

## Assessment, Diagnosis and Science-Based Interventions

### Evaluation and Assessment of Autism Spectrum Disorder

By Cynthia Martin, PsyD,  
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Weill Cornell Medical College

**A**utism Spectrum Disorder (ASD) is a generally life-long neurodevelopmental disorder characterized by impairments in social communication and social interaction and the presence of restricted and repetitive behavior. There is significant heterogeneity among individuals with ASD, and symptoms of ASD can change over time (Lord, Bishop, & Anderson, 2015). From the childhood to adult years, there are varying levels of support an individual with ASD may need in home, school, community, and workplace settings (Howlin, Goode, Hutton, & Rutter, 2004).

Symptoms of ASD generally emerge between a child's first and second birthday (Landa, Holman, & Garrett-Mayer, 2007). When using standardized evaluation tools in combination with clinical judgment,



children under 24 months old are most often accurately identified (Guthrie, Swineford, Nottke, & Wetherby, 2013; Kleinman et al., 2008). Early detection of ASD leads

to early intervention. By detecting ASD early and also providing subsequent early intervention we can help a child make substantial progress in language skills,

cognitive abilities, and adaptive skills, all of which improves long-term prognosis (Dawson et al., 2010; Estes et al., 2015; Pickles et al., 2016; Rogers et al., 2012).

#### Symptoms of Autism Spectrum Disorder

ASD is diagnosed using the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (American Psychiatric Association, 2013). The DSM-5 specifies that an individual must have deficits in social communication and social interaction as well as present with restricted and repetitive behavior, either currently or by history. Illustrative examples of symptoms are provided within the DSM-5. Although all children with an ASD diagnosis have deficits in social communication and social interaction as well as restricted, repetitive behavior, each child can potentially have a very different manifestation of those particular symptoms. Symptom level can be heavily moderated by a child's age,

*see Evaluation on page 27*

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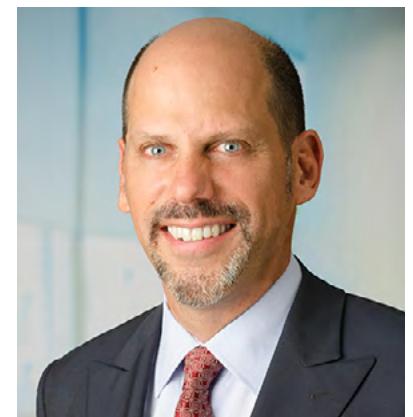
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## An Autism Spectrum News Exclusive Interview with the Co-Directors of the New Shrub Oak International School

By David H. Minot, BA  
 Publisher  
 Autism Spectrum News

The Shrub Oak International School, located in New York's Westchester County, is scheduled to open their doors in September of 2018. Shrub Oak promises to be a "world-class, private, special education boarding and day school preparing students for independent adult life and employment. Serving the sophisticated needs of an international co-ed population of young adults on the Autism Spectrum, the school's innovative relationship-based program is grounded in evidence-based principles that build on each student's specific needs and interests. Shrub Oak's modern, technology-infused facility is set on 127 acres of farmland where students can learn everyday living skills in a natural environment."

*Autism Spectrum News* is delighted to share with you this exclusive interview with Shrub Oak Co-Directors Gil Tippy, PsyD, and Dianne Zager, PhD.

**What is your past experience and what will your role be at Shrub Oak?**

Gil Tippy, PsyD: For the last 35+ years



**Shrub Oak Co-Directors  
 Dianne Zager, PhD, and Gil Tippy, PsyD**

I've been a teacher and/or psychologist in the public and private schools, and currently I am a clinical psychiatrist. I'm coming from the Rebecca School in NYC where I was one of the founders and the clinical director. At Shrub Oak International, my position will be Co-Director and Head of Clinical. I will be responsible for the occupational and physical therapy, speech and language support, mental health sup-

port, and I'll also be supervising the farm, equestrian program and the music therapy program (which will employ Nordoff-Robbins trained music therapists).

Dianne Zager, PhD: My career in autism has spanned around 40 years. Most recently I've been a professor of special education at Pace University in NYC where I trained future educators. I am also a professor emeritus at CW-Post campus, Long Island University. I started my career teaching students at the Adams School in NYC, where I taught students who had conduct disorders and significant learning disabilities. I have conducted extensive research and writing in the area of transition for students with autism over the years and directed the research committee at The Center for Developmental Disabilities in Long Island, NY. I have been President of the NYS Council for Exceptional Children, the Northeastern Educational Research Association, and the Division on Autism and Developmental Disabilities for the Council for Exceptional Children. It's been my goal over my long career to push the envelope and improve the quality of services for students with significant disabilities, especially autism. I will be Co-Director of Shrub Oak with Gil and Dean of Education, overseeing the educational programming curriculum.

**What was the inspiration to create a residential school for autism, and what is the school's mission?**

Dianne: The mission of Shrub Oak is empower our students to successfully pursue higher education and/or meaningful career paths, while increasing independence for adult life, enabling all students to be participating and contributing members of their community. Our goal is for the students who graduate from Shrub Oak to be ready to either pursue further education or begin meaningful career paths. We are preparing our students for successful transition from school to adult living and employment and to be fully participating members of the community that they choose to reside in.

Gil: In opening a residential school, our vision is to create a seamless environment tying together academic time, student life, and support services. This integrated model of support includes all of the experience that Dianne brings as well as a developmental perspective that I bring from my experience. This is then put together into a program that supports individuals for 24 hours per day across their entire living situation: The academic time - in classrooms, out on the campus farm and the equestrian

see *Shrub Oak* on page 22

## Integrating Evidence-Based Models to Educate Adolescents with Autism

By Dianne Zager, PhD  
 and Tracey Frank, MS  
 Shrub Oak International School

Individuals with autism spectrum disorder require specialized education programming that takes into account their complex learning characteristics. While certain practices have been shown to be effective in educating students on the spectrum; historically, the field has been vulnerable to claims of practices that have not been supported. To prevent adoption of ineffective and perhaps even harmful intervention, it is necessary to examine the evidence base prior to implementing particular approaches. In this paper, we discuss three intervention models, each of which has established a strong evidence base in improving student outcomes, with regard to their utility in transition planning.

The three recommended models - the Ziggurat Intervention Model (Aspy & Grossman, 2007); SCERTS Model (Prizant, Wetherby, Rubin, Rydell, & Laurent, 2003); and the Self-Determined Career Development Model (SDCDM) (Wehmer, 2010) - are designed specifically to guide educators who are working with students with ASD and related developmental disabilities. The Ziggurat Model organizes and builds upon students' characteristics, strengths, interests, and sensory needs. The SCERTS model considers student development through a transactional



**Dianne Zager, PhD**

perspective, focusing on social communication, emotional regulation, and family dynamics. The SDCCDM addresses self-determination competence and career development for secondary and postsecondary students. By combining aspects of these three over-arching models, a comprehensive understanding of the student may be obtained. From such understanding, appropriate teaching strategies can be selected and integrated to meet the evolving needs of adolescents with ASD.

Without understanding student needs and applying this knowledge to the selec-



**Tracey Frank, MS**

tion and implementation of intervention strategies, discussing what to teach is just rhetoric. A comprehensive program that incorporates the student's (a) skill and knowledge levels in academics, communication, behavior, and social interaction; (b) strengths and interests; and (c) sensory issues can be built through collective orchestration of the SCERTS and Ziggurat models. A rich picture of the student's learning needs emerges when the *Underlying Characteristics Checklist* and the *Individual Strengths Inventory* are linked to the Ziggurat Model (see Smith Myles, Smith,

Aspy, Grossman, & Henry, 2012). Further, when employed in conjunction with the Self-Determined Career Development Model, these person-centered frameworks enable strategic planning to meet targeted community living employment goals. In the following section, we provide a brief overview of each model with discussion of benefits derived by combining components from each. For additional information about the models discussed, readers are directed to the references at the conclusion of this article.

### The Ziggurat Model

The Ziggurat Model was designed to guide parents, teachers and clinicians in program development, particularly in identifying key areas of critical intervention (Smith Myles et. al., 2012). The name *ziggurat* is derived from an ancient Mesopotamian architectural invention. Similar to Egyptian pyramids, the ancient ziggurat had four sides and rose up to reach the gods. Ziggurats were different than pyramids, however, as the exterior walls were tiered. The five tiered levels in The Ziggurat Model intervention from the foundation up include: (1) sensory differences and biological needs; (2) reinforcement; (3) structure; (4) visual/tactile supports; and (5) tasks, demands and skills to teach. The first four steps assist educators in understanding

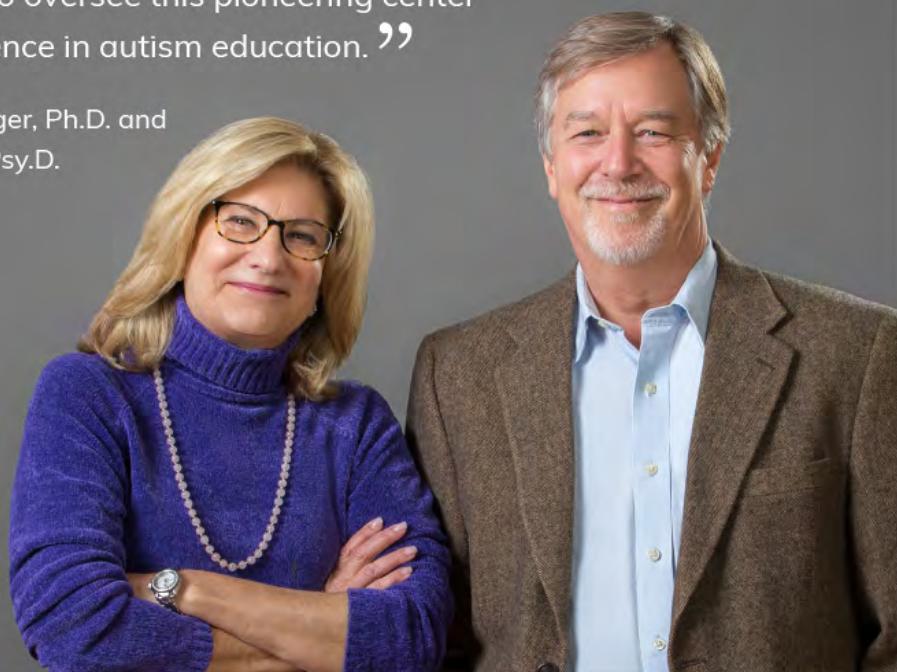
see *Integrating* on page 25



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# Autism and ADHD: DSM-5 Conditions with Significant Symptom Overlap

By **Sam Goldstein, PhD**  
Assistant Clinical Instructor  
University of Utah  
School of Medicine

In the last twelve years, a number of peer reviewed studies have demonstrated the elevated incidence of ADHD symptoms within populations of children receiving DSM-IV-TR and DSM-5 diagnoses of Autism, Autism Spectrum Disorder, Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified. Previous research by our group and others has, for example, found a significant overlap between these two conditions (Goldstein & Schwebach, 2004; Goldstein and Naglieri, 2009; van der Meer, Lappenschaar, Hartman, Greven, et. al. 2014). Traits of ASD and ADHD are strongly related in the general population as well as in clinical groups. In 2004 we reported that 26% of children in our sample of what was then referred to as Pervasive Developmental Disorder – Not Otherwise Specified, met the criteria for a diagnosis of ADHD – Combined Type, while 33% met the criteria for ADHD – Predominantly Inattentive Type (Goldstein & Schwebach, 2004). Thus, the majority (59%) of those with PDD – NOS or Autism met criteria for Comorbid ADHD. The percentage of children with ADHD comorbid with Au-



**Sam Goldstein, PhD**

tism Spectrum Disorder is still not completely understood, but there is a significant overlap (Mayes, Calhoun, Mays & Molitoris, 2012).

It has yet to be clearly demonstrated whether these data suggest a one or two way co-morbidity. The combined group also appears to experience a much higher rate of functional impairment than those youth with ASD or ADHD alone.

Self-regulatory problems related to attention, hyperactivity and impulse control are characteristics of ASD and from this author's view should be considered as part of the future diagnostic criteria for this condition. The omission of this consideration in DSM-5 appears as much an oversight as an intentional effort to not address this issue.

However, improvements were made with the recent publication of the Fifth Edition of the American Psychiatric Association Diagnostic Criteria. However, it is still the case, as noted, that problems with attention, impulse control and hyperactivity, are not considered within diagnostic criteria for ASD. For the first time, however, both conditions can be simultaneously diagnosed. Interestingly, the DSM notes that approximately 70% of individuals with ASD may suffer from one co-morbid mental disorder and 40% may suffer from two or more co-morbid mental disorders. When criteria for both ADHD and ASD are met, the DSM 5 recommends that both diagnoses should be given. However, even with these improvements, an appreciation of the relationship between ASD and ADHD has yet to be fully appreciated and recognized by the American Psychiatric Association in the construction of diagnostic protocols.

In this article, I briefly summarize research findings from several sources. First, I review the results of studies involving

children with ASD and ADHD that were part of the standardization sample for the Autism Spectrum Rating Scales (ASRS, 2009). Next, I combine data from a number of our studies, allowing comparison of neuro-cognitive abilities for youth with ASD and ADHD. A series of analyses of covariance (ANCOVAs) and multivariate analyses for covariance (MANCOVAs) were conducted to investigate whether scores on the Autism Spectrum Rating Scales can distinguish between the groups when the demographic variables were controlled statistically. The independent variable (IV) of interest was group membership, and the demographic characteristics of the samples (e.g., age, gender, race/ethnicity, parental education level, and geographic region) were controlled for by including these variables as covariates. In an attempt to control for Type I errors that might occur with multiple analyses, a more conservative criterion of  $p < .01$  was used for all  $F$ -tests and all planned comparisons. In addition to significance levels, an estimate of effect size (with Cohen's  $d$ ) is provided for every effect.

