet ultimately persevered and defied the predictions of "never." He was segregated in his classroom for two years, and assaulted by a peer. He attended an expensive private school that only expected students to complete six math problems in an hour with a calculator. He was socially promoted from 7<sup>th</sup> grade to 9<sup>th</sup> grade. He was isolated and threatened by a teacher who verbally abused him every time he passed him in the hallway. He was rescued by a team of angels in Tennessee: a few good teachers and a whole lot of hockey players. He graduated high school with an honors 3.1 GPA. A private college took \$30,000 for a semester and then abandoned him. Building on what he had accomplished, since the school abandoned him (living independently, managing money, persevering) we moved him to Marshall University in West Virginia. Another team of angels came into his life carrying footballs and colored schedules. Six relocations later, he's living in his own apartment, managing his money, cooking, using public transportation and is on track to graduate with honors in December. PK achieved all the so many things that the doctors predicted he would "never" do. This introverted man who loves predictability, who only eats around six foods still wound up with a wandering spirit that loves to travel, and that wandering spirit went to France this summer!

*"When I stood on the beaches at Normandy, I felt like I was standing in the line of fire, even though our guys, and the Germans couldn't see me while I could see them. I felt like I was there in another life."*

**First, the World War II Museum in New Orleans**  
It all started last summer, when PK and I visited New Orleans for an autism conference. He was insistent on going because the National World War II Museum is located there and, since he's a history major, he didn't want to miss that. Within an hour of the visit, PK found the brochures for the guided academic tours sponsored by the museum, and he knew that he had to do this, and I decided that I would join him! We learned that he

could sign up for a course for college credit, visiting and studying about the war on the beaches of Normandy. The trip would include Omaha, Utah, and Sword Beaches, the British, American and German cemeteries, and museums galore. This was a dream come true for PK and me but it would require planning, anticipation, and determination by everyone involved.

**Making the Unpredictable, Predictable**

In terms of addressing PK's unique needs, we'd have to learn about the program and what the typical student experience included; from that foundation we could identify where adaptations, accommodations and/or modifications would be needed. We needed to consider his needs related to housing, transportation and meals, as well as academic accommodations. He needed a quiet place to sleep, access to suitable foods (he has no

sense of smell or taste so this is important) and insuring the tour could adjust for his need for predictable schedules. Regarding academics, we worked with the Marshall University team to create a letter of disability, so the sponsoring college would know that PK would be using scanned books with Kurzweil and would have to dictate his work. The college was also informed that PK is phobic about public speaking.

At home, we spent a lot of time planning, and discussing with PK what to expect in terms of food during his trip. There would be no Wendy's fast-food, but plenty of French fries; no hotdogs, but he would get macaroni and butter. We would bring Hershey's syrup to ensure that PK could have chocolate milk, microwaveable macaroni and cheese, and some other favorite foods: peanut butter, Reese's cups, and ramen noodles. PK's anxiety began to diminish and was replaced with enthusiasm and excitement.

**Getting Adjusted**

Although the program officially started in New Orleans, we decided to bypass the first two days in New Orleans and arrive in Paris early. Not only would this mean we could have more time in Paris, but PK would also have a few days to adjust to the time difference and to explore the city. During his first two days in Paris, he visited a special exhibit about World Wars I and II at the Les Invalides Army Museum, and climbed to see the gargoyles on Notre Dame. On the third day, we rested and PK

confidently wandered around a large shopping mall, just like he would've at home! Finally, on the fourth day, we met up with his tour group at Charles de Gaulle Airport.

### Introductions

We boarded the tour bus and found it filled with 18 undergraduate students, his professor, and the guide from the museum. It was good to meet the professor because the professor had been generous and understanding about PK's academic accommodations. (PK crammed the week before the trip with all the readings, reports, and online Moodle posts, but PK was able to do three weeks of work in one week!)

The guide asked us to introduce ourselves. PK is comfortable about having others understand him better through disclosure, but he's not yet found his own words to do so. So he introduced himself, talked about his school and studies and then I introduced myself. I explained that I am a PhD student who researches autism. This very sweet, sensitive group of students connected the dots. THIS is the benefit of full inclusion — there are no students at this point who have not had an autistic person in their lives. PK was particularly blessed with this specific group of students.

### The Tour

The tour first stopped at the Avenue des Champs-Élysées and the Eiffel Tower for lunch, after which we rode for several hours to Bayeux near the Normandy beaches. PK enjoyed the first of several group dinners, where he ate macaroni and butter. For the "on your own" meal nights, he had the microwaveable foods, and he managed well with his other meals.

PK gave the three required speeches and completed all the coursework for the program. He was especially thrilled to visit St. Mere Eglise which was featured in the movie "The Longest Day." He also got to reproduce an historical photo at a large Chateau where Rommel had once stood, scooped sand from all the beaches, put his feet in the English Channel, and had dinner with an 89-year-old former French Résistance fighter.

He cursed the Germans and all they destroyed. He mourned, deeply, the souls of all who served. He listened intently to every story the group leader told, and to the extra lessons about the RAF and British forces. He visibly grieved at the American Cemetery and sought out the grave of a West Virginia soldier to lay a rose (just as he lays a rose at Marshall University when they memorialize another strong, brave group of men — The Marshall

Football Team of 1970 who were victims of a tragic plane crash). Towards the end of his trip, when they played the National Anthem and Taps with a 21-gun salute, I looked to check on PK and my heart burst with pride when I saw him comforting the others who were moved to tears.

"I'm very sorry to tell you," said the doctors. Well, so am I. I'm very sorry to tell you, you were wrong about everything.

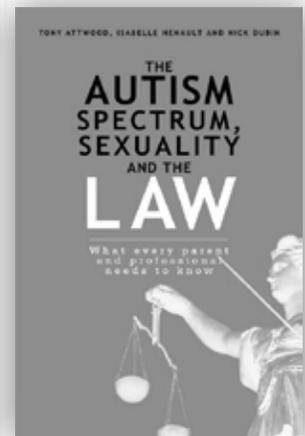
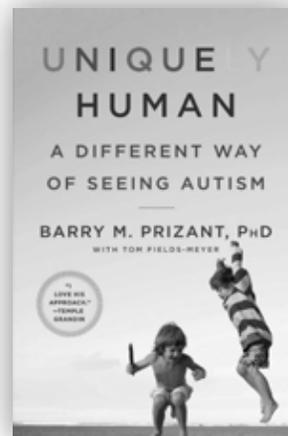
Dena Gassner, MSW, is a PhD candidate in social welfare at Adelphi University who has presented internationally. She is a national board member of Arc US and the professional advisory board for AHA. She facilitates the AHA women's group.

AHA is a Certified Training Partner of IBCCES's Certified Autism Specialist Program. Autism Specialist CE hours obtained at the AHA conferences can be used toward certification as an Autism Specialist (CAS) with the International Board of Credentialing and Continuing Education Standards (IBCCES).

**For further information go to [ibcces.org](http://ibcces.org)**

## AHA's Annual Spring Conference

Keynotes: Barry Prizant, PhD, CCC-SLP, and Nick Dubin, PsyD



# SAVE THE DATE!

Sunday, May 6, 2018

8:15 am – 4:30 pm

Breakout Sessions, Resources, Books and more!

Adelphi University

[conference@ahany.org](mailto:conference@ahany.org)

## Don't Underestimate the "Just in Case"

by Esther Zelmanovitz, Esq.



There are many excuses to procrastinate estate planning. "I don't need estate planning, I'm young," "I don't have much money anyway," or "My spouse will take care of my kids." But what happens when life takes an unanticipated turn and tragedy strikes? We

hope to live long, healthy, and peaceful lives, but estate planning documents are critical to have "just in case."

The following documents may be the most important documents you will ever prepare:

- A Durable Power of Attorney can protect your property if you become unable to manage your financial affairs. Your appointed agent can act on your behalf for financial matters such as paying your bills, banking, insurance matters, filing tax returns, collecting government benefits, and even estate planning.
- Advance medical directives (Health Care Proxy and Living Will) allow you to appoint an agent to make medical decisions on your behalf if you become unable to do so and lets others know what your wishes are regarding your treatment, including end of life decisions.
- A Last Will and Testament directs the distribution of your property after you pass. A will may include special distribution provisions, for example, to protect a disabled beneficiary's needs.

Consider the following two scenarios.

Scenario One: While on vacation with his two sons, Bob\*, a healthy and active 63 year old man, has a sudden stroke leaving him with permanent, severe brain damage. Bob did not have estate planning documents.

No one has legal authority to manage Bob's finances and legal matters. Checks cannot be signed. Interest and late fees accumulate on his credit card bills. Bob's investments are at risk. College tuition for Bob's son becomes overdue for next semester. Bob can't access government benefits. Further, although Bob's family all love Bob, they have differing opinions on what type of medical treatment Bob should receive, but do not know what Bob would have wanted, resulting in contention among his close-knit family.

Ultimately, a guardianship proceeding is needed. In a guardianship proceeding, a court would determine if the facts warrant appointment of a guardian to make financial and/or health care decisions on Bob's behalf and the court would further determine who that guardian would be. The process can be lengthy, expensive, and possibly even adversarial if, for example, family members conflict with

each other. Advance estate planning could have prevented this avoidable anguish.

Scenario two: Susan\* is a single mother of three. Her oldest child, Johnny, is 22 years old with special needs and receiving government benefits. Susan is killed in a tragic car accident. She did not do any estate planning.

Without a will, the court, and not Susan, will decide who will become guardian of Susan's minor children. Additionally, the law provides that Susan's estate will be inherited outright equally by her children. Johnny's outright inheritance results in risk to Johnny's eligibility for government benefits. While mourning the loss of his mother, Johnny would need to quickly seek legal help to plan for the disposition of his inheritance and protect the continuance of his government benefits. Furthermore, his planning options would be limited. For example, even if he swiftly creates a first party special needs trust, the trust would require a Medicaid payback provision upon his death, which would result in Susan's other beneficiaries being unable to access any remaining funds in the trust.

On the other hand, if Susan had, before her death, prepared a will directing Johnny's share into a (third party) supplemental needs trust for his benefit, Johnny would seamlessly be able to continue receiving his government benefits without emergency planning. Further, any funds remaining in the trust after Johnny passes would be left to Susan's remaining beneficiaries.

Having estate planning documents in place will give you peace of mind that not only your chosen agents will be able to act on your behalf and in accordance with your stated wishes, but also that your loved ones will be able to focus on what is truly important and not have to deal with preventable legal hardship.

Wouldn't it be better to do estate planning that is never needed rather than find yourself or your family in a situation where you need it but didn't do it? Ask yourself which you would regret more. Be smart and do your estate planning "just in case" there comes a time when you need it. Do not wait until it is too late.

\*fictional characters for example purposes

Esther Zelmanovitz, is the principal of Esther Schwartz Zelmanovitz, PLLC, with offices in Great Neck. Ms. Zelmanovitz focuses her law practice in the areas of estate planning, elder law, special needs trusts, and probate and estate administration. It is her goal to help each client achieve peace of mind and knowledge that they have taken legal measures to protect their assets so that they can focus on what's truly important in their lives.

## OPWDD Eligibility Simply Explained

by Joanne Sgambati, PhD, BCBA-D, LBA



The Office for Persons with Developmental Disabilities (**OPWDD**), is the New York State office that provides funding for services for people with developmental disabilities. If you have a child with autism who is aging out or graduating in a few years, you will want to consider getting these adult services. OPWDD adult services can include Self Direction, funding so that you can individualize many support services for your child such as Supported Employment (SEMP) to help them on a job, or Community Habilitation Staff to help them with shopping, travel training, daily living skills, or attending a class at college or gym. Other services could be agency run, like a Day Habilitation, and there are also housing supports. Basically, all adult services are supplied through OPWDD. The very first hurdle to acquiring such services is becoming “eligible.”

In order to be considered eligible for OPWDD service, the individual must be diagnosed with a developmental disability that is “recognized” by OPWDD and the onset must have occurred before the individual turned 22 years old. You will need to submit documentation: an annual physical with Tuberculosis test (done within the past year), a psychosocial evaluation, a psychological evaluation (including an IQ and Adaptive Function Scale), and for diagnoses other than an “Intellectual Disability” a medical or “specialty report” will be needed that includes health status and diagnostic findings to support the qualifying diagnosis – also known as the “Autism Specialty Report.” The “Autism Specialty Report” is quite detailed and can be a crucial part of the eligibility decision. It’s imperative parents find a psychologist familiar with Autism Spectrum Disorder, OPWDD requirements, and experience writing up this specialized report. For further information on the “Autism Specialty Report” go to the OPWDD website. OPWDD may request other documentations on a case by case basis as well.

**Once you have all the required documentation, you will need to submit it directly to OPWDD for evaluation for eligibility.** OPWDD has regional offices called the Developmental Disabilities Regional Offices (DDROs). The contact numbers for all regions in New York State can be found on the OPWDD website. Long Island is

Region 5 (631-434-6000). Leave your name and contact info and say that you want the “**Front Door Assessment.**” If they don’t return your call in few days, call again. (Front Door: [www.youtube.com/watch?v=zSc\\_uQXm6fQ](http://www.youtube.com/watch?v=zSc_uQXm6fQ) )

The Front Door training will give you an understanding of OPWDD’s mission and purpose, as well as outline the process of how you can become eligible for OPWDD supports and services, the types of supports and services available, and where you can go to get assistance. The front door facilitator will give you a list of Non-Medicaid Service Coordinators that will assist you with applying for Medicaid and Medicaid Waiver HCBS (Home and Community Based Services). It is up to you to make phone calls to connect to a Non-Medicaid Service Coordinator. When registering for an Information Session please let the facilitator know if you need translation services or have other accessibility needs.

When LIDDRO calls you back they will schedule a Phone Assessment or what is called an **Eligibility Assessment and Authorization (EAA) session** to establish what services you will be approved for. They ask you questions about your child’s abilities. **This may sound like a casual interview but it is actually a very important assessment and determines type of services and the level of funding you will need from OPWDD.** Talk about the individual and how they function on their worst day not their best! You must answer realistically. Ask yourself “Does he/she need reminders to do the task? Can he/she do it completely independently? Consistently? Thoroughly?” If the answer to any of these questions is “No” then you should answer “No, he or she cannot do it.” In other words, don’t overestimate your child’s abilities because it will sound like he or she is fully capable and independent with that skill and not in need of supportive services. They may also tell you to apply for OPWDD eligibility, review what assessments you need, send you forms to fill out, and schedule the Front Door information training about all OPWDD services and how to access them. Make sure when you go to your scheduled Front Door Training that you sign in so you get a certificate of completion mailed to you.

To apply for OPWDD “eligibility” the application is on their website with an explanation of their 3 step review process, the needed assessments, such as: a physical with TB in the past year, a “psychological,” a “psycho-

social or social history,” (video on needed evaluations: [www.youtube.com/watch?v=-yz6as8ZMf0](http://www.youtube.com/watch?v=-yz6as8ZMf0) ) and details regarding the “Autism Specialty Report.” Most of these assessments can be done at the school district’s expense as part of appropriate necessary transition services. If your child has graduated from school, the cost of these evaluations will become your responsibility.

After all the reports and application are submitted, you will receive a Decision letter from OPWDD. If deemed “eligible” your child will receive a TABS ID#. This TABS ID# will follow your child through the eligibility process. The coveted “Decision” letter from OPWDD will state your child is “eligible.” Keep that eligibility letter safe! Make multiple copies and keep in a safe place. It is an extremely important document.

For more detailed information on eligibility criteria for OPWDD services, visit [opwdd.ny.gov](http://opwdd.ny.gov) or [parenttoparentnys.org](http://parenttoparentnys.org).

Joanne Sgambati, PhD, BCBA-D, LBA, is a Licensed Clinical Psychologist, a certified School Psychologist, and a Licensed Behavior Analyst. Dr. Sgambati specializes in ABA & ASD but also works with many other developmental disabilities age 5 to adult. She is the Director of LI Psychological Services at Eden II/ Genesis programs. Dr. Sgambati is a Consultant Psychologist at Fay J. Lindner Center for Autism and Developmental Disabilities. She is an adjunct professor at Hofstra University. Dr. Sgambati also has a private practice. She is also the mom of two daughters with HFA/ASD.

*Subscribe to AHA's eNews and receive important information about current news, articles, events within the autism community.*  
[ahany.org](http://ahany.org)

### Spouse/Partner Group

This group is for partners of individuals with ASD or an ASD profile. It will provide opportunities to connect with other spouse/partners in neurodiverse relationships. Group members will be able to share their experiences and receive supportive feedback from others in the group. This group is in partnership with Spectrum Services and is facilitated by Leslie Sickels, LCSW, and Pat Schissel, LMSW, Executive Director of AHA. There is no fee to attend.

The group meets monthly on the first Tuesday of the month, 6:30 pm - 8:00pm at Spectrum Services, 303 Fifth Avenue, Suite 1003, 10th Floor, New York, NY (between 31st & 32nd Streets).  
Oct 3, Nov 7, Dec 5. Future meeting dates can be found on the AHA website.

*Back to School, cont'd from page 4*

derstand their social environment. Parents should be aware of these challenges and provide opportunities for discussion in a supportive manner.