Planned comparisons were made between ASD and ADHD groups. The ASD group scored significantly higher than the ADHD group on all scales, except for the Self-Regulation and Attention scales on both parent and teacher forms. This is not

see *DSM-5* on page 28

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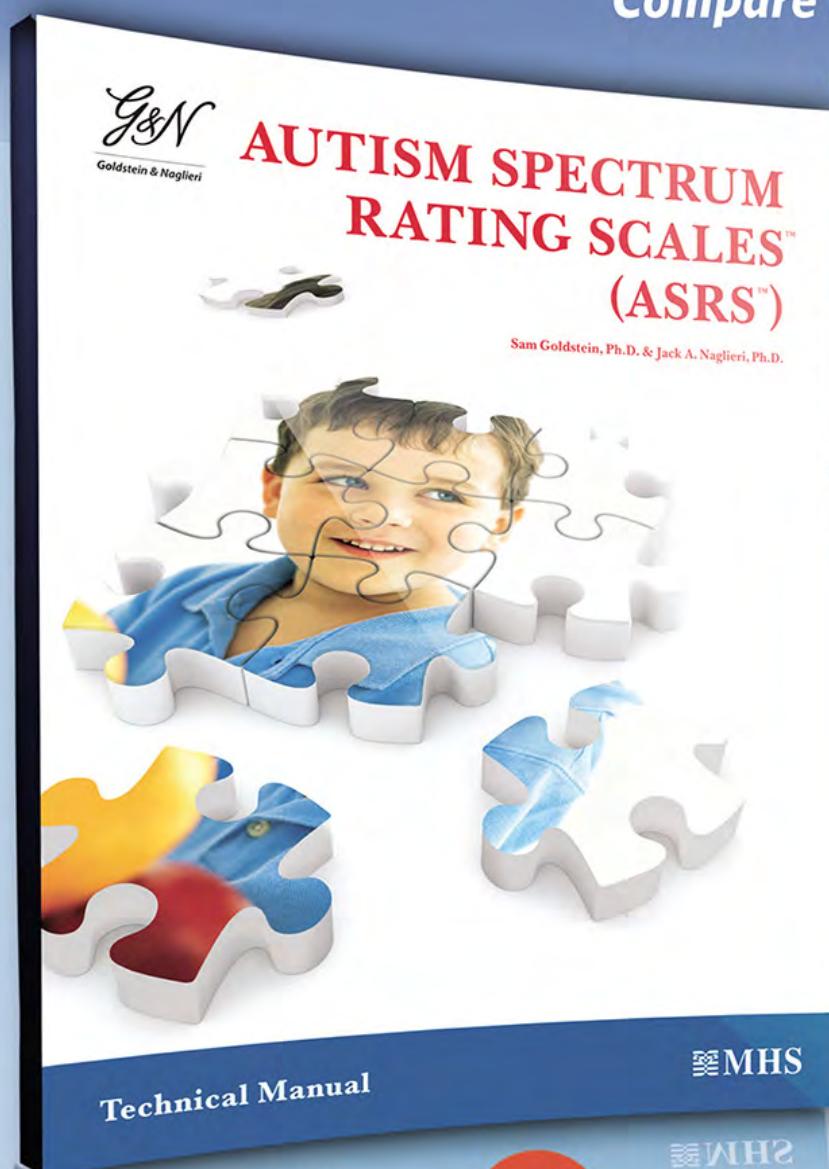
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# The Failure to Accurately Diagnose Girls with Asperger's Syndrome

By Marcia Eckerd, PhD  
Psychologist

The work of Dr. William Mandy has explored the traditionally accepted gender ratio regarding the prevalence of Asperger's Syndrome in and girls; most studies cite a higher ratio of boys as having Asperger's Syndrome (AS). The research of Dr. Mandy and his associates show that girls with Asperger's are under-diagnosed. They found that to some extent, the imbalance (an example of a 4 boys:1 girl) is due to the assumption of a male model for the presentation of Asperger's Syndrome. Dr. Mandy and his associates have found that girls with Asperger's Syndrome look very different from Asperger boys, who are our model of what AS looks like.

Dr. Mandy's associate Rachel Loomis, DCLinPsy, looked at 54 studies of the ratio of males to females with AS, and found the average result was 4 boys:1 girl. There was a lot of variability among studies, however, in part due to how the AS was determined. Studies that used previous diagnoses of AS found a 4.5:1 ratio. However, studies that looked at who would meet the criteria for AS, whether or not they had been diagnosed previously, found a 3:1 ratio.

Intrigued, Loomis and Mandy looked at the study subjects, focusing on the personality and behavioral traits associated with



Marcia Eckerd, PhD

AS, such as inflexibility, literal and black and white thinking, areas of intense interest, repetitive behavior, over focus on factual details, getting "stuck" on a topic, and poor theory of mind. She found that when they looked at subjects whose scores were extremely high for having AS traits, rather than looking at the official diagnostic criteria, the ratio of males to females was now 2:1. Girls with AS traits weren't being diagnosed with AS.

The answer is that girls with AS present differently from the boys. The diagnostic criteria call for a lack of social engagement and areas of intense interest, which in boys usually presented as either very awkward socially or not socially engaged.

When the researchers looked at the AS girls, the girls were more socially oriented than the boys. They often engaged in activities including others. Adult women with AS talked about being able to put on a social mask, having observed social behavior closely; this social mask often felt like "not me" and a lot of work.

Girls tended to camouflage AS behaviors. They realize early that their "real" selves aren't accepted, and often prefer blending in with peers to feeling "weird." Girls' interests were also more gender appropriate. We think of AS boys as being experts on dinosaurs, train schedules or obscure math; the girls tended to be interested in less unusual subjects, particularly animals.

This is consistent with my experience. I've worked with girls with AS who are perceived as having friends because they are around other girls on the playground or text with other girls or boys. However, this doesn't necessarily mean they sustain relationships or find them fulfilling. One unnamed woman's quote is especially poignant: "I can fit in, I can behave like others up to a point, but it isn't me and doesn't fulfill anything within me. It's empty and meaningless."

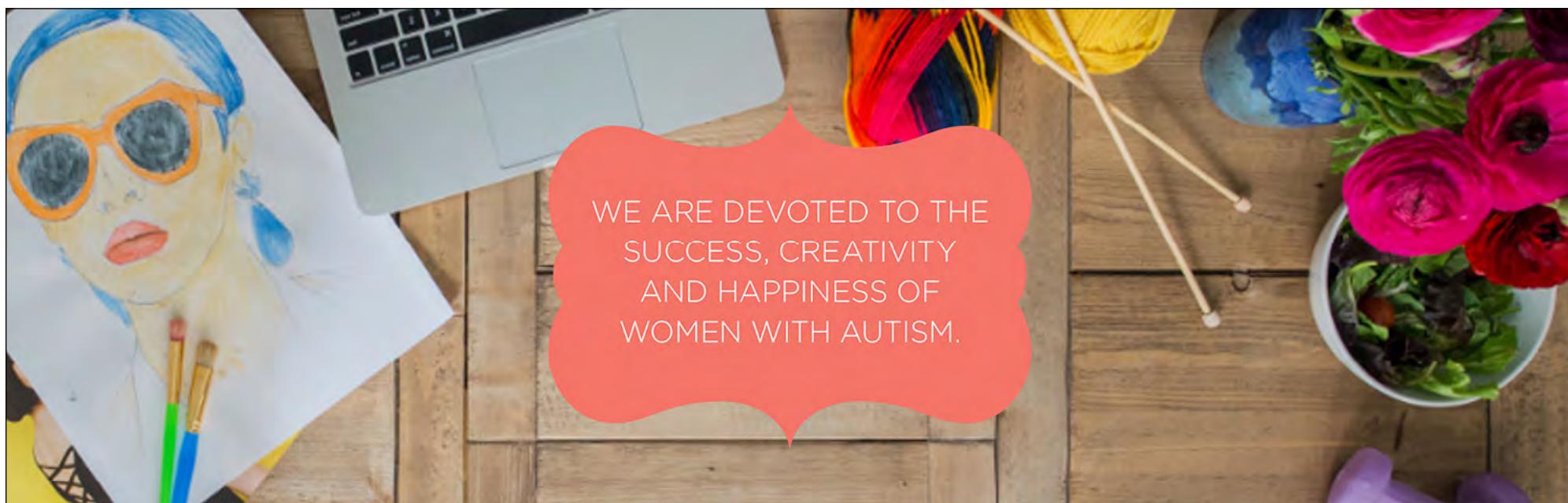
One of my AS patients, Gina, is able to "turn on" being social when it meets her interests, seeming to be quite appropriate. She equally turns social behavior off when it would be expected but doesn't interest her. All my girls, including Gina, were very hurt by when they felt they weren't accepted, and like everyone with AS, they had significant anxiety.

When diagnosed, boys are identified earlier. Boy's scores were found to be very low on a social communications checklist when they were 7, there was a dip at 10, and then a plateau of the same score at 13 and 16. Girls initially scored much more normally at age 7, also dipped at 10, and then scored much more like the boys at 13 and 16, ages where the demands and complexity of social communication are much greater.

Teenage years are often the worst for girls to find a social niche. It's hard for girls to understand why they're not accepted. They often become increasingly cynical. Fitting in never really works, and they're never really fluent in playing the social game. Being smart is no longer enough to get by. When they do have friends, they're hurt that are far down the "friend list" for the other girls.

There are boys who don't fit the typical picture of boys with AS too, and who have many of the same traits as the girls, and girls who are more like the boys.

see *Diagnose on page 12*



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# Adult ASD Diagnosis: “It’s Not a Label – It’s an Explanation”

**Karl Wittig, P.E.**  
**Advisory Board Chair**  
**Aspies For Social Success (AFSS)**

About a year ago, I attended a conference workshop on adult autism diagnoses which addressed their value to those on the spectrum. I was surprised, and even shocked, to learn that there is controversy about the value of these diagnoses, particularly for less-impaired adults who have managed to attain an otherwise adequate quality of life in spite of their condition.

Personally, I could not disagree more strongly with this view.

As an older adult on the spectrum who was diagnosed late in life and has met many others who had a similar experience, I can both attest to the self-knowledge and understanding that is gained from this diagnosis and appreciate the practical utility that it can have as well.

My own journey to diagnosis lasted over 10 years, beginning in the late 1980’s and culminating with a credible self-diagnosis in late 2000. It started shortly after the 1988 release of the movie *Rain Man*, which for many was the first time they ever heard of autism, and which resulted in substantial interest among the general public along with a plethora of news reports, articles, documentaries, and books on the subject. Whenever I witnessed a portrayal,



**Karl Wittig, PE**

real or fictional, of an autistic person, I immediately noticed similarities to myself in terms of behaviors, mannerisms, interests, etc. I had comparable reactions to written accounts and descriptions of autistic individuals and traits. Because I was not as severely impaired as they were, however, I did not take this very seriously at the time. I thought that, at most, I simply shared a few personality traits and perhaps felt some identification with these people.

It was not until the mid-1990’s that I first encountered reports about milder variants of autism such as Asperger Syndrome (not recognized in the U.S. until 1994), and accounts of less-impaired autistics, that I began to consider the possibility that I might be living with such a condition myself. Unfortunately, there was little information to be found about this at the time. Interested as I was, I could not find any sources of it. I inadvertently came across such a source at a major bookstore in New York City, where I live, that had a small selection (about a third of a bookcase shelf) of autism books in its childhood education division – I somehow noticed them while looking for the technical books division! Still, the information in these pertained to more severely-impaired individuals; although most if not all of the milder traits applied to me, I had none of the more serious deficits or challenges characteristic of autism; in particular, I had never been non-verbal. Even then, I could yet again not help but notice many similarities whenever I saw depictions, on TV news programs or documentary films, of autistic persons.

It was not until internet search engines became commonplace that, after spending a weekend with a friend looking up a variety of things online, it occurred to me that I could do this to find information about autism which might apply to my own case. This was on the evening of August 15, 2000.

Although by then I fully expected that

I would learn something of significance, I was not prepared for what happened next. As I looked at diagnostic criteria for Asperger Syndrome and “high functioning” autism (as it was then called), along with lists of typical traits, behaviors, deficits, and challenges, I immediately realized that nearly all of them unmistakably applied to me, at least to some degree. One such list, posted on the website of a local parents’ group, enumerated 18 common characteristics, of which I had exhibited 17 over the course of my life. What also struck me was that these were not vague, general descriptions that could apply to anybody, but rather specific ones which were all very unusual.

I cannot overemphasize the significance of this for me – it was literally as though, at the age of 44 years, my entire life had just been explained to me in one fell swoop. I finally understood why I had always faced challenges in so many aspects of socialization and daily living that the overwhelming majority of people had little or no difficulty with. Over the years, I had explored some of the “pop-psychology” and “self-help” movements of the 1970’s and 80’s with few benefits. Even mental-health professionals had been of limited help; as it happens, most knew little if anything about autism and virtually none had even heard of Asperger Syndrome.

Even though I was finally convinced that

see *Adult ASD* on page 24

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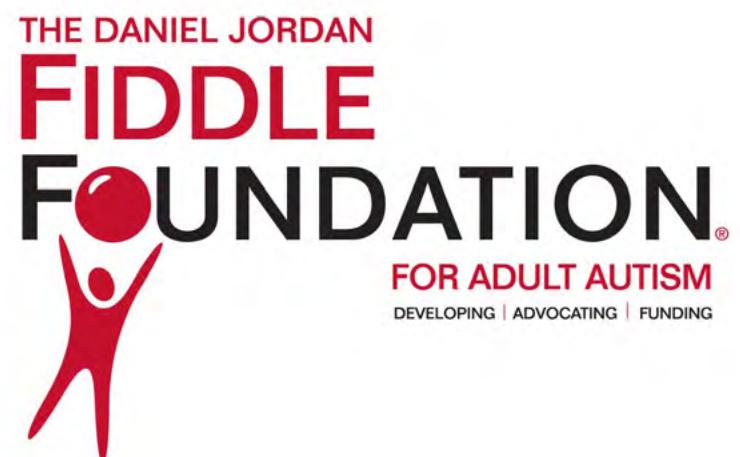
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## So Your Child Was Diagnosed with ASD: What Comes Next?

By Jill Harris, PhD  
 Director of Research Development  
 and Coordinator of Autism Services  
 Children's Specialized Hospital

Receiving an Autism Spectrum Disorder (ASD) diagnosis for a child may be accompanied by a variety of reactions. For many parents and caregivers, the diagnosis may confirm what they had suspected. For others, it may come as a shock. Parents commonly note whether they had expected an ASD diagnosis or not, they often hoped they would have been told that there was nothing wrong. Remember to ask for and accept help.

While it may take some time to deal with the emotional reaction to an ASD diagnosis, action is needed to ensure the child receives appropriate services. The actions can be broken down by category and potential resources.

### Develop an Action Plan

The action plan outlines first steps in securing services. Helpful resources include the Autism Speaks First 100 Days tool kit geared toward children under four years old ([100 day tool kit for < 4 years old](#)) and Autism Speaks First 100 Days tool kit for school-aged children ([100 Day Kit – School Age](#)).



Jill Harris, PhD

Autism Speaks also operates an Autism Response Team at 888-288-4762; En Español: 888-772-9050 for information and resources local to the area.

### Find Out About the Diagnosis

Free parent/caregiver workshops may be offered through diagnostic centers or ASD support groups. This provides not just an

overview of ASD diagnostic and treatment services but also an opportunity to connect with other families who are also newly diagnosed to share tips and support. For example, Children's Specialized Hospital provides "Navigating the Journey" workshops that include multidisciplinary experts discussing social, behavioral, medical, communication, occupational therapy, educational advocacy issues as well as a panel of experienced parents of children with ASD.

The internet can be helpful but make sure the source is reliable, evidence-based and relevant for your child. Additional Resources:

- Autism Speaks website has information as well as toolkits on topics including dealing with challenging behavior, sleep issues, dentist and doctor visits, etc. For lists information regarding local services: [www.autismspeaks.org](http://www.autismspeaks.org)
- The Autism Society website has general ASD information as well as information on many topics ranging from legal resources, understanding research and advocacy. [www.autismsociety.org](http://www.autismsociety.org)
- Children's Specialized Hospital Real Life Tips "Understanding the Diagnosis of ASD" [Tip sheet](http://www.youtube.com/watch?v=9S4Y4V00e4c) and Video: [www.youtube.com/watch?v=9S4Y4V00e4c](http://www.youtube.com/watch?v=9S4Y4V00e4c)

### Obtain Intervention

For children from birth to age three, Early Intervention (part C) programming can arrange a free screening to confirm eligibility and to develop an individualized family service plan. Early Intervention services vary from state to state but are typically home-based with focus on training the parent/caretaker to implement the intervention with the child. Depending on the state, the services may be free or provided on a cost-shared basis.

For children 3 or older, contact the local school district to request evaluation and services. It is important that the parent/guardian submit the request in writing in order start the clock ticking to ensure a timely response from the district.

It is important to ensure that all intervention is evidence-based, individualized, data is recorded and that progress is being measured and analyzed. Additional Resources:

- Wrightslaw site has information about educational services including early intervention: [www.wrightslaw.com](http://www.wrightslaw.com)
- Autism Science Foundation has information regarding ASD treatments: <http://autismsciencefoundation.org/what-is-autism/treatment-options/>

see *Your Child* on page 21



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## Behavioral Treatment Components to Address Delayed or Denied Reinforcement

By Stephanie A.C. Kuhn, PhD, LP, BCBA-D  
Assistant Professor  
Western Connecticut State University

The introduction of delays to reinforcement has been an important part of the behavioral literature and clinical treatment practice since the use of functional analysis and assessment procedures and function-based interventions became best practice (Hagopian, Boelter, & Jarmolowicz, 2011). One commonly used intervention for addressing challenging behavior is functional communication training (FCT). FCT involves providing reinforcement for an alternative, appropriate communication response. The reinforcer provided within FCT procedures is the same reinforcer that was identified to maintain problem behavior. This intervention is most often combined with extinction procedures for maximum effectiveness. In the case of challenging behavior that is maintained by access to preferred items or access to attention, the individual is taught to request those items or attention by verbally requesting, handing a card, using a voice output device, or by some other appropriate method. At the onset of treatment, these alternative, appropriate requests result in immediate reinforcement and have been shown to be



Stephanie A.C. Kuhn, PhD, LP, BCBA-D

associated with a rapid and substantial decrease in challenging behavior.

The literature on FCT has described various procedures for increasing delays to reinforcement while maintaining low levels of problem behavior including gradually increasing delays between the FCR (Functional Communication Response) and reinforcement (i.e., delay schedule) and the use of multiple and chained schedules of reinforcement. Multiple schedules involve periods of time where the FCR results in

reinforcement and periods of time where FCT does not result in reinforcement (i.e., extinction for communication response). These conditions, reinforcement vs. extinction, for communication are “signaled” such that the condition in effect is identifiable by the individual. For example, a green card is displayed when FCR will result in reinforcement and a red card is displayed when FCR will result in extinction (e.g., Fisher, Kuhn, & Thompson, 1998). In chained schedules, a response requirement such as a certain number of demands must be met prior to switching to a schedule where FCR results in reinforcement. Until the response requirement has been met, FCT responses do not result in reinforcement (i.e., extinction). After the response requirement has met, the first FCR response results in reinforcement (e.g., Lalli, Casey, & Kates 1995).

It has been suggested that delays in the typical environment differ from the arrangements discussed thus far and are instead sudden, unexpected, and unplanned and that caregivers may not know if a reinforcer is available until the request has been made (Ghaemmaghami, Hanley, & Jessel, 2016). Therefore, clinical research and practice has devoted some recent attention to addressing situations in which reinforcement is either delayed or denied. Mace, Pratt, Prager, and Pritchard (2011)

evaluated three methods of saying “No” on escalating problem behavior. The three methods consisted of: 1) saying “No” following the FCR and providing an explanation; 2) denying access following the FCR while providing an alternative preferred activity; and 3) denying immediate access and requiring a contingency of completion of a low preference task and computer access. Results indicated that denying access while providing an alternative activity and denying immediate access and requiring a contingency to complete a low preference task were both effective at reducing problem behavior. One limitation of this study is that there was only one participant.

Hanley, Jin, Vanselow, & Hanratty (2014) offered several suggestions for reducing negative side effects of delay procedures including the use of probabilistic immediate reinforcement (i.e., some FCRs result in immediate reinforcement) and the addition of a response requirement during the delay (i.e., contingency-based delay). They also required a tolerance response from the individual following the cue to wait (i.e., stating, “okay”) and used varied delay cue statements such as “wait,” “not yet,” and “in a minute.” In a follow up study with four participants, contingency-based progressive delays were found

see Reinforcement on page 26

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## The Use of Technology as an Evidence-Based Practice

**By Kaori Nepo, PhD, BCBA-D**  
**Director of Research and**  
**International Development**  
**Chimes International**

Individuals with Autism Spectrum Disorder (ASD) are characterized by difficulties in social communication and the presence of repetitive behaviors and restricted interests (American Psychological Association, 2013). In addition, individuals with ASD often exhibit challenging behaviors, such as physical aggressions and self-injurious behaviors. These characteristics likely prevent the individuals from developing meaningful friendships and productive leisure skills. They also may reduce their chances of accessing community activities, and obtaining and maintaining jobs (Persson, 2000). Previous studies suggest that early detection and early intervention are necessary to maximize the potential of individuals with ASD (Lord, 1995; Mays & Gillon, 1993). Further, Evidence-Based Practices (EBPs) have quickly gained attention in Education, especially in Special Education, for identifying interventions that will produce the most favorable outcomes. In 2005, a special issue of the journal, *Exceptional Children*, identified quality indicators for EBPs (Odom, et al., 2005). These quality measures were later incorporated into EBP reviews, including What Works Clearing Handbook and the



**Kaori Nepo, PhD, BCBA-D**

Standards for Evidence Based Practice in Special Education by CEC (2014).

Given the heightened focus on EBPs in Special Education, there have been some published literature reviews (e.g. National Autism Center, 2009; Odom, Collet-Klingenberg, Rogers, & Hatton, 2010) that have identified effective interventions for individuals with ASD. To expand upon the previous reviews with more rigorous and systematic evaluation process, Wong et al. (2015) conducted a systematic review of previously published studies to identify EBPs for individuals with ASD, while

using those quality indicators. The article identified 27 practices that met the criteria of EBPs. Examples include Discrete Trial Training, Functional Behavior Assessment, Functional Communication Training, technology-aided instruction and intervention, and Visual Support.

Extending the literature review by Wong et al., Odom et al. (2015) investigated various means of incorporating commonly available technology into interventions for individuals with ASD. They concluded that several high-tech devices can be effectively integrated with other EBPs, such as video modeling/prompting, self-management, feedback and coaching to improve social, communication, and organizational skills.

The advancement of technology in the past few decades has made many high-tech devices available that help to overcome the limitations experienced by people with ASD. Some of the advantages are: significantly improved portability, greater functionality, more flexibility, and reduced cost. Furthermore, these commonly available high-tech devices could potentially reduce the stigma associated with traditional and specialized devices.

First, the portability of the devices has greatly improved with recent technology. Thus, the users will no longer have to carry bulky and specialized devices created only for individuals with disabilities. For example, the conventional Augmentative and Alternative Communication (AAC) device,

Dynavox, is more than six times larger and eight times heavier than commonly available mobile devices with AAC capability, such as iPod Touch®. Users can now carry the iPod Touch® in their pockets or purses and then put them into the palms of their hands when they wish to make a request.

Second, conventional devices were typically made for teaching specific skills such as communicating and following schedules while providing auditory and video prompts. When individuals with ASD require such interventions to acquire and maintain socially significant skills, they often must access multiple devices. This presents difficulties, not only in navigating between devices, but also in generalizing skills to the natural environment. The current technology can integrate these functions into one device. This is especially advantageous when people are moving from one physical environment to another.

Third, these devices have become more flexible. Incorporating the concept of Universal Design for Learning (King-Sear, 2009; Meyer & Rose, 2000), current high-tech devices have many accessibility options. For example, a user can change views such as the contrast or the size of icons that appear on the screens of computers and mobile devices. Many touch screen devices can be adjusted for the sensitivity of physical contact. Additionally, text to speech,

*see Technology on page 24*



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### **Diagnose from page 8**

Clinicians are biased towards the typical male model, so an AS diagnosis often isn't even considered for girls. Older girls are usually diagnosed as having borderline personality disorder, anxiety or depression without any thought of AS. Girls often have 4-5 years of treatment on as many as 5 antidepressants and they have years of talking therapy with no suggestion of an AS diagnosis.

All of this misunderstanding and misdiagnosis makes it much harder for AS girls and women to understand themselves. They know they're different but can't define how. They are often extremely hard on themselves. For many, it's a relief to have an explanation and a group that fits them.

Mental health professionals, pediatricians, primary care physicians and school professionals need education on recogniz-

ing AS girls so they can help them. Women will describe confusion and anxiety stemming from a lack of understanding of their early experience; many are not diagnosed, self-diagnose, or are diagnosed as adults. AS girls need support, understanding and coaching just like AS boys. Without a diagnosis, their lack of socially appropriate behavior is misunderstood so that teachers dislike them, parents fail to support them appropriately and the women themselves suffer the low self-esteem. The more clinicians recognize these women at a younger age, the greater and more positive effect it will have on their lives.

*Dr. Eckerd has been in practice as a licensed psychologist since 1985. She serves on the CT Autism Spectrum Disorder Advisory Council, the Clinical Advisory Committee of the Asperger's and Autism Associ-*

*ation of New England. She helped establish the Yale-Norwalk Hospital collaboration Pediatric Development and Therapy Center. She is on the professional advisory board of Smart Kids with LD as well as the voluntary faculty in Psychiatry at Norwalk Hospital.*

*For more information about Dr. Eckerd, visit [www.marciaeckerd.com](http://www.marciaeckerd.com).*

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# Assessing If a Diagnosis is Necessary: Clinical Utility of an Autism Diagnosis Across the Lifespan

By Karen Parenti, MS, PsyD,  
Mary Jane Weiss, PhD, BCBA-D,  
and Maggie Haag, LSW  
Melmark

Family members of individuals with autism spectrum disorders (ASD) often have mixed feelings about labeling their loved ones with the term autism as this represents a life-long disability. They may be concerned about stigma, fearing that others will avoid, judge, or exclude their family member with autism. They may also worry that a diagnosis will obscure the ability of others to see the person with ASD in an unbiased way, and that the knowledge of the diagnosis might impact their efforts to form relationships with the individual with ASD.

Every family's decision is highly personal and specific, and there is no singular solution that works across individuals with ASD. The heterogeneity of the profiles of learners with ASD necessitates a highly individualized assessment of the individual's characteristics as well as a thorough assessment of the family's concerns and goals for the individual with ASD. That assessment must include an analysis of the advantages and the liabilities associated with obtaining and with sharing a diagnosis of ASD.



**Karen Parenti, MS, PsyD**

Family members' fears vary based on the age and characteristics of the person with ASD (e.g., Ludlow, Skelly, & Rohleder, 2011). For example, parents of a young child with ASD might be primarily concerned with how such knowledge could impact inclusive educational placements. Such parents might fear that teacher expectations could be largely diminished by the label, and that the child will not be pushed



**Mary Jane Weiss, PhD, BCBA-D**

to his full potential. They may also be apprehensive about specialized placements because they might restrict access to other services and experiences available to regular education services. They may also fear that the knowledge of the diagnosis might make other children less likely to socially connect with the child with ASD. Additionally, they may also worry that the label will be affixed to the child for the duration



**Maggie Haag, LSW**

of his or her educational experiences or for his or her lifespan. They may worry that they have made a decision that will permanently alter the way in which they enter educational and vocational contexts.

For parents of older individuals with ASD, there may be concern that a diagnosis is largely irrelevant. They may believe

*see Necessary on page 29*

# AUTISM SPECTRUM NEWS DESK

## AHRC NYC Welcomes New Executive Director

By Staff Writer  
Autism Spectrum News

We are pleased to inform you that the AHRC New York City Board of Directors has announced the hiring of its next Executive Director. It was with a great deal of excitement and confidence and after an exhaustive search spanning several months that the AHRC Board of Directors announced that Marco R. Damiani has been selected to fill this position commencing December, 2017.

Many of you may know Mr. Damiani who is a highly accomplished and well respected senior health and human services executive. His career reflects many years of progressive not-for-profit I/DD and government experience in the fields of healthcare, behavioral health, community based services and long-term care as an agency executive here in New York



**Marco R. Damiani**

City. He currently serves as the Chief Executive Officer of Metro Community Health Centers, Inc.; is the Chairman of the Alliance for Integrated Care of New York; a former YAI Executive Vice Pres-

ident and Senior Director of Clinical & Family Services; and former Assistant Executive Director for Residential and Family Support Services at United Cerebral Palsy of New York City, amongst many other positions of ever increasing responsibility and influence spanning the last thirty-five years.