### High School Support Strategies:

1. Understand each student’s unique executive functioning profile, and provide corresponding supports. It is crucial to remember that individuals with ASD who exhibit intellectual strengths often experience executive functioning difficulties and it is crucial to provide supports around development of compensatory strategies.
2. Provide direct, concrete instruction to learn organizational strategies and establish routines that foster success. Direct instruction does not mean completing the task for your child. Providing “just enough” support is key. Remember, adolescents often respond better to instruction from an “outside” expert, rather than a parent.
3. Preparation is the best tool to combat the challenges often associated with a new school building. Visiting the school multiple times before the first day, reviewing maps, identifying entrances and other important areas in the building can set your student up for a successful transition.

This is only a sample of tips and tricks that may be helpful toward a smooth transition into the new school year. Please stay tuned and visit [www.spectrumservicesnyc.com](http://www.spectrumservicesnyc.com) to learn about the upcoming parenting workshop I will be leading.

Dr. Nicole Alicino is a post-doctoral fellow working in private practice at Spectrum Services. She received her PhD in School Psychology from Fordham University. Prior to pursuing her doctoral degree she earned a master’s degree in Educational Psychology from Fordham University and worked as a licensed school psychologist in underserved communities in New York City. She has expertise in working with individuals on the Autism Spectrum and a solid foundation working with patients with anxiety, depression and related disorders. Dr. Alicino offers neuropsychological and diagnostic evaluations for children and adults, including adult Asperger’s assessments, and psychotherapy for individuals and families.



### Music Lessons for People with Autism

**Dr. Stephen Shore**  
Assistant Professor of Special Education at Adelphi University  
Piano, recorder, brass, and others  
All levels welcome  
**(857) 225-0304**

Email [tumbalaika@aol.com](mailto:tumbalaika@aol.com) for more information

*Impaired Theory of Mind, cont'd from page 7*  
moment. Instead, I have to accept the limits of my own impaired perspective-taking and am left to wonder – “is this a matter of not seeing the stairs, or that the staircase truly does not exist for them in that situation?” These are the times I come to my patients with questions so I may provide them with answers.

So, I breathe in their frustration and despair. I try to listen with compassion and understand their reality and how their perception can still feel so real to them. I feel at odds because no matter how much I question, listen and reflect, there is something in my patients’ stories that makes me feel like I’m looking down from atop the staircase and never fully sharing their perspective of looking up.

It’s ironic that two of the hallmark difficulties of people with OCD and autism – dealing with uncertainty and perspective-taking (or, in psychology speak, “Theory of Mind”) – are at the root of my own insecurities about falling short as a psychologist or being disconnected from the people I work with. While the basics of human suffering are fairly relatable for the average therapist – worry, fear, anger, sadness, heartbreak, and disappointment – there seems to be something about my patients’ experiences that I may never fully grasp. From an intellectual standpoint, I can understand the mechanics of how their minds work, but the truth is, I am far more interested in empathy than academic analysis.

I have found what’s best is to follow the same strategies and therapeutic skills that I practice with my patients. Every day, I ask them to sit with discomfort, to approach fears and challenges, and even just be aware and observe their anxieties, worries, obsessions, odd feelings, and urges instead of judging, denying, or trying to change them. I model how to make an educated guess about what others may be thinking and feeling, encourage asking questions versus making assumptions, and challenge patients to try and connect with their own emotional experiences to better understand others’ perspectives. And so, this is what I do for myself as well.

For instance, the week after we change the time for daylight savings is always tough for me. My inner clock is thrown off and my sleep becomes fairly dysregulated. I feel like I’m dragging through the day and then can’t shut off my mind at night when all I want to do is sleep. I feel “not just right” and a little emotionally down. I try to approach these moments with curiosity. I note how an arbitrary social rule telling me what time of day it is, when I must wake up, go to work, and sleep can have profound

physical and cognitive effects on me. I recognize this may be how my patients with autism feel – constrained simply because a societal norm is at odds with the way their unique brain works. So, I pay attention to the deep frustration of a confounding week in which I can’t perform at my best because “falling back” or “springing forward” is mismatched with my circadian rhythm.

And while I love to travel, I don’t like the pressure of needing my passport. In weeks leading up to a trip, I’m plagued with intrusive worries: “Where is my passport?” and “When does it expire?” even though I very much know the answers to these questions. On the trip itself, I get urges to constantly check my pocket, check my bag, or check the safe in my hotel – all futile attempts to quash the uncomfortable feelings I get whenever I think about my passport. The funny thing is that I have never lost my passport or know anyone who has. I now realize these irrational, unwanted thoughts and feelings are similar to what my patients with OCD can experience almost daily, and that my attempts to feel better by looking for my passport could be considered a compulsive behavior. So, instead of checking for my passport on a trip, I have learned to try to be an active observer of my experience. I notice my urges and thoughts. I sit with the accompanying flutter of my heart, pit in my belly, tension in my jaw, and the swirling thoughts in my head and just try to be a witness to them. I take in these moments and desperately try to hold onto my discomfort to help bridge the gap between my patients and me.

It is in experiences like these, something that can’t be learned at any conference, journal article, or academic work that I begin to feel like I am standing eye to eye, or I to I, with my patients. I will likely always feel like a therapist with some type of impaired theory of mind, but perhaps by continuing to ask questions, my patients will provide me with the answers.

---

Rebecca Sachs, PhD, is a New York City-based psychologist specializing in treatment of autism, OCD, and anxiety.

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## ASTEP Rebrands as Integrate Autism Employment Advisors

by Marcia Scheiner, MBA



Employer interest in Autism@Work programs is growing rapidly. To best position ourselves with employers as they seek partners to establish effective programs to recruit and retain individuals on the spectrum, we rebranded and changed ASTEP's name to Integrate Autism Employment Advisors (Integrate) in March 2017. And the response has been excellent!

The GOOD NEWS is that more and more employers are noticing the efforts of companies like DXC (formerly HPE), SAP, JPMorgan Chase, Microsoft, EY and Ford, and are beginning to develop programs to hire individuals with autism. The early adopters of formal Autism@Work programs have formed a group to share their knowledge with other companies, so employers can benefit from their experience.

In talking to some of the early adopters of Autism@Work programs, the SURPRISING NEWS is they are having difficulty filling their pipelines with candidates. Many have said they would hire twice as many people as they have, if they could find them. For all of those unemployed individuals on the spectrum, and those of us who know them, I am sure this seems shocking. So how do we bridge this gap between willing employers and unemployed individuals on the spectrum?

An important way is to help individuals on the spectrum connect with employers, even when those employers aren't in hiring mode. Integrate's Employer Connect program, now in its seventh year, has engaged over 30 employers and 150 young adults in networking sessions. This Fall we will welcome our largest group ever – 23 individuals – and will hold networking events with employers including The Economist, PwC, Cisco, Barclays, Viacom, City of NY, Becton Dickinson, and LinkedIn. Approximately 40% of the individuals who've attended our Employer Connect program have used their improved job search and networking skills to obtain full-time employment.

We must support individuals on the spectrum by making connections for them with business professionals who will conduct mock/informational interviews with them and provide constructive feedback. Use social media tools like LinkedIn to expand professional networks. And

remember, a job search needs to be treated like a job, with significant time commitment and structure. While the number of ready and willing employers is growing, it is important for job candidates to stay ahead of that curve.

Marcia Scheiner is the founder and President of Integrate Autism Employment Advisors (Integrate). Prior to founding Integrate in 2010, Ms. Scheiner spent 25 years as an executive in the financial services industry. At Integrate, Ms. Scheiner works with employers to help them identify, recruit and retain professionals on the autism spectrum. Ms. Scheiner is a graduate of Wellesley College and has an MBA from Columbia University's Graduate School of Business. She is also the parent of a young adult son with Asperger Syndrome.

## AFSS/Aspies for Social Success Update

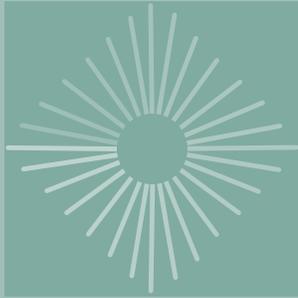
by Stephen Katz



Headquartered in New York City, Aspies For Social Success, AFSS, is a peer-run organization that provides support and social groups, as well as cultural events, to adults 18 and over who have either been diagnosed with Asperger's Syndrome or an Autism Spectrum Disorder (ASD), who believe they might be on the Autism Spectrum, or who for other reasons have difficulty with social communication, sensory processing, or executive functioning. AFSS is working to build a more inclusive community for individuals who otherwise may not have many opportunities or be able to find others with whom to socialize. AFSS does not charge members any fees; their income comes exclusively from fundraising.