Mr. Damiani serves on several Boards related to the field of intellectual and developmental disabilities and is currently the Chair of the influential Manhattan Developmental Disabilities Council. He has played a leadership role in the identification, development and acquisition and millions of dollars in grant funding from government and non-governmental funding sources. He is highly knowledgeable in policy and practice around managed care, value based payments and transformational supports. He is committed to professionals in our field and to the people we support and their families. All of which will, no doubt contribute to his success at

AHRC New York City.

Mr. Damiani will assume his new position in early December 2017 as Gary Lind concludes his five years with the organization. Gary and Marco will be working together over the coming weeks to facilitate a smooth transition. It is our collective vision to always provide services and supports to people with intellectual and developmental disabilities and their families that are second to none. The team at AHRC New York City has shown time and again its commitment to excellence and a passion for the AHRC mission. We have every confidence that we will continue our forward momentum and assure a successful future for the organization and for those whom we are privileged to support.

We extend a warm welcome to Marco Damiani.

For more information about AHRC NYC, visit [www.ahrcnyc.org](http://www.ahrcnyc.org).

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## Champions of the Autism and Behavioral Health Communities To Be Honored at May 16th Reception in New York City



**Tino Hernandez**



**Ilene Lainer and Michelle Smigel**



**Mitchell Netburn**



**Jim Spink**

By Staff Writer  
Autism Spectrum News

**M**ental Health News Education, Inc. (MHNE), the nonprofit organization that publishes *Autism Spectrum News* and *Behavioral Health News*, will be honoring outstanding champions of the autism and behavioral health communities at its annual Leadership Awards Reception on May 16, 2018, at the NYU Kimmel Center in NYC from 5:00 PM to 8:00 PM. To register, visit [mhnews-autism.org/AwardsReception.htm](http://mhnews-autism.org/AwardsReception.htm).

Constance Brown-Bellamy, MHNE Board Chair, made the announcement stating, "MHNE has selected leaders from four of the nation's most prominent organizations to be honored at our annual awards reception this year." They are: NEXT for AUTISM Co-Founder and President, Ilene Lainer and Board Member, Michelle Smigel; Jim Spink, President, Tri-State/Mid-Atlantic Region at Beacon Health Options; Mitchell Netburn, President and CEO of Project Renewal; and Tino Hernandez, President and CEO of Samaritan Daytop Village.

Ira Minot, Founder and Executive Director of MHNE stated, "We are indeed honored to have this opportunity to recognize these champions of the communities we serve. We are also pleased to announce that Joshua Rubin, Principal at Health Management Associates and MHNE Board Member, has graciously accepted to serve as Event Chair for our 2018 Leadership Awards Reception. Josh has served in leadership positions at many prominent autism and behavioral health organizations in the New York region."

In a joint statement, Debbie Pantin, CEO of VIP Community Services and MHNE Vice-Chair, and Josh Rubin remarked, "Both the autism and behavioral health communities will shine at our 2018 networking and awards celebration, and we invite all of our friends and colleagues to come out and join us in honoring our outstanding Leadership Awards recipients."

Proceeds from this event will go towards expanding and developing the nonprofit educational mission of *Autism Spectrum News* and *Behavioral Health News*. With these publications, Mental Health News Education, Inc. aims to reduce stigma, promote awareness and disseminate evidence-based information that serves to improve the lives of individuals with mental

illness, substance use disorders and autism spectrum disorders, their families, and the provider community that serves them.

Ilene Lainer and Michelle Smigel  
Co-Founder and President / Board Member  
NEXT for AUTISM  
"2018 Advocacy Award"

Ilene Lainer, NEXT for AUTISM Co-Founder and President, is responsible for the strategic vision and tactical direction of NEXT for AUTISM. She became a leader in the autism community for both professional and personal reasons. Ilene co-founded NEXT for AUTISM because she is committed to transforming the system of services and pursuing the latest innovations, so that all families living with autism would have access to the educational, social, recreational, and support services they need. Formerly a partner at the law firm of Grotta, Glassman & Hoffman, P.A., Ilene practiced labor and employment law on behalf of management for nearly two decades, developing a strong interest in working with clients that were in the midst of internal structural change. Ilene has served on the Board of Classic Stage Company. She has published and spoken widely about autism topics, and is currently on the Board of Trustees of the NYC Autism Charter School and on Advisory Committees for Felicity House and the Center for Autism and the Developing Brain.

Michelle Smigel, NEXT for AUTISM Board Member, and Co-Creator of Night of Too Many Stars, was a young mom working toward a prominent position at the Museum of Natural History and occasionally writing the best parts of her husband Robert's Saturday Night Live cartoons, when her first son, Daniel, was diagnosed with autism. Like many parents, she was horrified by the lack of options and resources for kids with autism, and she and Robert started Night of Too Many Stars, a televised benefit that, since 2006, has raised over 30 million dollars for autism schools, services and programs all over the country. She is a proud mom of three perfect boys.

Jim Spink, President  
Tri-State/Mid-Atlantic Region  
Beacon Health Options  
"2018 Leadership Award"

Jim Spink is the Market President for the Tri-State/ Mid-Atlantic Region at Bea-

con Health Options - the nation's premier managed behavioral healthcare organization. As a founding member of Beacon Health Strategies in 1997, Jim has held numerous roles within the organization, most recently serving as Beacon's President until the merger with Value Options in 2014. Building on an extensive background in behavioral health and developmental disabilities policy and program development, Jim has pioneered medical and behavioral health integration within payor and provider systems. Further, Jim has focused his education on the implementation of the American Disabilities Act (ADA), focusing on disability as a civil rights concern.

Mr. Spink received a dual degree in psychology and English literature from the University of Massachusetts at Amherst and a MPA in Public Administration/Disability Studies from Suffolk University in Boston, Massachusetts.

Mitchell Netburn  
President and CEO  
Project Renewal  
"2018 Community Service Award"

A native New Yorker, Mitchell Netburn has over 25 years of public interest experience. Since 2010, Mitchell has been the President and CEO of Project Renewal. At Project Renewal he is responsible for the strategic vision and management of the agency to ensure it fulfills its mission to end the cycle of homelessness for adults and children by empowering them to obtain health, homes and jobs. Mitchell oversees the agency's innovative and award winning programs which collectively serve 15,000 clients per year, including 2,754 people in shelters and permanent housing. Project Renewal has a staff of 900 employees and an annual budget of \$80 million.

Previously, Mitchell was the Senior Vice President at F·E·G·S Health and Human Services System where he directed a welfare-to-work initiative serving 24,000 disabled clients annually. Mitchell succeeded in tripling the number of clients moving from welfare to independence, gaining both national and international recognition for this holistic client-centered model. Prior to joining F·E·G·S, Mitchell served as the Executive Director for the Los Angeles Homeless Services Authority where he coordinated all homeless programs for the City and County of Los Angeles.

Before moving to Los Angeles, Mr. Netburn was the First Deputy Commissioner at the New York City Department of Homeless Services where he ensured quality shelter and programs were provided to 23,000 people per night. Mitchell also held the positions of Chief of Staff to the NYC Deputy Mayor for Education and Human Services as well as the Agency Chief Contracting Officer and the Assistant Commissioner for the Ryan White CARE Act Program at the NYC Department of Health and Mental Hygiene.

Mr. Netburn has a J.D. from the University of Wisconsin-Madison Law School and a B.A. from Oberlin College.

Tino Hernandez  
President and CEO  
Samaritan Daytop Village  
"2018 Lifetime Achievement Award"

Tino Hernandez is President and CEO of Samaritan Daytop Village. Samaritan Daytop Village is one of the largest non-profit providers of community-based health and human services in New York State. Serving more than 28,000 people each year, the agency operates a network of more than 50 facilities, across 10 counties in New York City, Long Island, Westchester and upstate New York.

Tino serves on the Governor's Behavioral Health Services Advisory Council and sits on the Executive Committee of the Coalition of Behavioral Health Agencies. Prior to joining Samaritan Daytop Village, Mr. Hernandez was the second-longest serving Chairperson of the New York City Housing Authority (NYCHA) and oversaw a public housing and Section 8 system serving more than 675,000 New Yorkers.

Mr. Hernandez previously served as Commissioner of the NYC Department of Juvenile Justice, Chief of Staff to the Deputy Mayor for Education and Human Services, Deputy Commissioner for Adult Services at the Department of Homeless Services, and Assistant Commissioner for HIV Program Services at the City's Health Department.

A licensed social worker, Mr. Hernandez obtained a Bachelor of Science degree from Adelphi University and a Masters in Social Work from the State University of New York at Albany. Mr. Hernandez is married and resides in Manhattan. He is the father of two children.



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PUBLISHER OF AUTISM SPECTRUM NEWS & BEHAVIORAL HEALTH NEWS

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Proceeds from this event will go towards expanding and developing the nonprofit educational mission of *Autism Spectrum News* and *Behavioral Health News*. With these publications, Mental Health News Education, Inc. aims to reduce stigma, promote awareness and disseminate evidence-based information that serves to improve the lives of individuals with mental illness, substance use disorders and autism spectrum disorders, their families, and the provider community that serves them.

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

By C. Faith Kappenberg, PhD, LCSW  
Director  
LI Early Childhood Direction Center

“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



C. Faith Kappenberg, PhD, LCSW

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

see *TEACCH* on page 20

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## Is Play Therapy an Evidenced-Based Intervention for Children with Autism?

By Heidi Hillman, PhD, BCBA-D  
Assistant Professor  
Eastern Washington University

As a board certified behavior analyst (BCBA), I work with families that have a child diagnosed with an autism spectrum disorder (ASD), and periodically see an increased interest in specific interventions. Multiple families start asking me whether a specific intervention is as effective as they are led to believe. Play therapy is one of those interventions. In the past year, 10 parents asked me whether play therapy is an effective intervention. That number of parents may not seem a lot, but when I see approximately 30 families a year, that is 33% of my families questioning a specific therapy. Even though my training is with behavioral interventions - specifically applied behavior analysis - I am not one to discount non-behavioral interventions as ineffective without considering the supporting evidence. So off to the library I went!

We know autism spectrum disorders are one of the fastest growing developmental disorders in the United States, with a prevalence rate of 1 out of 68 children (CDC, 2016). This discouraging fact provides more reason to identify effective, evidence-based treatments for children with ASD. Currently, autism interventions based on behavioral theories - such



Heidi Hillman, PhD, BCBA-D

as applied behavior analysis - are the gold standard since they are documented as effective. However, some researchers in the autism field (e.g., Gallo-Lopz & Rubin, 2012; Greenspan & Wieder, 2006; Ray, Sullivan, & Carlson, 2012) proposed play therapy as a potential intervention for children with ASD, since play therapy addresses core issues of children with ASD such as social and relationship concerns. Since children with ASD have difficulty relating to others, play may be a wonderful tool for

helping them move beyond self-absorption into varied, shared interactions.

The purpose of this paper is to (a) discuss what play therapy is, (b) discuss whether play therapy is an effective intervention for children with ASD, and (c) take away points.

Play therapy involves children engaging in play activities of their choice. The play therapy environment gives children with ASD opportunities to express themselves in ways that are most comfortable. Unlike many behavioral interventions, the play therapist's job is participating in a relationship with the child through play (Ray, Sullivan, & Carlson, 2012). One type of play therapy is child-centered play therapy, a relationship based intervention based on Axline's (1969) early work, explaining that the client - not the therapist - was the primary agent of change. Instead of the therapist leading therapy, children are in charge of the pace, direction, and content of the therapeutic journey. In child-centered play therapy the therapist enters the world of the child and uses the relationship as an intervention, rather than training children to engage in specific behaviors that may conflict with their natural ways of being.

I conducted a comprehensive search of the literature and very little research was published on using play therapy for children with ASD. I found only five studies (Carden, 2009; Josefi & Ryan, 2004; Kenny & Winick, 2000; Mitteldorf, Hendricks, &

Landreth, 2001; Salter, Beamish, & Davie, 2016). In summary, all five studies used child-centered play therapy to increase social behaviors and play interactions of children with ASD. Participants ranged from five to 11 years old. All five studies reported a small increase in social engagement and increased play interactions among the participants. Even though the results are encouraging, there are limitations. All five studies used a case study design - meaning that each study focused on one participant. Since case studies are not a strong experimental design it is difficult to generalize results to the larger community. In addition, we do not know whether the change in the participant's behavior was due to the intervention - in this case play therapy - or other extraneous variables since the intervention was not implemented with additional participants. Hence, it is difficult to say that the play therapy intervention was effective in all five studies. The participants in the five studies either were engaged in other autism interventions outside of the study or the studies themselves used play therapy along with other interventions. Hence we do not know the impact of play therapy specifically on behavior change since play therapy was not an isolated intervention. Lastly, all five studies did not address social interaction with peers, and there is little information on generalization of skills

see *Play Therapy* on page 30

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# AUTISM SPECTRUM NEWS DESK

## CDC Study: Autism is Associated with Amount of Time Between Births

By The Centers for Disease Control and Prevention (CDC)

A study from the Centers for Disease Control and Prevention (CDC) and research partners found that shorter and longer time periods between births are linked to having a child with autism spectrum disorder (ASD). The findings from this study can help healthcare providers convey information to their patients about the ideal timing between pregnancies. Read the scientific summary of the article here: [www.ncbi.nlm.nih.gov/pubmed/29164825](http://www.ncbi.nlm.nih.gov/pubmed/29164825).

### Main Findings

- Children conceived less than 18 months after their mother's previous birth or children conceived 60 or more months after their mother's previous birth were more likely to have ASD when compared to children conceived



between 18 to 59 months after their mother's previous birth. The relationship is stronger in children with severe ASD symptoms.

- The linkage between birth spacing (the period of time between pregnancies) and having a child with ASD appeared to be unique to ASD, as there was no

linkage found between birth spacing and having children with other developmental disabilities.

- The linkage between birth spacing and having a child with ASD was not explained by unplanned pregnancy, an underlying fertility disorder in the mother, or high blood pressure or diabetes during pregnancy.

The findings from this study can help healthcare providers counsel their patients on pregnancy spacing. Couples thinking about getting pregnant can discuss pregnancy planning with a doctor or healthcare provider.