Over the summer they had a number of activities that allowed for socialization, and lively discussion for those in this growing group. There were daytime and evening groups that met at the New York Public Library and in various restaurants, a visit to the New Hall of Science, a picnic, and an Effective Communication Workshop. As of *On The Spectrum* going to press, the fall calendar for AFSS is not yet up but we are sure there will be lots of interesting activities for all. You can access AFSS and their calendar and learn more about them here: [www.nyautismcommunity.org](http://www.nyautismcommunity.org)

Stephen Katz is the Executive Director of Aspies For Social Success (AFSS). Stephen facilitates a variety of support, social and cultural groups for adults on the autism spectrum. Additionally, his background includes training with the Miracle Project, the musical theatre arts program for special needs kids, and certificates from New York University and The New York League of Early Learning. Previously, Mr. Katz has worked in advertising, marketing and finance. He is also an artist and has studied at the prestigious Art Students League and Parsons School of Design.



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**Integrate Autism Employment Advisors Inc (Integrate)** works with employers to identify, recruit and retain qualified professionals on the autism spectrum in inclusive, competitive employment.

[www.integrateadvisors.org](http://www.integrateadvisors.org)

**Marcia Scheiner**, Founder and President

**Asperger Syndrome and High Functioning Autism Association (AHA)** provides support programs, conferences, activities, email and phone referral with reliable, up-to-date information for individuals and families. [www.ahany.org](http://www.ahany.org)

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

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[www.aspergercenter.com](http://www.aspergercenter.com) for articles of interest for families and adults with Asperger syndrome.

[www.spectrumservicesnyc.com](http://www.spectrumservicesnyc.com) for clinical services and contact information.

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# People Who Make a Difference:

These are individuals with passion and drive who devote time and energy on behalf of you, your families and your patients. In this issue we have chosen Keith Myles, PhD.



*We are saddened to announce the passing of Dr. Keith Myles, president and co-founder of AAPC Publishing. Dr. Myles died June 19, 2017 at the age of 79.*

## **Keith B. Myles, PhD: In Memoriam**

Realizing the lack of affordable, evidence-based autism resources, Dr. Myles co-founded AAPC Publishing 18 years ago after having been involved in various business leadership positions, including serving as a professor at Rockhurst University in Kansas City, Missouri. Starting with one book, *Asperger Syndrome and Difficult Moments*, by co-founder Brenda Smith Myles, PhD, a leading autism researcher, AAPC has grown to become a leading publisher of autism-related resources, including books, CDs, DVDs, and other resources, many of which have been translated into other languages and sold throughout the world.

Even in the face of his health problems, Keith Myles continued to be a driving force behind AAPC Publishing. He took great pride in his work and enjoyed the many connections he made throughout the autism community and publishing network.

Dr. Keith Myles will be profoundly missed not only by his siblings, children, grandchildren, and great-grandchildren, but also by the authors and staff he mentored over the years. AAPC Publishing remains committed to his vision of publishing high-quality, inexpensive books for family members, professionals, and individuals on the autism spectrum.

*Brenda Myles, James Jones, & Serdar Marun of AAPC Publishing*

The autism community has lost a great man. Dr. Keith Myles provided an avenue for the publication of countless affordable quality publications to assist families and professionals. He also hosted valuable autism conferences. Of utmost importance, he sincerely liked and cared about people with autism. He will be missed.

*Diane Adreon, EdD, Associate Director UM-NSU Center for Autism & Related Disabilities, Miami, FL*

Keith Myles made it possible for me to pursue a dream. In 2002, I proposed a book idea involving a simple 5-point scale; that discussion led to many years of creative collaboration. Keith was on a journey to assist and support anyone seeking information about the autism spectrum. I will always be grateful that he invited me to walk with him for a while.

*Kari Dunn Buron, MS, Autism Education Specialist. AAPC Author of *The Incredible 5-Point Scale/When My Worries Get Too Big!**

Keith Myles will be missed by many. Because of the publishing company he co-founded with Brenda Myles in 1999, the autism community has been forever changed! Quality, affordable, evidence-based books, CDs and DVDs have helped people worldwide to understand autism better than ever before.

*Judy Endow, MSW, LCSW, Author, Artist, Speaker, Consultant*

I have just learned of the passing of Keith Myles, President of Autism Asperger Publishing. Through his work at AAPC, Keith will be remembered as a pioneer in informing professionals, families and the general public about autism. My deepest

sympathy goes out to his family. Brenda Smith Myles will be taking over as President of AAPC. Brenda is known internationally for her expertise in the field of autism and disability.

*Susan J. Moreno, CEO and Founder, OASIS@MAAP, MAAP Services for Autism and Asperger Syndrome*

Although my father made a remarkable impact on the autism community, I simply remember him as “my dad.” My father had a soft heart and a unique exuberance. He could make anybody feel welcome with his warm energy and boisterous laugh. He was very proud of AAPC and of his mission to make resources that help individuals on the autism spectrum, as well as their friends and family, more accessible. I will miss him.

*Haley Morgan Myles, Daughter*

I found Keith to be available to me just about any time. Sometimes I'd call the office at 4am – and he picked up! When I asked what he was doing in the office so early, he'd ask why I called so early. Later, I expressed concern that perhaps I was calling too often and distracting him from his work, so I laid down a decree that I would call him only on days ending with “Y.” Complete silence on the other end... followed by the loud belly laugh Keith was so famous for! Well... I can't ring up Keith anymore – but can remain thankful for all he's done for me and the autism community at large. But only on days ending with Y!

*Stephen Shore, EdD, Author, Speaker, Assistant Professor, Adelphi University, Garden City, NY*

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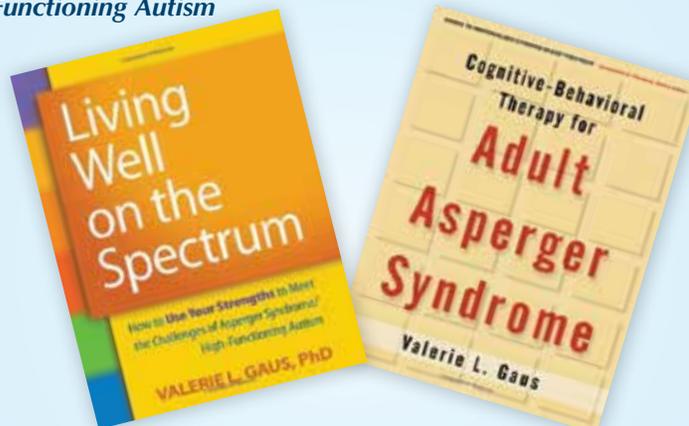
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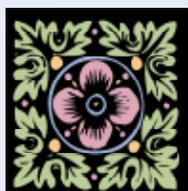
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The Fay J. Lindner Center in partnership with Asperger Syndrome and High Functioning Autism Association (AHA) are pleased to announce two new support groups beginning Fall 2017.

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This group is for post-high school aged adults who identify as being both on the ASD and LGBTQ spectrum.

**Where:** FJL Center Waiting Room:  
189 Wheatley Road

**Time:** 3:00pm-4:30pm

**When:** First Thursdays of the Month:  
Oct 5, Nov 2, Dec 7

## **Family & Friends of LGBTQ**

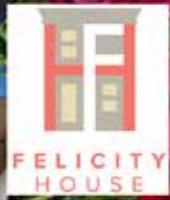
This support group is a safe space for family and friends who support an individual who identifies as being on the LGBTQ spectrum.

**Where:** FJL Center Waiting Room:  
189 Wheatley Road

**Time:** 2:00pm-3:00pm

**When:** First Thursdays of the Month:  
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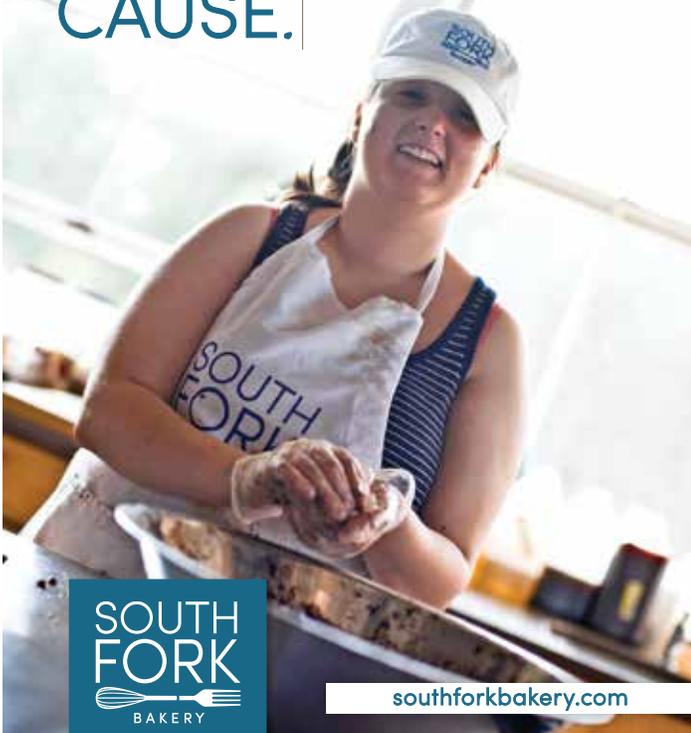
Zach now lives independently, has a job and an associate's degree. His father, Eric, says

“Zach has become really good at managing his life. He is able to speak up for himself, ask the right questions and get the problem solved. Seeing him achieve all that was an incredible feeling.”