### About This Study

This study used data from the [Study to Explore Early Development \(SEED\)](#), the largest study in the United States to help

see [CDC Study on page 23](#)

### TEACCH from page 18

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).*

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## Post-Secondary Employment for Young Adults with ASD

By Sean T. Miller, MA  
Stony Brook University  
and Lauren E. Andersen, MA  
Teachers College, Columbia University

The transition to adulthood represents a particularly vulnerable time for youth with autism spectrum disorder (ASD), as the entitlements of the children's service system end and families encounter fragmented systems of care (Friedman, Warfield, & Parish, 2013). Post-secondary transition can be defined as the process by which students culminate their high school experiences and enter adulthood. For students with severe disabilities who have significant learning challenges, their post-secondary goal may be to obtain competitive employment. The goal of this paper is to examine a post-secondary employment trends and outcomes for individuals with autism.

Individuals with autism spectrum disorder face a variety of challenges in gaining and maintaining paid employment, despite their willingness to work. Historically, adults with autism are unlikely to be gainfully employed. Rutter, Greenfeld, & Lockyer (1967) conducted a study on 63 individuals who were diagnosed with autism in the 1950s. When these individuals with autism reached the age of adulthood, only three had paid jobs, meaning 96% were unemployed. Since then, little



Sean T. Miller, MA

progress has been made. In 1992, Kobayashi & Murata conducted a study on 187 young adults with autism. Of the 187 adults interviewed in 1992, only one fourth or 75% were unemployed. Although the rates of unemployment among individuals with autism in the 1950s and 1990s are quite alarming, when comparing these two studies to modern day statistics, employment rates are showing some improvement.

At present, employment rates among



Lauren E. Andersen, MA

individuals with autism are inconsistent across different studies. In a recent study, Newman, Wagner, Cameto, & Knokey (2009) found that 37% of individuals with autism spectrum disorder had been employed for 12 months or more when they were surveyed four years after their high school exit. Furthermore, data collected from the National Longitudinal Transition Survey-2 (NLTS-2) in 2011 indicate that 15% of adults with autism held paid employment after leaving high school.

While there are some positive trends in individuals with autism holding competitive employment positions, especially since the 1950s, individuals with autism are still faced with many unique challenges. Those with an autism diagnosis are less likely to be employed than individuals with other disabilities, such as learning disabilities, intellectual disability, or speech and language impairment (Shattuck, Narendorf, Cooper, Sterzing, Wagner, & Taylor, 2012). In the first wave of data collected in the NLTS-2, only 15% of young adults with autism were employed compared to 54% of individuals with other disabilities who were employed (Cameto, 2003)

There are a variety of studies that have documented the difficulty that individuals with autism have when maintaining employment due to issues that may be inherent to their disability. Individuals with autism may lose their job because of social problems or behavioral issues (Hurlbutt & Chalmers, 2004; Unger, 1999). Chiang, Cheung, Li, & Tsai (2013) also found that social communication deficits and restricted and repetitive patterns of behavior in individuals with autism adversely affected their opportunity to enter gainful employment. This is a particularly challenging hurdle for individuals with autism to overcome, as the very classification of autism spectrum disorder typically includes difficulty in

see *Employment on page 28*



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### Your Child from page 10

- For information regarding evidence-based interventions: The National Autism Center's National Standards Project [www.nationalautismcenter.org/resources/for-families/](http://www.nationalautismcenter.org/resources/for-families/)
- The National Professional Development Center's Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: [fpg.unc.edu/sites/fpg.unc.edu/files/resources/reports-and-policy-briefs/2014-EBP-Report.pdf](http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/reports-and-policy-briefs/2014-EBP-Report.pdf)

#### Care for the Caregiver

When a child receives a diagnosis of

ASD, it likely affects the whole family and may feel overwhelming. It is important for caregivers to try to get rest, exercise and take a break when possible. In addition to your existing sources of emotional support, you can build a new support system through local support groups (in person or online), or with a professional therapist or counselor. Statewide ASD information and advocacy organizations may have local resources. In New Jersey, a 24 hour hotline, Mom 2 Mom is manned by trained parents and other family members and is monitored by a trained mental health professional: [www.mom2mom.us.com](http://www.mom2mom.us.com). Additional resource:

- Autism Speaks Family Support tool kits: [Family Support Tool Kits](#)

#### Explore Disability Eligibility

Children and adults with ASD may be eligible for Social Security Disability services if there is documentation of serious limitation in understanding, remembering, or using information; interacting with others; focusing on activities; and adapting or managing oneself. Additional resource:

- Social Security Administration SSI overview - [www.ssa.gov/pubs/EN-05-10026.pdf](http://www.ssa.gov/pubs/EN-05-10026.pdf)

#### Consider Case Management Support

ASD is a complex condition and often involves services across a variety of providers and settings. Case management can

help coordinate care, provide information, assist with applications for services, and advocate with educational, insurance or other service providers. Case management may be available through state developmental disability agencies, county special child health services, or other advocacy agencies. In New Jersey, for example, each county has a Special Child Health Case Management unit that assists with linking to services and advocacy. [www.state.nj.us/health/fhs/specialneeds/contacts.shtml](http://www.state.nj.us/health/fhs/specialneeds/contacts.shtml)

#### Consider Anticipatory Guidance

It is helpful to anticipate developmental

see *Your Child on page 30*

### **Shrub Oak from page 4**

program; the student life piece - in the dorms, in the community, effectively bringing people into the community; and clinical support. This will all be integrated at Shrub Oak 24 hours per day, 365 days a year. This model is what inspired the school.

### **What will the clinical approach be to supporting your students?**

Dianne: The program that will be provided in any part of Shrub Oak will be completely customized and individualized for each student. The educational approach will be evidence- and research-based and will always be an empirically-validated program. We will utilize the major approaches that have solid evidence-based research behind them. We will be collecting data on every student's progress and will be informing our practice through data. This is something that sets Oak Shrub apart from other schools that will tell you that they primarily employ a single method of intervention such as ABA or DIR/Floortime. We are not buying into a single philosophy or approach, we are buying into the student. We will take from every approach that has an evidence-base to show that it does work and we will meet that student where that student's needs are. The data we collect will be continually referenced to ensure that we are meeting their needs.

Brenda-Smith Myles, who is an Advisory Board Member, will help us plan our educational program. We will use the Ziggurat Program, developed by Ruth Aspy and Barry Grossman, as a framework which complements all of the existing evidence-based programs. It enables you to look at the child through a biological and etiological lens and assess their sensory issues, learning issues, behavioral and social needs, etc., and then develop a configuration of strategies and methods that will meet that student's needs. This will then be changed and tweaked as the student develops. We will take those pieces, put it into a relationship-based, strength-based model, where we are paying attention to the student's strengths, preferences, sensory needs, interests, and provide a program where the motivation is intrinsic so that students will be engaged and motivated in their learning activities.

We will be working with older students, primarily ages 14 – 22 years old, with a handful of adults going up to age 35. We won't have any kind of strict discrete trial ABA. Teenagers and young adults need parameters set so they know what they are expected to do, and how to behave. We will catch them being good, and praise and reward them in many ways. But most of this will be naturally occurring reinforcement; not an artificial setting like a 9 am – 3 pm school. Shrub Oak will be a 24 hour/7 days per week/365 days a year life and community for them, so it will become a really active community of learners working and living together.

We are taking the best of the evidence-based approaches and the research-based and emerging best practices and our team of highly experienced professionals will integrate that for the student. I don't think this is done anywhere.

### **How will you meet the academic needs of your students?**

Dianne: We are going to have two paths. One will be a college and career path and one will be a skills and achievement path. The college and career path will be geared towards academically talented students who are likely to go on and pursue post-secondary education college education. The skills and achievement path will be for students who are more directed towards being prepared for a career. They will have an academic program, but not a high school diploma-type program. Regardless of the path, every student will receive a credential from Shrub Oak. One credential will be the Shrub Oak high school curriculum diploma and the other will be the Skills and Achievement diploma.

Classrooms will typically be "8-1-3," or a 2 to 1 ratio. This means that in every classroom of eight students, there will be a teacher with a Master's level education with a certification as a special education teacher and also three teaching assistants, who will most likely be working towards becoming Master-level teachers. In addition to this typical teacher to student ratio, clinicians will be with the students regardless of what activities they are involved with, be they snowshoeing, swimming, on the farm, in the glass works studio, etc. For example, if students are going to an art class, they will be supported by the art teacher, the Master's level classroom teacher, the three teaching assistants, and a few clinicians. So we are looking at a very high student to teacher and clinician ratio.

We will design each education program with an IEP that meets that student's educational goals and needs. It will be student-centered, person-centered and will be heavily focused on self-determination. Michael Wehmeyer, PhD, professor at the University of Kansas and renowned international guru on self-determination, is on our Advisory Board. He will be doing staff development on self-determination. Our Advisory Board is made up of the leaders who have created the evidence-based strategies and methods in the educational world for students with autism. They will be guiding and supporting the staff at Shrub Oak.

I know that we are doing something that really needs to be done, and that will be a model for other places to replicate.

### **How will Shrub Oak International provide students the opportunity to integrate with the community?**

Gil: I'm a big believer that individuals with autism have much to bring to the community. Knowing that we are coming from a strength-based model, not only will we be utilizing the community resources, we will also be providing service to the community. Too often, communities see the individuals with autism as being people who the community needs to help. I actually think that we are going to be reaching into the community to say that we have a lot to offer and we are going to come to your aid. For example, we will eventually have an organic farm on the campus and we will create a CSA (Community-Supported Agriculture). The way a CSA functions is that you get a box of produce from the farm

once a week if you sign into it. Normally the model for this is that people pay to participate in a CSA. My goal for Shrub Oak would be to run a CSA for individuals who are identified in the community as needing additional nutritional support. The Shrub Oak students who are helping to produce this good and healthy food would work together to create products that can be made available to people who may not have the financial means to access that kind of food.

Too long have we stood here and said, "Community, come and support us." In fact, the autism community and the community of folks who have autism actually have a tremendous amount to offer society. So when we think about coming into the community, it will be with the notion of, "Here's what we can offer you, and here's why you need us."

### **How will the admissions process work? What does the typical Shrub Oak student look like?**

Gil: After an application is submitted, students will come in for an integrated assessment. Dianne, her staff, and I will then be given the opportunity to interview the prospective student. There will also be an occupational therapist and speech and language pathologist looking at what support needs this student might need if they were to attend Shrub Oak. I would love to have a clinical music therapist there as well. After this intake, the student would take a campus tour.

A large percentage of students will most likely come from the NY-metropolitan area. Having traveled around the country, spoken at many different places, and being on the advisory boards of some different autism organizations, I have seen that there is a real need nationally. So I can imagine that we will receive applications from people all over the country.

We will have individuals in need of a wide range of support that exhibit a range of behavioral issues and being on either end of the spectrum does not exclude anyone from attending Shrub Oak. I have always thought that behavior is really a communication, and we need to find a way to make communication more effective so that negative behaviors go down. I can see Shrub Oak accepting students who are highly verbal, going to be the valedictorians of their high school classes, who have some social-emotional challenges that are really impeding their ability and perhaps need some additional sensory support at school. I can also see students at Shrub Oak who need additional support in their communication, require a lot of physiological intervention, and who are big consumers of occupational and physical therapy, speech and language services, clinical music therapy, and mental health services.

So for me, the criteria that would make a student a good fit for Shrub Oak would be: can you benefit from this intervention program, and can we offer you what you deserve to have.

Dianne: We will have a wide range of students applying. If we can meet their needs, we will accept them. If we cannot meet their needs, once someone has approached us we will help them find somewhere that will and can.

### **How will Shrub Oak help students transition to life after school?**

Dianne: For the last three decades, my focus has been on transition from school to independent adult living, community integration, and transition to employment and post-secondary education. During this time, I've been working with my graduate students to teach them how to implement this. Now, I'm fortunate to have the opportunity to direct a program that will be doing what I've been teaching and researching for the last 30 years.

We know that there is 75% unemployment and under-employment of individuals with autism. We are going to change that. Shrub Oak's entire focus is on preparation and success for life. Our academics will be geared towards one or the other pathways for students as mentioned earlier. We will have transition coordinators working with businesses in the community to set up internships for students. As Gil said, our students will be helping the community. The surrounding community has many businesses and opportunities where our students will have a lot to offer and where they can learn and explore different careers. We'll make relationships with colleges and universities that will understand the Shrub Oak curriculum so that our college-bound students will be able to go to colleges where they will be able to receive the support they need to continue their academic and career-focused educations.

We will assess everything we do to make sure that those students are having meaningful internships and explorations of the world and the career or educational path that is ahead of them. In order to do this, we've hired Tracey Frank to be Director of Education. Tracey is especially qualified as she was one of the best students and graduate research assistants that I had in a federally funded autism transition program at CW Post years ago. She has garnered additional degrees at Johns Hopkins and has been working as a teacher and coordinator for students with autism for several years. She has left her job in Maryland to join the Shrub Oak team. We share a very similar focus and a passion for transition.

Our education program will transcend the four walls of any classroom. The program at Shrub Oak will look nothing like the traditional classroom school day. Our vision is that the school day and education at Shrub Oak will use the entire campus and surrounding community. We will integrate academics and career development skills in the natural setting.

In addition, we will maintain active lines of communication with the parents. It is imperative to really listen and pay attention to the parents and families of the students to ensure their needs are fully met.

### **How can people find out more information about Shrub Oak?**

Gil: The first thing you should do if you are interested in learning more about the Shrub Oak International School is to visit the website at [www.ShrubOak.org](http://www.ShrubOak.org). Once people make contact, then we will all be available to help guide them through the process of applying.

# Social and Emotional Learning: Transitioning to Adulthood

By Amy Golden, MS, BCBA  
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Behavior Therapy Associates

**S**ocial and emotional learning is a complex process in which children and adults acquire and utilize skills that are necessary to interact with oneself and others in a positive manner. Core competencies for individuals to learn include managing one's emotions, setting and achieving positive life goals, establishing and maintaining positive interpersonal relationships, feeling and showing empathy for others, and making responsible decisions (Collaborative for Academic, Social, and Emotional Learning, 2010). These critical abilities are necessary for maintaining successful relationships with others, gaining meaningful employment, navigating daily life skills, and problem-solving issues that arise in life, particularly as one moves toward adulthood and greater independence. Due to the primary characteristics of autism, individuals on the spectrum tend to fall short in these crucial skills if not provided access to systematic, intensive supports to address these areas of need.

A recent study (Jones, et al., 2015) in the American Journal of Public Health documented the relationship between the social and emotional skills of kindergarten students and future wellness in 25-year-olds.



Amy Golden, MS, BCBA

Interestingly, this study demonstrated that there were statistically significant associations among measured social and emotional skills in kindergarten and critical young adult outcomes. The authors identified these outcomes across many domains that impact one's social and emotional well-being, including education, employment, criminal activity, substance use, and mental health. Understanding this significant association is important for early identifi-



Michael Selbst, PhD, BCBA-D

cation and intervention to provide social and emotional learning when children are young and to continue these supports throughout the school years.

A primary emphasis of a student's educational programming should be on the development of social skills to succeed in life. Recognizing this need early on is especially important for individuals with autism. Due to the complexities of developing comprehensive programming to ad-

dress the myriad of potential core deficits, as well as the likelihood of substantial lessening of services as the student ages out of the school system, identification of social and emotional goals should be a priority throughout formal schooling and needs to continue through adulthood. While many individuals whose development is typical will acquire and demonstrate prosocial skills as a result of social modeling, those on the autism spectrum require direct and sustained intervention, planned procedures to foster generalization, and monitoring of their progress.

Initial and ongoing efforts should be made to identify an individual's strengths and areas of needed development through assessment of social and emotional skills. There are various measures that can assist, such as the Adaptive Behavior Assessment System - Third Edition (Harrison & Oakland, 2015), which can be administered on behalf of individuals of all ages and helps to assess the capability of the individual to live independently as an adult. Similarly, the Vineland Adaptive Behavior Scales - Third Edition (Sparrow, et al., 2016) can be used across the lifespan to assist with program planning and progress monitoring. Additionally, The Assessment of Functional Living Skills (Partington & Mueller, 2012) provides a detailed assessment of practical life skills to maximize

see Adulthood on page 26

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## CDC Study from page 20

identify factors that may put children at risk for ASD. Researchers analyzed information collected from more than 1,500 second- or later-born children enrolled in SEED.

### Our Work

CDC's National Center on Birth Defects

and Developmental Disabilities is working to improve our understanding of ASD through the **Autism and Developmental Disabilities Monitoring (ADDMM) Network** and SEED. CDC conducts or funds these activities to: Learn more about the number of people who have ASD; and Identify factors that may put children at risk for ASD and other developmental disabilities.

This information can help communities

direct outreach efforts to those who need it most.

### More Information

[www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism)

[www.cdc.gov/ncbddd/autism/addm.html](http://www.cdc.gov/ncbddd/autism/addm.html)

[www.cdc.gov/ncbddd/autism/seed.html](http://www.cdc.gov/ncbddd/autism/seed.html)

[www.cdc.gov/actearly](http://www.cdc.gov/actearly)

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### Adult ASD from page 9

there definitely was something to this, I immediately decided to find a specialist who could confirm it to be sure that I was not just kidding myself – had this been the case, I would have felt very foolish. It is at this point that my story takes an unusual turn because, for reasons of which I am not certain, my mother had maintained a diary of my development in early childhood. When I examined it, I found descriptions of many classic, even textbook, autistic traits and behaviors: at the age of 2 ½ years, I was playing with my toys by lining them up in long rows; although I never lost speech, and my language usage was essentially perfect, I continually reversed my pronouns; I was very focused on whatever captivated my interest, but otherwise oblivious to many aspects of my environment; I was also sensitive to certain sounds and noises and to the flash of a camera, and could not tolerate the motion of elevators. Also described at length were my incessant perseverations on subjects of interest (anything electrical or mechanical, which led to a career as an engineer), as well as her exasperation with my overly-selective eating habits (which I have to this day). I was able to find a specialist to whom I presented this evidence, and he agreed that I was clearly living with some degree of autism. Had it not been for this, it would have been very difficult, at my age,

to make a conclusive determination but, with this information, there could be no doubt. I really was autistic.

I responded to this knowledge by learning as much about the autism spectrum as I possibly could. I read every online and print article and book that I could find, went to every lecture and conference in the region that I could get to, and started attending support groups on a regular basis. Coming from a scientific background as I do, it was of great value to finally learn the reasons underlying many challenges, difficulties, and personal differences of which I had long been aware but never understood. Of even greater value, however, were the first-person accounts of other adults on the autism spectrum in books, memoirs, articles, and talks where they described their experiences, as well as those shared by members of support groups I attended. I would regularly hear stories so similar (often identical) to my own that it was downright uncanny and even scary at times.

Once again, I cannot overemphasize the value of self-knowledge and understanding that comes from an adult diagnosis, and have found that it becomes even more significant as the age of diagnosis increases (as reported by many older adults I have met). This should hardly come as a surprise – the later in life one is diagnosed, the longer one has been living with this condition yet never understood why they had faced the

challenges that it presented for them all of those years. Although not everyone is as receptive to such a diagnosis, for many of us it is nothing less than life-changing.

As significant as all of this is, we also need to consider the practical utility of ASD diagnosis. Many of the challenges faced by adults on the spectrum involve finding and maintaining employment. In particular, the reasons underlying their difficulties are usually very different from those of the general population. As such, it can be very useful for autistics to have an understanding of those reasons. If one is in need of benefits, services, or accommodations of any kind on the basis of living with ASD, a formal diagnosis is almost always required. If one is participating in the mainstream job market, however, a thorough understanding of the deficits responsible for challenges faced can be of great value in addressing them. This can come from either formal diagnosis or comprehensive self-diagnosis using quality resources available online (of which there are quite a few). Shortly after my own diagnosis, I spoke to a well-known figure in adult autism at a regional conference, and asked how I should address this regarding my employer. I was told that there was no reason to raise the issue, as I had been working there for many years in what was then considered a secure position. At the time, this was

very prudent advice – times have certainly changed since then.

Because of economic downturns in the early 21<sup>st</sup> century, resulting in the 2008 financial crisis, as well as the replacement of workers by new technologies, the nature of employment has changed significantly. In particular, employers now attach greater importance than ever to employee attributes that autistics are generally deficient in (interpersonal and communication skills, flexibility, adaptability, etc.) As such, it is essential for autistics to be aware of their deficits so that these can be addressed and so that any and all necessary services and accommodations can be obtained.

It is by now well-known that the prevalence of autism in the U.S. is much higher than was previously believed – 1 in 68 is the currently-accepted figure. Statistical data such as this at best can only provide general information about the impact of autism on our society. It cannot address many of the specific problems, and is certainly of little value to people who are actually on the spectrum. Those who live with ASD, and have done so for an entire lifetime, need to be aware of this, for self-knowledge as well as for practical reasons. We need to make sure that this happens whenever and wherever possible.

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### Technology from page 12

captions, and speech to text functions are available in many high-tech devices. These accessibility options are now readily available to accommodate various needs of users.

Previous studies have identified three key components of technological devices that are related to reducing stigma: a) aesthetic appearance, b) customizability, and c) generalizability (Bipso, & Branco, 2009; Conley, 2012; Doughty, 2011; Parrette, & Scherer, 2004; Shinohara, & Wobbrock, 2011; Vaes, Stappers, Standaert, & Desager, 2012). One of the advantages of commonly available high-tech devices over earlier technology is that they could reduce the stigma due to the factors specified above.

To take into account the previously mentioned advantages, Chimes conducted two studies employing commonly available high-tech devices, including the iPod Touch® and the iPad®. In the first study (Nepo, Tincani, Axelrod, & Meszaros, 2014), three adults with ASD and Intellectual Disabilities (ID) were taught to use the iPod Touch® as an AAC, to communicate their needs and wants. A voice output app, My Talk, was on the users' iPod Touch® with preferred items derived from preference assessments programmed within the app. With most-to-least prompting procedures, the participants learned to discriminate between different pictures and to tap a corresponding picture to request an item. The acquired skills generalized to natural environments.

In the second study, six adults with ASD and ID were taught to engage in leisure activities on the iPad® (Nepo, Tincani, Axelrod, & Meszaros, 2017). Those individuals did not have functional and productive leisure skills prior to the intervention. All the participants acquired the skills of navigating for, and engaging in, four to five leisure activities on the iPad®. These activities were: playing games, listening to music, and

watching video clips. Then, the participants learned to refer to a visual schedule of those leisure activities and to complete multiple activities in a row on the iPad®. The skills also generalized to the participants' natural environments such as at the cafeteria or a doctor's appointment. Additionally, the participants' caregivers completed a survey after the completion of the study. The results indicated that the intervention, which incorporated commonly available technology, was socially acceptable, effective, and possibly reduced the social stigma associated with more specialized devices.

Further, Chimes plans to conduct another study to investigate the impact of an automated data collection/ health information system (Virtual Health) on the accuracy and latency of behavioral data collection and the quality of health services. We expect to reduce the response effort required of staff in collecting data by using an app on a mobile device. We also expect to increase the reliability and validity of data collection, while decreasing the latency of data submission to clinicians. A function to alert the clinicians, health professionals, and team members should also reduce medication errors and provide immediate access to medical and other related information. This should help the clinical team to make better and more comprehensive clinical decisions. These outcomes should ultimately improve the quality of overall services to our clients.

For information about research at Chimes, please contact Kaori Nepo at [kaori.nepo@chimes.org](mailto:kaori.nepo@chimes.org) or visit [www.chimes.org](http://www.chimes.org).

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**Integrating from page 4**

the student, thus facilitating identification of goals that are well-suited to student needs. Components of the process include the *Ziggurat Worksheet* (Aspy & Grossman, 2007) and the *Comprehensive Autism Planning System (CAPS)* (Henry & Smith Myles, 2007).

**The SCERTS Model**

Looking at intervention planning through a somewhat different lens, the SCERTS intervention model (Prizant, Wetherby, Rubin, & Laurent, 2003) also develops an in-depth profile for each student, while placing increased emphasis on family support. This model focuses on social communication, emotional regulation, and transactional support (Wetherby & Prizant, 2005). Both the SCERTS and Ziggurat models address core challenges of individuals with autism and are built upon solid foundations of empirical data. They each highlight critical areas for learning and development, essential to successful transition intervention.

**The Self-Determined Career Development Model (SDCDM)**

While the SCERTS and Ziggurat models provide a substantial amount of important information for program development, a pitfall of these programs is that they do not directly guide and monitor self-determination development. Building self-determination competency is central to educational programming for adolescents

and young adults. Too often this critical aspect of secondary education is overlooked. Skills that comprise self-determination include: choice making, decision making, problem solving, goal setting, risk taking with safety, self-regulation, self-instruction, locus of control, perceptions of self-efficacy, self-advocacy, self-awareness, and self-knowledge (Bremer, Kachal, & Schoeller, 2003; Deci & Ryan, 2000). Research has shown that individuals who are more self-determined are more likely to achieve positive adult outcomes than peers who are not self-determined (Palmer & Wehmeyer, 2003).

The Self-Determined Career Development Model (SDCDM) enhances learning through questions that help steer future planning, and is positively correlated with improved adult outcomes and employment success. The SDCDM is designed to guide the transition to employment process and to monitor progress toward goals, so that the action plan or goal may be revised when necessary. Phases of SDCDM emphasize self-advocacy and decision-making and include (a) goal setting, (b) constructing learning plans, and (c) adjusting behaviors.

**Summary**

In summary, when planning an individualized transition program and selecting intervention strategies it is necessary to consider the student's needs, interests, and strengths. A thorough understanding of the learner's profile is necessary, especially with regard to underlying characteristics associated with autism. Based on accurate comprehensive information, realistic goals

and objectives can be identified. Ziggurat intervention, SCERTS and SDCCDM are complementary evidence-based tools to help guide educators in the critical and essential transition process.

*Dianne Zager, PhD, is Co-Director & Dean of Education, and Tracey Frank, MS, is Director of Education at Shrub Oak International School. For more information, please visit [www.shruboak.org](http://www.shruboak.org).*

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### Reinforcement from page 11

to be more effective overall than time based progressive delays (Ghaemmaghami et al., 2016). In other words, when a delay to reinforcement was put in place, the procedure that required the individual to engage in some response (i.e., play activity, leisure activity, academic demand, etc.) was more effective than the time-based wait procedure without the response requirement. These results varied somewhat from the results of the Mace et al. (2011) study, suggesting that additional studies are warranted.

While delays to reinforcement are often appropriate, there are situations in which reinforcement is not available, even after a delay. Denied access procedures, also referred to as "Accepting No" and "Tolerating No," have been described wherein the individual makes a request, is told "no" (i.e., the request is denied) and if he/she does not engage in problem behavior they are offered an alternative item. If the individual makes a request, is told "no," and engages in problem behavior, the request is not reinforced (i.e., extinction) and "accepting behavior" is reinforced with differential reinforcement. It is then stated that the child "accepts no in the future" (Carbone, 2014). Hanley et al. (2014) describe a procedure referred to as delay and denial tolerance training wherein two of every five FCRs result in a delay or denial response. The procedures are similar to those described above wherein problem behavior did not result in reinforcement (i.e., extinction), the individual

was taught a specific response to the denial cue statement that consisted of responding by taking a breath and saying "okay," and the individual was required to engage in an alternative response (i.e., play, work task, etc.). Both of these procedures begin with short intervals between denial, being told "no," etc. and then gradually increase the time between denial and reinforcement delivery.

Overall, results of studies examining delay and denial tolerance training or tolerating "no" suggest that there are several key components to effective programs to delay or deny reinforcement. First, a functional analysis for functional behavioral assessment is conducted in order to identify the reinforcer maintaining challenging behavior. Next, the individual must be taught to emit a functional communication response (FCR) in order to access the reinforcer while challenging behavior no longer results in reinforcement (i.e., extinction). Once problem behavior decreases to near-zero levels and communication responses occur at efficient levels, short delays to reinforcement can be introduced. A signal for the delay is used and can be varied (i.e., "wait," "hold on," etc.) and the individual can be required to respond with a specific response (e.g., "okay"). In addition, the procedure can include some ratio of immediate reinforcement for each occurrence of delayed reinforcement on a varied schedule (i.e., not predictable). That is, sometimes when the individual requests reinforcement with the FCR response he/she is not required to wait and reinforcement is delivered immediately. During the

delay the individual can be offered the option (i.e., a choice) of engaging in an alternative activity (if problem behavior has not occurred) or be required to complete an alternative activity and/or complete leisure or task demands (i.e., a contingency requirement). Next, these delays can then be gradually increased while monitoring levels of problem behavior and communication. If the levels of problem behavior remain low and communication continues to occur at efficient levels (i.e., when reinforcement is available) the delays can be increased until a desired schedule is met. While there is no precise method for determining which procedure is right for a particular individual, practitioners can use clinical judgment to determine which variation to evaluate initially while examining data on the effectiveness of the procedure can be used to guide decisions to evaluate variations of the procedures.