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## All Around the Town

*Our board, staff members and volunteers are involved with autism awareness, education and advocacy locally and around town, bringing knowledge about AHA, Asperger syndrome, and related conditions*

### Autism Speaks Long Island Town Hall at Hofstra University

This resource fair and panel discussion focuses on services and resources available to adults on the autism spectrum. Jodi Kaplan and Carol Koch attended and manned AHA's table. – March 16, 2017

### First You Need A Vision: Transition Planning for Teens with Asperger Profiles /Webinar

A transition plan should provide a vision for the future that takes into consideration the teen's hopes and dreams and the teen's realistic motivation to achieve them. Leslie Feinberg participated. – March 24, 2017

### Yes She Can – Advocates for Adults with Autism Awards



At Manhattanville College where Leslie Cattan, Amy Gravino and Ron Suskind were recognized as outstanding individuals who have made significant contributions to improve the lives of adults with autism spectrum disorders. Pat Schissel, Bernice Polinsky and Bea Gravino attended. – March 28, 2017

### Life Course Outcomes Research Program: Learning How Life Turns Out for People on the Autism Spectrum/Webinar

Professor Paul Shattuck of Drexel University's Autism Institute and his research team extrapolate data from pre-existing research data bases with the hopes of answering questions that can equate "best practices" in public policy to positive outcomes for those with ASD. Offered by Simons Foundation. Leslie Feinberg participated. – March 29, 2017

### TED Talks – Autism Science Foundation (ASF)

At their fourth annual Day of Learning ASF attendees heard from such outstanding speakers as Dr. Wendy Chung, Director of Clinical Research, Simons Foundation; Dr. David Mandell, Professor, Director, Center for Mental Health Policy and Services, University of Pennsylvania; and Dr. James McPartland, Associate Professor, Director, Developmental Disabilities Clinic, Child Study Center, Yale University among others. Pat Schissel attended. – March 30, 2017

### The United Nations World Autism Day (WAAD) "Toward Autonomy and Self-Determination"



Professor Simon Baron-Cohen spoke about human rights issues: acceptance and respect. Dr. Barry Prizant addressing the rights of people with disabilities and a shift to a shared vision of humanity. A Call to Action: Employment for Persons with Autism. Pat Schissel, Bernice Polinsky, Leslie Feinberg, Dena Gassner and Alison Harrad attended. – March 31, 2017

### Keep The Change @ Tribeca Film Festival (KTC)

The film won The Founders Award for Best Narrative Feature and Best New Narrative Director to Rachel Israel for Keep the Change. Pat Schissel and Kate Cody attended. – April 22, 2017

### The 10th Annual Hilibrand Autism Symposium offered by UJA Federation of New York



Parents and professionals supporting young adults with ASD to become aware

of ways to foster independence, focus on self-advocacy, housing and entrepreneurship. Pat Schissel and Leslie Feinberg attended. – April 26, 2017

### The Annual Parent Leadership Summit

A day devoted to continuing the conversation about the importance of community connections and understanding other's perspective. Building bridges for parents and families across Long Island. Leslie Feinberg attended. – May 6, 2017

### Moving Forward in Children's Mental Health (MH): Promoting the Positive by Planting Seeds for Success

The NYS Office of MH (LI field office) collaborating with agencies and mental health providers on the effects of mental illness on our children and best practices for interventions. Leslie Feinberg attended. – May 10, 2017

### Literacy Nassau's Recognition Night



Next Chapter Book Club, Literacy Nassau's program co-facilitators, Leslie Feinberg and AHA member Susan Astre were recognized as 'Facilitators of the Year.' Leslie Feinberg and Susan Astre attended. – May 18, 2017

### Understanding Mental Illness

Leslie Feinberg completed the 12 week Family-to-Family program offered by National Alliance on Mental Illness. – May 18, 2017

### Community Technical Assistance Center /Webinar

Dr. Peter Gerhardt focused on the need for adaptive behavior skills in ASD and transition to be integrated in ways that the student experiences and understands the value with naturally occurring reinforcement at home, in their community and school environments. Leslie Feinberg participated. – May 23, 2017

### YouthPowerNY!/Webinar

Described the launch of a LGBTQ initiative geared towards the community served. As a result, AHA partnered with the Fay J Lindner Center for Autism to now offer a monthly support group to adults identifying both as on the autism spectrum and LGBTQ. Additionally, a monthly support group will be offered to parents of anyone identifying as LGBTQ, to offer support and education. Leslie Feinberg participated. – June 22, 2017

### Autism Spectrum News and Behavioral Health News Leadership Awards Dinner



Dr. Fred Volkmar and other leaders were honored for their commitment to improving the lives of countless individuals. Bernice Polinsky attended. – June 29, 2017

### Mental Health Association of Nassau County: Introduction to Group Dynamics and Process

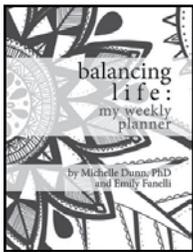
Workshop presented by Jeanne Byrnes, MS, CRC, LMHC. Information and ideas gleaned from this workshop will help AHA facilitators of the parents of teens and parents of older teens/adults groups. Leslie Feinberg attended. – July 27, 2017

### Common Challenges and Realistic Strategies for Neurodiverse Couples/Webinar

Grace Myhill, MSW on helping couples identify how their neurological similarities and differences affect the dynamics and interaction of their relationship. Leslie Feinberg participated. – July 23, 2017

**Balancing Life:  
My Weekly Planner, a Tool  
For Teaching Time Management**

by Michelle Dunn, PhD & Emily Fanelli  
overview by Michelle Dunn, PhD



This planner is different! It not only provides a place to record tasks to be done but it teaches time management, specifically, how to complete short-term and long-term responsibilities, while balancing the time devoted to those responsibilities with that allotted

to chores, appointments, free time, social life, and even eating and sleeping.

Managing time in order to meet the varied and complex responsibilities of life can be particularly difficult for people with Autism Spectrum Disorder. Weak time management can make responsibilities overwhelming, resulting in anxiety, procrastination and sometimes “freezing.” It can prohibit people from achieving their academic, occupational, or social potential, and threaten life satisfaction.

There are a number of ways in which people have difficulty managing their time: 1) Some people make “to do” lists, including all of the short and long-term tasks they think must be accomplished on a given day and in the near future. They do not prioritize or assign a reasonable number of tasks for each day. This becomes an overwhelming mountain of work, and it is never finished; 2) Some people don’t break down the big, long-term tasks into specific, manageable steps to be planned and carried out on separate days, in advance of the due date; 3) Some get distracted by favorite activities, which may include going online to watch videos, play games, or look at social media. Free time is not planned – it intrudes; and 4) Some use separate planners for work/chores and for socializing/appointments. They often run out of time for work because they do not plan it with appointments in mind.

This unique planner/time management system reduces anxiety and increases productivity by teaching the user to: 1) plan for what can realistically be accomplished in one day; 2) employ the adaptive strategies of task analysis and of doing one thing at a time; 3) plan free time in order to avoid succumbing to distractions; and 4) balance all of the activities of life.

*Tired Dog Publishing, 2017*

Michelle Dunn, PhD, is director of the Montefiore-Einstein Center for Autism and Communication Disorders and Professor of Clinical

Neurology at the Albert Einstein College of Medicine. She is a neuropsychologist and researcher (in brain behavior relationships & intervention methods), who has written numerous journal articles, chapters, and books including *Autism in Your Classroom*, and *SOS: Social Skills in Our Schools*, a comprehensive curriculum, implemented in schools in New York City, Thailand, and Guam. She has provided training to school and college staff in intervention methods for children and young adults with communication disorders, autism, executive function deficits, and other learning disabilities. Currently her work involves developing, implementing, and empirically assessing innovative treatments. Her great joy is in translating what she learns through research into clinical practice.

**Excelling With Autism Across the Lifespan:  
Deliberate Practice and Critical Mass**

by Brenda Smith Myles, Ruth Aspy,  
Kerry Mataya, Hollis Shaffe  
overview by Brenda Smith Myles



This book introduces a new way to optimize the progress and independence of learners on the autism spectrum by viewing instruction and supports from a novel perspective.