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independence. Each of these tools can be used to determine the individual's baseline skills so that proper goal selection and educational planning can take place most efficiently.

Many social and emotional skills can be taught through the 3-D approach of "discuss, demonstrate, do" (Asher, et al., 2010). Within the discussion step, individuals are taught the rationale for learning the skill and the steps involved. An example of this is teaching the student why to initiate a text message and how they can ask a friend for help. The second step involves the instructor or a peer model demonstrating the skill while the student watches. Last, the student participates in the skill by doing it while receiving coaching and feedback. Role-play may continue until the learner demonstrates proficiency with the skill, and then additional practice opportunities should be planned with support. Such support oftentimes is provided via a job coach or supervisor, trained instructional assistant, or parent/guardian.

It is also important to consider whether the individual possesses the knowledge of the skill and can perform it under certain circumstances but not others. In this case, the student may have deficits in performance or generalization. *Performance* deficits may be seen when the individual can discuss the skill, list what to do or demonstrate it in practice, but he or she does not consistently exhibit the skill when needed. The individual exhibiting skills only in certain controlled situations or only with familiar people may have difficulty

generalizing acquired skills and therefore may need additional practice opportunities in novel settings with coaching. Furthermore, once the skill has been mastered and generalized, fluency (i.e., the rate and accuracy in which the skill is demonstrated) should be addressed to ensure that the learner can perform the skill quickly enough to use it effectively. Helping the individual to master the skill with automaticity is critical so that they can integrate the skill into their everyday life and navigate an infinite number of situations they may encounter.

Thus, while the 3-D approach for teaching skills provides a simple method for instruction, individuals may need significant supports to effectively use these skills in the natural environment. Utilizing evidence-based strategies to develop these skills will maximize the likelihood of skill acquisition, performance, and generalization (Wong, et al., 2013). These include, but are not limited to, modeling, reinforcement, peer-mediated instruction, social narratives, task analysis, video modeling, visual supports, etc.

Real life practice is crucial for long-term success and increasing levels of independence. The adults providing support need to carefully and systematically plan to fade these same supports (e.g., prompts, reinforcement procedures) as appropriate. Thus, there is a fundamental difference between shadowing and monitoring progress compared to hovering. Individuals with autism need guidance to identify what is important to them (e.g., living independently, socializing with peers, leisure activities), to set short- and long-term goals that correspond to these

(e.g., obtaining and maintaining employment, using public transportation, participating in clubs), and developing the associated skills to successfully move toward these valued paths. For many individuals on the autism spectrum, much adult support is necessary to help identify these areas. Yet, with a focus on the future, a commitment to present actions, and a well-developed plan, the transition (and journey) to and through adulthood may be more successful.

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**Evaluation from page 1**

language level (Gotham, Pickles, & Lord, 2012), cognitive abilities (Bishop, Richler, & Lord, 2006; Matson & Shoemaker, 2009), and whether or not they have comorbid psychological or medical conditions (Grzadzinski, Huerta, & Lord, 2013).

*Impairments in Social Communication and Social Interaction* - Deficits in social communication and social interaction are core features of an ASD diagnosis, with subcategories including: (1) impairment in social response, (2) deficits in nonverbal communication, and (3) difficulty with or understanding relationships (American Psychiatric Association, 2013). Children with ASD show deficits in their ability to use verbal and nonverbal communication behaviors when regulating social interactions and simultaneously often have difficulty understanding social relationships at the level anticipated for their age. Examples are provided in table 1.

When considering an ASD diagnosis it is important to understand how a child's social and communication impairments manifest within a broader developmental picture and how impairments vary across settings. For example, a young child might initiate eye contact more frequently with a parent than a teacher. Similarly, it is common for young children with autism to direct positive social communication behaviors (e.g., pointing, eye contact, vocalization) towards an adult in a situation where the child is highly motivated to get something (e.g., snack, toy) but less so during pragmatic contexts that are solely related to shared interest (e.g., showing or giving toys to others). In addition to considering context, it is also important to consider moderators such as language level.

A child's language skills will affect symptom presentation. Young children who have largely met language milestones (e.g., obtained phrase speech by 30 months) may seemingly appear to be on target developmentally because they have the ability to speak. Most often however they have seemingly subtle but atypical features to their language development. A verbally fluent 2.5 year old may talk at length about factual information related to a highly specific topic but simultaneously not respond appropriately to basic questions about personal experiences.

*Presence of Restricted and Repetitive Behaviors (RRBs)* - Restricted and Repetitive Behaviors (RRBs) are the second set of core symptoms of ASD (American Psychiatric Association, 2013). Per the DSM-5, there are four types of RRBs, including: (1) Stereotyped and repetitive behavior; (2) Inflexibility; (3) Restricted or fixated interests; and (4) abnormal response to sensory stimuli. How these symptoms manifest into observable behavior can vary greatly. Examples are provided in table 2.

Research has shown that RRBs are generally present in young children with ASD and stable across time as a child enter preschool (Joseph, Thurm, Farmer, & Shumway, 2013; Kim & Lord, 2010; Morgan, Wetherby, & Barber, 2008). However, identifying RRBs is sometimes a challenging endeavor. It is sometimes difficult for a parent to recognize an RRB as a symptom of ASD, especially if their child is young and has not yet entered structured social settings, such as nursery school. If a parent does not recognize an RRB as a symptom



**Bethany Vibert, PsyD, So Hyun Kim, PhD, and Cynthia Martin, PsyD**

of ASD it is unlikely the parent will report the behavior as a problem to a clinician. Children with ASD will not all display the same RRBs (Bishop et al, 2013; Kim & Lord, 2010; Morgan, Wetherby, & Barber, 2008). It is possible that a child with ASD will never display the RRB that a parent may more readily associated with an ASD diagnosis. For instance, parents may unintentionally place more weight on certain behaviors, such as repeated hand flapping, and discount other repetitive behaviors such as a highly focused interest in vehicles. However, from a diagnostic perspective, all types of RRBs are equally weighted and a child only needs to have two clear RRBs to meet criteria for an ASD diagnosis.

Moreover, it is important to keep in mind that the initial manifestation of RRBs may not be concerning or appear overly unusual because they may seem age-appropriate (e.g., a two year old boy who likes trucks). Other times, parents and other professionals might mistake an RRB for a sign of intellectual giftedness (e.g., an 18-month-old who can recite the alphabet and form words with magnetic letters). Unfortunately, even seemingly "harmless" RRBs can become problematic to a child's development over time. Engaging in repetitive actions with toys or objects (e.g., spelling words on the refrigerator with magnets for a significant portion of the day), becoming over focused on a particular topic (e.g., frequently talking about trucks or dinosaurs), or being inflexible with change (e.g., extended tantrum because one of the letters is missing) can negatively affect a child's ability to interact with other children and to succeed in structured settings such as preschool.

Evaluations at the Center for Autism and the Developing Brain (CADB)

Given the complexity and heterogeneity in an ASD diagnosis, we find that parents and children benefit from comprehensive evaluations that integrate multiple sources of information such as parent interviews and clinician observations (Kim & Lord, 2012; Risi et al., 2006). Evaluating a child across different contexts allows for comprehensive assessment of the child's cognitive, language, motor, social, and adaptive functioning (Lord & Jones, 2012). Given that these skills can moderate a child's autism symptoms and affect prognosis, we find it necessary to evaluate all facets of a child's functioning. By understanding how symptoms of autism fit within the larger developmental picture of the child, it helps the family better understand how autism is individually affecting their child, which can guide decisions about treatment.

*Parent Interview.* It is not enough to read a list of symptoms to parents asking if the child meets diagnostic criteria (Stenberg et al., 2014; Weitlauf et al., 2015). Studies support improved accuracy in diagnoses with the use of standardized assessment tools and parent interviews in conjunction with child assessment measures (Lord & Jones, 2012). The Autism Diagnostic Interview, Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) is an example of parent guided assessment tools that provide comprehensive and historical accounts of autism-related symptomatology. Additionally, adaptive behavior measures such as the Vineland Adaptive Behavior Scales, Third Edition (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) provides important information about a child's every-day functioning in areas such as communication, daily living, and socialization.

*Child Testing.* Although parents' account of their child's symptoms is important, relying solely on parent report can decrease the accuracy of an ASD diagnosis (Taylor et al., 2014), resulting in both false-positives

(Charman et al., 2007; DiGuseppi et al., 2010; Hus et al., 2013) and false-negatives (Taylor et al., 2014; Mazefsky, Kao, & Oswald, 2011; Eaves, Wingert, Ho, & Mickelson, 2006). Thus, direct testing and observation of the child is an important component of the evaluation process (Lord & Jones, 2012). The use of standardized diagnostic measures and observations to directly assess the child's social, communication, play, and behavioral functioning within the context of common social situations are recommended by the New York State Early Intervention Program (NYS Department of Health, 2017). The Autism Diagnostic Observation Schedule-2 (ADOS-2; Lord et al., 2000) has been considered one of the gold standard diagnostic measures, which has shown high sensitivity and specificity for an ASD diagnosis when administered by a trained and reliable clinician (Gotham, Risi, Pickles, & Lord, 2007; Hus & Lord, 2014; Kim & Lord, 2012). Additionally, measures such as the Mullen Scales of Early Learning (MSEL; Mullen, 1995) or Differential Ability Scales, Second Edition (DAS-2; Elliot, 2007) can be used to capture the child's language level as well as cognitive and motor functioning.

**Future Directions**

*Using assessment to evaluate treatment progress* - Standardized tests of cognitive, language, and adaptive functioning can be repeated following treatment to assess for gains. Measuring progress in social, communication, and play skills is more challenging. The ADOS-2 may not be sensitive enough to detect subtle changes in social communication symptoms over time in children receiving intervention (Anagnostou et al., 2015), although use of the ADOS

*see Evaluation on page 30*

Table 1. Examples of Impairments in Social Communication & Social Interaction

Impairment in social response	Deficits in nonverbal communication	Difficulty with relationships
<ul style="list-style-type: none"> <li>Limited or inconsistent responding to name.</li> <li>Resisting physical contact or physical contact is mostly on the child's terms.</li> <li>Confusing personal pronouns (e.g., saying "you" instead of "I").</li> <li>Giving unrelated answers to questions.</li> <li>Poor conversational skills.</li> </ul>	<ul style="list-style-type: none"> <li>Limited or lack of pointing or not responding to pointing.</li> <li>Few or no use of gestures (e.g., does not wave goodbye or waves only when prompted).</li> <li>Inconsistent eye-contact or eye contact that is mostly on the "child's terms."</li> <li>Poor joint attention.</li> <li>Having flat or inappropriate facial expressions.</li> </ul>	<ul style="list-style-type: none"> <li>Limited interest in peers, preferring to play alone.</li> <li>Not share interests with others (showing/giving toys).</li> <li>Interacting primarily to achieve a desired goal (e.g., to request).</li> <li>Difficulty recognizing social cues.</li> <li>Difficulty changing behavior to fit the situation.</li> </ul>

Table 2. Examples of Restricted and Repetitive Behavior

Stereotyped and repetitive behavior	Inflexibility	Restricted or fixated interests	Abnormal response to sensory stimuli
<ul style="list-style-type: none"> <li>Lining up toys or other objects.</li> <li>Using toys or objects in nonfunctional ways (e.g., holding but not using).</li> <li>Using repetitive or idiosyncratic phrases.</li> <li>Echolalia of speech.</li> <li>Flapping hands, rocking body, or spinning self in circles.</li> </ul>	<ul style="list-style-type: none"> <li>Being very particular about how toys and personal belongings are arranged.</li> <li>Getting upset by minor changes.</li> <li>Having to follow certain routines.</li> <li>Playing with toys the same way every time.</li> <li>Insisting on eating the same food or wearing the same clothes, daily.</li> </ul>	<ul style="list-style-type: none"> <li>Having strong interests that are unusual for the child's age (e.g., an 18-month-old who fixates on numbers, or a 4-year-old who memorizes international transit systems).</li> <li>Having intense interests, even if age appropriate (e.g., trucks for a 2-year-old, baseball for a 10-year-old).</li> <li>Focusing on parts of objects (e.g., wheels).</li> </ul>	<ul style="list-style-type: none"> <li>Visually examining toys or objects, looking from the side of one's eye.</li> <li>Fascination with sounds, bringing objects to ear.</li> <li>Repeated smelling of objects.</li> <li>High pain tolerance, not bothered by falls.</li> <li>Sensitivity to light, daily noises, or textures (e.g., clothing, certain foods).</li> </ul>

**DSM-5 from page 6**

unexpected given that the behaviors assessed on these scales are consistently reported in both populations. Importantly, the youth with ADHD were not rated higher than the youth with ASD on these scales. This finding indicates that problems with attention and self-regulation were just as severe in the ASD group as they were in the ADHD group. The majority of the effect sizes for the significant effects were large (mean  $d = 1.01$ , ranging from 0.48 to 1.44 across the two forms). Not surprisingly, the effect sizes for the non-significant planned comparisons were very small, with minimal effects between the ASD and ADHD groups on both the Self-Regulation and Attention scales.

In this sample of over 400 children with ASD and over 250 children with ADHD, we found nearly identical scores for behaviors related to poor self-regulation. These findings suggest that problems with self-regulation are as severe in the ASD group as in the ADHD group. We further found that children with ASD and ADHD, while demonstrating somewhat similar behavioral profiles for problems with attention, hyperactivity and impulsivity, demonstrated different neuro-cognitive profiles. Children with ADHD appeared to have significantly more problems with behaviors associated with planning while those with ASD appeared to have significant more problems with attention to relevant detail.

Based on these data, the following clinical guidelines are recommended:

1. Diagnosticians must appreciate that DSM-5 conditions such as ASD and ADHD are diagnosed based on behavior not etiology or neuro-cognitive abilities. Multiple causes can be related to similar behaviors diagnostic of ADHD and ASD. The data set generated thus far strongly suggest the following:

- (a) Youth with ADHD and ASD have different behavioral profiles or behaviors

related to social communication and unusual behavior but are essentially identical in patterns of problems related to behavioral self-regulation.