Ultimately, we want everybody – including those with autism spectrum disorder (ASD) – to be able to move about their world as independently as possible, making informed decisions about their wants and needs, and have a high quality of life. We want everybody – including those with ASD – to be successful, not only with tasks and activities they have been taught to do, but also with tasks and activities that they have not received instruction on.

In other words, we want everyone to be able to obtain a body of knowledge based on their experiences and to apply this knowledge flexibly to novel situations. This is called critical mass. Think of critical mass as true mastery of a skill. Critical mass, in this sense, is the point where an individual has gained the ability to apply learned information to situations, activities, or skills for which instruction has not been provided.

Critical mass is not just about developing habits and routines, nor is it rote memory. It means having the ability to take known information and apply it in both new and similar situations. Critical mass has increasingly been seen as a universal concept, equally applicable to water and magnets as to animals and humans. Today, the study of critical mass is central to almost all discussions of behavior and norms because the dynamics of system change are remarkably constant across disciplines. This information,

*Excelling With Autism, cont'd on page 34*

*Excelling With Autism, cont'd from page 33*  
however, has not reached the world of autism.

Why is critical mass important? The answer is simple – most individuals with ASD are not reaching their potential. For example, the unemployment rate for those on the spectrum is higher than for any other disability group. Independent living and community participation rates are equally low. This is so because they often do not reach the level of mastery of pivotal skills that would allow them to utilize those skills flexibly in order to be successfully independent – they do not reach critical mass.

How do we support individuals with ASD to achieve critical mass? We provide deliberate practice. K. Andres Ericsson, a Swedish psychologist, has written about the role of deliberateness in reaching a high level of competence. Ericsson has made a career of identifying the elements necessary to create expert performance in areas such as chess, world class gymnastics, memory, and laparoscopic surgery.

This book reviews the concept of critical mass, and how to use the four components of deliberate practice (developing specific goals, ensuring focus, providing feedback, and assisting the learner to move out of the comfort zone) to address ASD neurology and ensure that individuals with ASD have the opportunity to reach their limitless potential.

*AAPC, 2017*

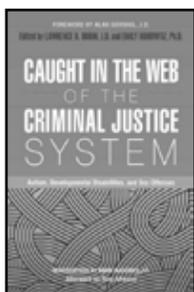
Hear more about Critical Mass from Brenda Smith Myles, outstanding keynote and presenter, at AHA's Fall Conference on Saturday, October 28, 2017!

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## **Caught in the Web of the Criminal Justice System: Autism, Developmental Disabilities, and Sex Offenses**

*by Lawrence A. Dubin, JD and Emily Horowitz, PhD  
overview by Lynda Geller, PhD*

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*Caught in the Web of the Criminal Justice System* is the culmination of the work of varied professionals who have united in the cause of illuminating the verboten topic of sex offenses, in particular child pornography viewing, with a special focus on those on the autism spectrum.

There has been a hesitancy to speak openly about this particular concern for fear of branding the entire ASD population as potential sex abusers, which could not be farther from the truth. However, so many men on the spectrum have been forever harmed by arrest, prosecution, mandatory sentences in prison, and registration on the public list of sex offenders, that the topic must

be brought to the attention of individuals, families, and professionals. This book is the most complete treatment of the subject ever attempted and is particularly valuable because of the multiple perspectives it includes.

The reader is drawn into the subject through personal narratives about how the Dubin family was affected by their son Nick's arrest and prosecution. But this book was written not to engender only sympathy or fear, but as a warning to others and a call to action against a legal system that has become increasingly influenced by hysteria, ignorance, and willful disregard of fact. In addition to the personal perspectives are the valuable contributions of mental health experts explicating the particular vulnerability of those on the spectrum to computer-based sexual images, the role of a forensic assessment, the inappropriateness of punishment instead of habilitation for such individuals, the dearth of evidence, as well as the false evidence, that anyone who looks at child pornography is likely to harm a child. From a legal perspective, are chapters regarding the history of the increasingly punitive and mandatory sex offender statutes, the difficulties encountered in defending clients so accused, actual statistics regarding the ineffectiveness and harm of current sex offender laws, and the effects of the fear promulgated as the result of some particularly tragic child murders. From a sociological and criminal justice perspective, the horrifying consequences of our system of incarceration and sex offender registration on the accused, on the family of the accused, on the child victims of the creation of child pornography, and on the general public, in terms of generating hysteria and fear, are explained in detail. The injustice and ineffectiveness of the current system are also examined from a philosophic and moral standpoint. Finally, there is a call for change from a legal and excessively punitive response to one of legal diversion and habilitation for those on the spectrum, as well as a more fairly based system for neurotypicals embroiled in this tragic system.

The editors are to be particularly commended for putting these diverse perspectives together into a flowing commentary that builds a comprehensive argument about what changes are needed in the whole concept of the criminality of viewing child pornography in general and, specifically, regarding the socio-sexually vulnerable population of those on the spectrum.

The book will be especially valuable to attorneys around the country who prosecute, defend, or judge these morally and legally dubious cases, as well as mental health professionals who research such issues or try to explain the

specifics of autism and how it relates to these legal issues in court. It can be hoped that legislators who are primarily responsible for establishing increasingly harsh penalties will read this and reconsider the ineffectiveness and cruelty of the current system as it relates to the ASD population. Lastly, this book serves as a cautionary tale to adolescents and young men on the spectrum and their families, as well as educators and professionals, that social and sexual education and treatments are key to preventing involvement of naïve and harmless individuals in this harsh system of questionable effectiveness.

JKP 2017

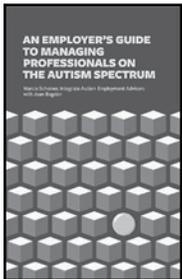
Lynda Geller, PhD, is the founder of Spectrum Services, a multidisciplinary and cooperative practice established to evaluate and treat the many complex needs of individuals on the autism spectrum. She is currently involved in evaluation and testimony for individuals on the autism spectrum who have been caught in the web of prosecution for child pornography.

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## **An Employer's Guide to Managing Professionals on the Autism Spectrum**

by Marcia Scheiner (*Integrate Autism Employment Advisors*) with Joan Bogden  
overview by Pat Schissel, LMSW

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*An Employer's Guide to Managing Professionals on the Autism Spectrum* is a must read for managers, mentors, HR professionals and co-workers who want concrete tools for understanding and guiding colleagues on the spectrum through the daily challenges they may experience at their jobs. The aim is to get the best from

those on the spectrum in high-skill or professional level positions. Many professionals and individuals with an autism diagnosis were interviewed and are quoted.

Integrate Autism Employment Advisors (formerly known as the Asperger Syndrome Training & Employment Partnership: ASTEP) was founded in 2010 by Marcia Scheiner to increase inclusive competitive employment opportunities for college graduates with autism. Integrate does this by working with employers to help them identify, recruit, and retain professionals on the autism spectrum.

In this book, each chapter is focused on a particular type of challenge a professional with an ASD profile may have and how it may present in the workplace. There are specific examples of behaviors, explanations of underlying issues, and respectful and effective ways to address them. Cross referencing is utilized when one issue relates to another chapter as well.

The book begins with an overview of working with individuals with ASD – those individuals you probably have run across already but did not quite “get.” The remainder of the book is divided into three main categories: *Social Issues at Work*; *Work Performance*; and *Sensory Challenges*. All have subheadings that can be easily accessed, allowing the reader to focus quickly on specific topics. *Social Issues at Work* discusses failure to fit in as one of the most common workplace challenges for people with ASD. The book discusses how to help individuals on the spectrum understand and respond to the “hidden curriculum” – the social information neurotypicals know without being taught – which includes non-verbal cues, gestures, and tone of voice.

Specific examples are given for some subtle misunderstandings that can get people into real trouble on the job. One situation described in the book that could easily be misconstrued by an individual with ASD is when a boss or manager says, “would you mind?” It’s important to understand that this is not a simple yes or no question, but rather a direct order. Another topic discussed is the importance of understanding the appropriate chain of command. Understanding the workplace hierarchy will help an employee determine who may be contacted (either verbally or via email) in a particular situation, and can help an employee reframe comments that might antagonize superiors or coworkers (like “That’s a stupid idea” or “Everyone knows that”) into ones that make someone more a part of a team and more likeable (like “Have you thought about using XYZ?” or asking “How would you deal with XYZ?”).

I particularly liked how common statements were turned into concrete interpretations for spectrumites. For example: “Can you take care of this report now?” which really means “I would like you to stop working on what you are doing and do this report first, then finish the other project.” Or “I need you to think outside of the box.” turns into “I would like you to come up with some ideas that are different than the ones we have been using.”

The book covers many other areas that will assist managers, mentors, and those who want to assist people with ASD to integrate into companies more easily and make a contribution. Disorganization, disclosure, sensory issues, and many more topics are discussed in an easily accessible manner.

This book was written by business people in consultation with individuals on the autism spectrum and professionals in the field; all with a solid understanding of the contribution those with an ASD diagnosis and a high level of

expertise can offer to the business community. Integrate has already made significant inroads into corporations one at a time. With this book as a tool the road may go more smoothly and more able people will be employed.

JKP, 2017

Pat Schissel, LMSW, is the Executive Director of AHA Association. She is a support group facilitator for many of AHA's support groups. Mrs. Schissel is on the editorial boards of the Autism Spectrum News and the Autism Spectrum Quarterly. Pat is the parent of an adult son on the autism spectrum.

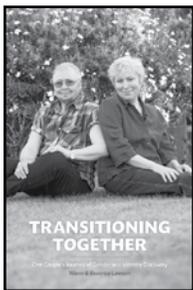
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## Transitioning Together: One Couple's Journey of Gender and Identity Discovery

by Wenn and Beatrice Lawson

overview by Dena L. Gassner, MSW, PhD Candidate

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Good grief! I am *gobsmacked* by this phenomenal book! Initially, I am honest to admit, the backstory presented in the first few chapters seemed to drag, although later it proved to be essential to the entirety of their story. However, once Wenn begins to explore the possibility that the discomfort he'd experienced in his entire life was the result of gender dysphoria (feelings of being in the wrong body) and a trans identity rather than being a lesbian, things became brilliantly engaging.

Yes, autism is a central theme as the authors haggle through communication differences, co-occurring mental health issues, anxiety and fears. But the heart of this story is the intimacy and specificity of their shared journey; it's a journey that will help so many couples and individuals dealing with changes in sexuality in many forms. Wenn and Beatrice Lawson both articulate beautifully the ambiguous grief ("Wendy" is no longer, but "Wenn" remains) and the co-existing challenges of the journey through co-dependency that the trans experience pushes to the forefront.

Wenn's authenticity about his feelings, in his body and spirit, and his cognitive changes are insightful and informative. He talks about gaining a "...clarity of mind and decisiveness in my thinking and decision making," and becoming "...my own person in ways I hadn't experienced before..." after he started taking testosterone. However, as a post-menopausal woman, this was an experience I, too, could relate to, since I also found an intense clarity of thought and reduced emotional turmoil not with testosterone, but without estrogen. Like Wenn, I am sometimes falsely perceived by women as being "bossy and direct" when I am simply just communicating. Wenn experienced this confusion, too.

The voice of Beatrice is critically powerful. She experiences the greatest ambiguous grief, at first thinking she was marrying a woman and coping with the social stigma and fear of being "gay." Later, Wenn's transition pressed her to the brink. She, like Wenn, is transparent and authentic explaining her sense of loss. She is also honest about her underlying resentment of male voices and bodies that were left-over baggage from her childhood experiences and, with vulnerability, describes the therapies and treatments she needed to maintain her own mental wellness.

Yes, this is an intimate and telling story of one family's transition. Yes, we see "Wendy" as a wife, mother and then as "Wenn" in his surgical transformation to maleness. Yes, we see Beatrice's grief, anger and acceptance. But what we also experience is a universal experience of finding one's personal identity, of essential growth and of change and unconditional love.

Don't walk – run to Jessica Kingsley's website and come along on this journey. A must-read for all professionals and anyone who wants to grow in their own self-understanding and acceptance that gender is fluid and beautiful.

JKP, 2017

Dena Gassner, MSW, is a PhD candidate in social welfare at Adelphi University who has presented internationally. She is a national board member of Arc US and the professional advisory board for AHA. She facilitates the AHA women's group.

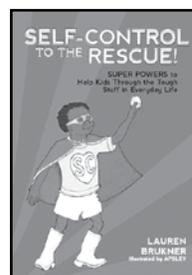
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## Self-Control to the Rescue! Super Powers to Help Kids Through the Tough Stuff in Everyday Life

by Lauren Brukner

overview by Laura Majersky-Lopez

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One day, as I went to help my son place his belongings in his cubby at his preschool, I noticed a little "superhero" cape. He was very sensitive and anxious, and he needed additional motivation and assurance each morning before entering his classroom, so the school psychologist equipped him with his very own superhero cape. *Self-Control to the Rescue!* reminded me of that experience with my son. The book offers every-day practical tools in dealing with life's "little challenges" for children preschool and up. Not just for those with ASD or anxiety, but for any child who has had a hard time focusing in class, getting out of bed in the morning, making friends, trouble falling asleep.... The book

includes visualization along with breathing techniques and other comfort tips.

*Self-Control to the Rescue!* recommends a reward system that works as a great motivator for kids. They earn coins based on what skill they master, allowing parents to choose a reward at the end.

Not only a handbook for kids, the book provides parents with advice in dealing with challenges such as morning routines (that hectic morning rush we all dread), homework routines and how to help siblings get along. The appendix contains useful charts that can be replicated helping to guide children through these challenges.

JKP, 2017

Laura Majersky-Lopez is a parent of a young child on the spectrum and manages Community Relations for AHA.

### Other Noteworthy Books



*All Birds Have Anxiety*, by Kathy Hoopmann, JKP 2017

*Developing Resilience in Young People with Autism Using Social Stories*, by Dr. Siobhan Timmins, JKP 2017

*Ketchup is My Favorite Vegetable: A Family Grows Up with Autism*, by Liane Kupferberg Carter, JKP 2016

*The Littlest Inventor*, by Mandi C. Mathis, Sensory World-Future Horizons, Inc. 2016

*To Siri with Love: A Mother, Her Autistic Son, and the Kindness of Machines*, by Judith Newman, Harper 2017

*Special Considerations for Students with High-Functioning Autism Spectrum Disorder: A Guide for Administrators*, by Diane Adreon & Brenda Smith Myles, PhD, AAPC 2017

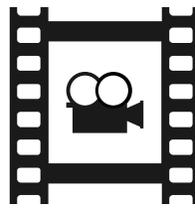
*Take Charge of Treatment for Your Child with Asperger's (ASD): Create a Personalized Guide to Success for Home, School, and the Community*, by Cornelia Pelzer Elwood and D. Scott McLeod, JKP 2016

*Talk with Me: A Step-by-Step Conversation Framework for Teaching Conversational Balance and Fluency for High-Functioning Individuals with Autism Spectrum Disorder*, by Kerry Mataya, M.Ed, Ruth Aspy, PhD and Hollis Shaffer, AAPC 2017

*Teaching Pre-Employment Skills to 14-17-Year Olds*, by Joanne Lara and Susan Osborne, JKP 2017

*Teaching Time Management to Learners with Autism Spectrum Disorder*, by Caroline DiPipi-Hoy, PhD and Daniel Steere, PhD, AAPC 2016

## In the Media:



### Atypical

Sam, a high school senior on the high-functioning end of the autism spectrum, doesn't quite fit in. This new series, starring Jennifer Jason Leigh, Keir Gilchrist and Michael Rapaport, follows Sam's quest to find love and gain independence, and puts Sam and his family on a path of self-discovery. Netflix.

### The Good Doctor

*The Good Doctor* is a new TV medical drama, developed by David Shore and Daniel Dae Kim and based on a South Korean series. It stars Freddie Highmore as Shaun Murphy, a young pediatric surgeon with autism and savant syndrome who, after a troubled childhood in a small town, has relocated to San Jose to join a prestigious pediatric department at St. Bonaventure Hospital. The show airs Mondays on ABC.

### Keep the Change

The endearing and naturalistic romantic comedy about a man and woman who live in a group home for adults with autism was awarded Best Narrative Film, Best New Director, and Special Jury Mention for the Nora Ephron Award at the Tribeca Film Festival. *Keep the Change* was also the winner of the FIPRESCI award (from the international film critics association) and Special Jury Mention for Best First Feature at the Karlovy Vary International Film Festival.

### Neurotribes

The film rights to Steve Silberman's book *Neurotribes: The Legacy of Autism*, were acquired by Paramount and Lorne Michaels. Silberman's book, which offers a model for accepting and understanding autism, also provides history of two of autism's pioneer researchers, Hans Asperger and Leo Kanner. *Neurotribes* was named one of the best books of 2015 by the New York Times, The Guardian and The Economist, and won the Samuel Johnson Prize for non-fiction.

### Uncommon Sense

*Uncommon Sense* is a new play about living with autism and the impact of autism on individuals, families, and communities. The award-winning Tectonic Theater Project company members/playwrights Anushka Paris-Carter and Andy Paris interviewed hundreds of people on the spectrum along with their loved ones and tells their stories through theatrical innovation, sensory immersion, and personal narrative. Performances, which will be produced in an inclusive environment, begin October 25, 2017 for five weeks at the Sheen Center in New York.

Contact us at [info@ahany.org](mailto:info@ahany.org) with any programs of interest you have found with an ASD theme or character.

## Remembering Dr. Isabelle Rapin



On May 24, 2017, we lost our esteemed colleague Dr. Isabelle Rapin, professor emerita in the Saul R Korey Department of Neurology and of pediatrics at Albert Einstein College of Medicine. She was 89.

Isabelle was a profound presence within pediatric neurology for more than half a century. Her insights and accomplishments helped to shape our thinking and approach to child diagnostics and treatment. A true clinician-scientist, she never tired of encouraging us to do and think more deeply about the neurological disorders we study, training generations of clinicians and biomedical scientists. Those of us who interacted with her as students, residents, and colleagues are truly fortunate; her teachings and influence will remain with us forever. That includes her reminder: "Every patient can teach us something we don't know."

Elissa Yozawitz, MD, Director, Neonatal Neurology, Assistant Professor, Department of Neurology and Pediatrics, Montefiore Medical Center, Albert Einstein College of Medicine.

## Temple Grandin Inducted Into the National Women's Hall of Fame



AHA congratulates our Professional Advisory Board member Dr. Temple Grandin who was inducted into the National Women's Hall of Fame this September. Dr. Grandin is one of the world's most well-known and respected individuals with autism. This incredible

woman, a Professor of Animal Sciences at Colorado State University, has worked hard to advocate for autism. She is well-known for her revolutionary work in the meat production industry which gave us a more ethical way to handle livestock. Entering a male-dominated field, she faced sexism and harassment but her determination and drive proved she could make it in her field as a woman. Previous inductees include Madeleine Albright, Maya Angelou, Susan B. Anthony, Hillary Rodham Clinton, Ruth Bader Ginsburg, Rosa Parks, Sally Ride, Eleanor Roosevelt and Oprah Winfrey.

### SUPPORT GROUP HELP NEEDED

AHA is looking for volunteers to help co-facilitate our Long Island support groups.

Please contact our office if you are interested.

[info@ahany.org](mailto:info@ahany.org)



Come join us at

## You're a Good Man Charlie Brown

### November 16<sup>th</sup> to 19<sup>th</sup> at

### The Flea Theater in NYC!

AHA members receive a 20% discount on tickets with code **ASN123**

Tickets: [www.epicplayersnyc.org](http://www.epicplayersnyc.org)

For questions, please email [info@epicplayersnyc.org](mailto:info@epicplayersnyc.org)

### AHA THANKS THE FOLLOWING FOR THEIR SUPPORT

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**GROUPS FOR PARENTS & FAMILY MEMBERS**

**MANHATTAN FAMILY GROUP\***

Tuesdays, 6:30 pm - 8:30 pm – **NEW TIME**  
303 Fifth Ave., Ste. 1003, 10th Fl., NY, NY (between 31-32 St.)  
Oct 10, Nov 14, Dec 12

**SPOUSE/PARTNER GROUP\***

Tuesdays, 6:30 pm - 8:00 pm – **NEW TIME**  
303 Fifth Ave., Ste. 1003, 10th Fl., NY, NY  
(between 31-32 St.)  
Oct 3, Nov 7, Dec 5

**NASSAU**

Thursdays, 7:30 pm - 9:00 pm  
Mid-Island Y JCC, 45 Manetto Hill Rd, Rm 110, Plainview  
Oct 19, Nov 9, Dec 7

**FAMILIES & FRIENDS OF LGBTQ \*\* – NEW GROUP!**

Safe space for family & friends who support an individual who identifies as being on the LGBTQ spectrum  
Thursdays, 2:00 pm - 3:00 pm  
Fay J. Lindner Center Waiting Rm, 189 Wheatley Rd, Brookville  
Oct 5, Nov 2, Dec 7

**NASSAU/WESTERN SUFFOLK**

Wednesdays, 11:00 am - 12:30 pm  
AHA Offices, 330 Broadway, Amityville  
Oct 4, Nov 1, Dec 6

**SUFFOLK**

Thursdays, 6:30 pm - 8:00 pm – **NEW DAY**  
NSYC, 272 N. Rocky Pt. Landing Rd., Rocky Point.  
NSYC is on the grounds of the JAE School on 25A in Rocky Pt.  
Nov 30, Dec (no meeting)

**FAMILIES OF OLDER TEENS & ADULTS**

Mondays, 7:00 pm - 9:00 pm  
775 Park Ave., 2<sup>nd</sup> Fl, Huntington, NY – **NEW LOCATION**  
Oct 2, Nov 6, Dec 4

**FAMILIES OF TEENS IN TRANSITION**

Saturdays, 11:00 am - 1:00 pm  
Mid-Island Y JCC, 45 Manetto Hill Rd., Rm 109, Plainview  
Oct 14, Nov 4, Dec 9

**GROUPS FOR INDIVIDUALS ON THE SPECTRUM**

**LONG ISLAND**

**TEEN GROUP**

(ages 13-19)  
Saturdays, 11:00 am - 1:00 pm  
Mid-Island Y JCC, 45 Manetto Hill Rd., Rm 110, Plainview  
Oct 14, Nov 4, Dec 9

**SUFFOLK ADULT GROUP**

Saturdays, 2:30 pm - 4:30 pm  
YAI, 555 Washington Ave., Brentwood  
Oct 14, Nov 4, Dec 9

**OUT ON THE SPECTRUM\*\* – NEW GROUP!**

For post-HS aged adults who identify as being both on the ASD and LGBTQ spectrums.  
Thursdays, 3:00 pm - 4:30 pm  
Fay J. Lindner Center Waiting Rm, 189 Wheatley Rd, Brookville  
Oct 5, Nov 2, Dec 7

\*Partnered with Spectrum Services – [spectrumservicesnyc.com](http://spectrumservicesnyc.com)

**MANHATTAN**

**ADULT GROUP\***

Tuesdays, 6:30 pm - 8:00 pm – **NEW TIME**  
303 Fifth Avenue, Ste. 1003, 10th Floor, NY, NY  
(between 31-32 St.)  
Oct 17, Nov 21, Dec 19

**WOMEN'S ADULT GROUP\***

Tuesdays, 6:30 pm - 8:00 pm – **NEW TIME**  
303 Fifth Avenue, Ste. 1003, 10th Fl., NY, NY (between 31-32 St.)  
Oct 24, Nov 28, Dec (no meeting)

\*\* Partnered with the Fay J. Lindner Center – [advantagecaredtc.org](http://advantagecaredtc.org)

**Contact Information:** AHA provides one-to-one advocacy support and referral. Our resources are a simple email away. Use our online Intake & Referral Form to provide information and get the support process started which can be found at [ahany.org/advocacy-and-referral-form](http://ahany.org/advocacy-and-referral-form)

**Support Meeting Information:** We have several groups to meet your individual needs: support for family members of school-age children, families of teens in transition, families of older teens and adults, teen and adult groups for individuals on the spectrum, a women's adult group, a spouse/partner group, our new families & friends of LGBTQ group, and OUT on the spectrum group for individuals who identify as both on the ASD and LGBTQ spectrums. There is no charge for AHA support meetings. All are welcome to attend. Pre-registration is not required. Membership in AHA is encouraged to support our continuing efforts to educate, advocate and create activities for individuals and their families. Children will not be admitted to meetings; we regret any inconvenience, but the presence of young children is distracting to participants.

## Save The Dates For These Exciting Events

- **Annual Fall Conference** – Saturday, October 28, 2017  
Adelphi University, Garden City, NY  
*Education and Lifelong Learning for Students on the Autism Spectrum*
- **Annual ROCK 'N' BOWL for Autism** – Sunday, November 19, 2017  
Farmingdale Lanes, Farmingdale, NY
- **Annual Spring Conference** – Sunday, May 6, 2018  
Adelphi University, Garden City, NY  
*Issues in Independent Living for Adolescents and Adults on the Autism Spectrum*  
**Keynotes: Barry Prizant, PhD, CCC-SLP, and Nick Dubin, PsyD**

### **AHA offers free monthly support groups in locations on Long Island and in New York City.**

We have several groups to meet your individual needs: support for family members of school-age children, families of teens in transition, families of older teens and adults, teen and adult groups for individuals on the spectrum, a women's adult group, a spouse/partner group, our new families & friends of LGBTQ group, and OUT on the spectrum group for individuals who identify as both on the ASD and LGBTQ spectrums. See page 39 for times and locations.

[info@ahany.org](mailto:info@ahany.org)

[ahany.org](http://ahany.org)

**888.918.9198**



**Asperger Syndrome &  
High Functioning Autism  
Association**

PO Box 916, Bethpage, NY 11714-0916