- (b) Youth with ASD and ADHD have different neuro-cognitive profiles. As a group, those with ADHD have poor performance on tasks involving planning. Youth with ASD perform poorly on tasks of attention.
  - (c) These findings suggest that youth who have many behavioral symptoms associated with ASD also show evidence of severe limitations in selective sustained and shifting attention.
  - (d) Our findings also support that children with ADHD demonstrate a different neuro-cognitive profile than those with ASD. Youth with ADHD were poor in planning while those with ASD were poor on tasks of attention.
  - (e) Most importantly, youth with ADHD and ASD combined experienced problems related to two components of executive function deficits (planning and attention), a phenomena that has been well understood and appreciated for many years.
2. Diagnosticians, educators and parents need to be aware that the process of assessment and diagnosis are two very different phenomena. The diagnoses of ADHD or ASD are dependent on meeting certain behavioral criteria defined in the DSM-5. These criteria are polythetic in that not all children demonstrate all symptoms. These diagnoses are necessary, however, but not sufficient to develop an understanding and appreciation of the data needed to design effective intervention.
  3. There is an important line of intervention research to help children develop better planning and attention

strategies. These cognitive approaches to behavioral change are increasingly researched, manualized and have demonstrated effectiveness. When these strategies are applied with fidelity, children with these ability weaknesses function better.

4. Medications to treat ADHD appear to be equally effective in improving self-regulatory problems in children with ASD. Thus, the increasing number of youth taking stimulants and related medications for ASD is not unexpected (Jahromi, Kasari, et al., 2009).
5. Non-medication interventions including activities such as skill building and strategy application are particularly beneficial when parents, educators and mental health professionals apply teaching these strategies with fidelity (Antschel, Polacek, McMahon, et al., 2011).
6. There is no peer reviewed available data to suggest children with the combined diagnoses have a unique set of differential traits.
7. There is no scientific data to suggest that children with the combined diagnoses experience more problems with anger, anxiety, depression or any other types of adverse, internalizing or externalizing behaviors.

Readers interested in further exploring diagnostic processes and current treatment are referred to Goldstein and Ozonoff (2017) and Goldstein and Naglieri (2013).

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**Employment from page 21**

communication and stereotypic behavior. Even if individuals with autism are employed, it is more challenging for these individuals to maintain their employment status due to issues surrounding their disability.

Social skills are vital to be able to interact with customers and co-workers and maintain employment. Special education teachers may refer to social skills in the workplace as the "soft skills" of work. Individuals with autism are held to similar standards as individuals without disabilities when in the work force. For example, it would be expected for any individual (with or without autism) to greet his/her co-workers and interact with his/her boss on a regular basis. Many individuals with autism have communication difficulties, despite the importance of social skills across all domains of functioning. One study found that for individuals with autism, having a high degree of social skills made it 5.4 times more likely for them to obtain competitive employment, when other factors were held constant (Chiang et al., 2013). This notion stresses the importance of focusing on social skill development for students with autism while they are still in high school, as social skills could make all

the difference in terms of employability for individuals with autism.

Another factor that effected the likelihood of individuals with autism obtaining gainful employment was the number of years that had passed since their high school graduation. This theme was found in many research articles that were reviewed. Typically, the first two years proceeding high school graduation is the time period in which individuals with autism are least likely to have gainful employment. Cameto (2003) found that individuals with autism had an employment rate of 15% the first year after high school. Similarly, Taylor and Seltzer (2011) discovered that young adults with autism who had recently graduated from high school had competitive employment rates of 17%. In one study, four years had passed since individuals with autism had graduated from high school and their rate of employment was 37% (Newman et al., 2009). Six years after individuals with autism graduated high school, 55% of these individuals had remained gainfully employed (Shattuck et al., 2012). These findings are particularly interesting because one may believe that at the culmination of high school, individuals with autism are best equipped to apply for a job, participate in a job interview, or have an updated

resume of prior work experiences while in high school. Despite this idea, these studies indicate that as years pass since high school graduation, individuals with autism are more likely to enter competitive employment, though it is unclear why.

Even if individuals with autism are competitively employed, their rate of pay is below that of their typical peers'. In 2007, the Department of Labor in the United States reported that the minimum hourly wage was \$8.03; however, the average rate of pay per hour for individuals with autism was \$7.90, which is below the national hourly wage (Chiang et al., 2013). Despite the difficulty in obtaining competitive employment due to social deficits or behavioral problems, individuals with autism do not always earn the same rate of pay for their work as their typical peers.

Although more individuals with autism are employed today than ever before, our work is not done. Overall, communities must value the importance of post-secondary employment for individuals with autism and treat them fairly. As a society, we must embrace the unique individuality of individuals with autism and all disabilities, and enable and encourage these individuals to enter competitive employment. When individuals with autism are gainfully em-

ployed, there are endless benefits for all.

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**Necessary from page 13**

that a diagnosis will increase fear and trepidation on the part of potential employers or community members. The knowledge could lead to false worries about behavioral instability, aggression, or unpredictability. Parents might feel that their child's level of acceptance by the community could be diminished by the knowledge of the diagnosis.

Diagnosis, however, has real utility for learners with ASD, at all ages. A specific diagnosis opens the door to specialized services that are designed for learners with that particular designation. For example, a diagnosis of ASD in early childhood will lead to a recommendation for applied behavior analysis (ABA). Specifically, providers will recommend early intensive behavioral intervention (EIBI), which will lead to the greatest gains. A specific diagnosis of ASD will also help to highlight the essential features that require intervention. It orients providers to the need to focus on social skills, on communication, on behavior regulation, and on skill acquisition across the wide range of adaptive and life skills. It also points providers in the direction of evidence-based interventions that have been associated with success with that population of learners. In the case of ASD, it may point clinicians toward the use of PECS, activity schedules, mand training procedures, discrete trial instruction, task analysis and chaining, incidental teaching, and other naturalistic procedures. For older learners, it will send clinicians in the direction of daily living skills, independence, and functionality and functional skill development. It will also highlight the need to focus on choice and independence and on the assessment of quality of life. In employment contexts, a diagnosis can be used to help others understand behaviors that may occur under stress, supports that will increase success, and social interactions that will lead to successful integration into the workplace.

In addition, diagnosis helps with the attributions others make to the behaviors associated with ASD. In the absence of a diagnostic framework, behaviors associated with ASD might be interpreted as volitional, oppositional, or as associated with a conduct disorder. Teachers may view the learner as deliberately defying

teacher instructions. They may view inconsistent demonstration of skills as purposeful as well, rather than as an indication of the fragile ability to demonstrate skills regularly. Parents who hear of a child's misbehavior may view the child as a bad influence or as a poor listener. They may discourage their child from forming social relationships with a poorly behaved child who they perceive as capable of making better choices. Indeed, peers also may be impacted in ways that reduce the likelihood of forming connections. They may view an unresponsive or inconsistent peer as disinterested in social connection, as preferring to be alone, or as disliking them personally. In the absence of an explanation, co-workers of adults with ASD may perceive a person with ASD as unusual, annoying, or threatening.

In other words, the explanations that others will make may not be maximally compassionate toward the individual with ASD. Instead, they may falsely attribute much more intent to the person with ASD than is appropriate or accurate. With an understanding of the diagnosis and its associated features, there is a higher likelihood that the person with ASD will be interpreted in the context of the diagnosis when appropriate. Perseverative responding or behavioral escalation will be understood to be a manifestation of ASD. Similarly, social responses that are odd, awkward, or inappropriate may be seen as circumstances in which the social conventions or expectations were not understood by the person with ASD.

With the contextual understanding of the diagnosis, fear and stigma are dramatically lessened. In addition, learning opportunities are identified. Supports may be put in place to avoid additional challenges in similar circumstances. Additionally, many community contexts and employers are happy to welcome people with disabilities into their settings as part of a broader mission to assist those in need and to provide opportunities for those with disabilities to meaningfully integrate into the local community.

An additional layer of diagnosis for families of people with ASD is the exploration and sharing of additional diagnoses that can further complicate the needs profile of the individual with ASD. Autism is associated with a variety of medical and psychiatric vulnerabilities that can lead to additional

behavioral challenges. Anxiety disorders are particularly prevalent and need specific intervention to ensure that they do not pose too much interference (e.g., Chok & Koesler, 2013; Leyfer et al., 2006). This is another area where families may struggle with whether such diagnoses are truly important to obtain. In general, the identification of concomitant medical diagnoses or psychiatric disorders helps to further refine treatment packages to ensure that all needs are accounted for.

#### Suggestions for Clinicians Working with Families of Individuals with ASD

1. Focus on the individual with ASD and ensure that the assessment and plan reflect their unique characteristics;
2. Consider both the pros and cons of sharing the diagnosis with educational and vocational settings;
3. Link the diagnosis and the unique ways in which it is manifested in this individual to supports that can increase success in the setting;
4. Involve the individual with ASD in the process as appropriate, and especially as adults; and
5. Seek treatments for ancillary psychiatric and medical diagnoses to ensure comprehensive treatment and the addressing of all relevant needs.

Diagnosis is always a double-edged sword for families. The definitive label of the specific disability of ASD brings both opportunity and limitations. An appropriate diagnosis often leads to specialized treatment that enables maximal skill acquisition and rapid reduction of challenging behaviors. It also provides access to evidence-based instructional procedures that maximize outcome. A diagnosis is also explanatory, serving to confirm suspicions, fill in gaps of understanding, provide information about course and prognosis, and provide a road map for effective intervention.

Even at later ages, a diagnosis helps to target interventions and supports that assist in attaining lifelong goals. Specifically, in adulthood, when services are no

longer entitlements, a diagnosis can help gain access to funding sources for services that are now eligibility based. At all ages, informing others about diagnosis ensures that others in the person's world understand the unique ways in which autism affects this individual's behavior. This can prevent misattributing behaviors that are part of the disability to personality, willfulness, or intentionality.

An understanding of how the disability can pose social, communication, behavioral, and functional challenges can alleviate the extent to which community members misunderstand the behaviors exhibited by those with ASD. Accurate diagnoses assist in putting behaviors in context, which can lead to compassionate responses and the provision of effective, ongoing supports and services.

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### Play Therapy from page 19

learned during play therapy to other situations and settings. Even with the limitations, child-centered play therapy has merit and deserves further investigation.

So what can we glean from the extant literature? For one, researchers are in the initial stages of determining whether play therapy is an effective intervention for children with autism. In order to recommend play therapy as an evidenced based intervention, researchers need to conduct better-designed research - more participants, play therapy as a sole intervention, assessing the impact of play therapy on behaviors over time, and stronger experimental designs - that allows us to confidently state behavior change was caused by play therapy. While the five studies did not show a discernible effectiveness of play therapy, the findings highlight the need for continued research into the potential effectiveness of play therapy for children with ASD.

Second, the theory behind play therapy makes it suitable in addressing some of the core difficulties exhibited by children with ASD (Ray, Sullivan, & Carlson, 2012) such as limited social interactions and communication difficulties. With play therapy, children have the opportunity to develop trust with the therapist and feel comfortable. Once a child feels safe, he or she may be motivated to engage socially with the play therapist, eventually generalizing his or her skills to home and school environments.

Third, a benefit of play therapy is that parents can take an active role. Parents can be included in play therapy sessions and over

time take on more of the therapist duties or conduct play therapy sessions at home. Hence, play therapy may be a cost effective intervention while also helping parents build stronger relationship with their children.

Fourth, behavioral interventions and play therapy can supplement one another. Play therapy allows children to practice communication and social skills in a relaxed environment. Child-centered play therapy does not teach children to play, but allow children to explore their own mode of playing at their own pace while developing social skills. A benefit of this is children may engage in spontaneous imitation of the parent or the therapist playing with them.

Fifth, using child-centered play therapy as an adjunctive intervention with behavioral interventions is likely to be effective because play therapy taps into areas of behavior - such as attachment behaviors and spontaneous play - not easily reached by behavioral interventions. If nothing else, it is likely children on the autism spectrum can benefit in some way from play therapy.

Over the years there has been growth in the research and understanding of children with ASD. As the number of children with ASD has grown, so have the number of interventions. It is vital for parents and professionals to learn about evidenced-based interventions when considering interventions for children with ASD so they are not wasting precious time and resources on ineffective interventions.

Child-centered play therapy may in the future become an evidence-based intervention, but for now it is too early to tell. More research on the efficacy of child-centered

play therapy needs to be conducted. Overall, this review provides a launch pad for extending the conversation on how we can incorporate play into effective interventions for children with ASD. Since play is central to the developmental of all children, and some children with ASD have deficiencies in play, it is important to look at methods of using play in future interventions for children with ASD - either using play therapy as a stand alone intervention or in conjunction with evidence-based behavioral interventions.

For more information about this article you may contact Heidi Hillman at [hhillman@ewu.edu](mailto:hhillman@ewu.edu).

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### Your Child from page 21

progress and to learn which activities may help engage the child and spur development. The CDC Milestone Moments resources are geared to children under five. A developmental tracking app is also available. Additional Resources:

- Milestone moments birth-age 5 years (English): [www.cdc.gov/ncbddd/actearly/pdf/parents\\_pdfs/milestonemoment-seng508.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/milestonemoment-seng508.pdf)
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### Get Involved in Recreation

Recreation can provide opportunities for socialization, promote wellness and build lifelong leisure skills. Recreation programs may be under ADA requirements to provide inclusive programming and supports. Some families seek recreation programs that are geared exclusively for children with special needs, while others prefer programs serving all children, with supports as needed. Resources include town and county recreation departments, YMCA/YWCA, scouting programs, and other public and private agencies.

### Sharing the Diagnosis with Others

Deciding when to discuss the diagnosis

with the child is an individual decision and influenced by the child's developmental age. It may be helpful to shape the discussion around how people have differences and similarities, strengths and challenges. The term for the child's pattern of strengths and challenges is ASD. While people with ASD have some things in common, they are all different.

It is often helpful to share the diagnosis with relatives, coaches, and others routinely involved with the child to ensure they have accurate information and to enlist their support. Additional resource:

- Partial list of books for children about ASD - [www.appliedbehavioranalysisprograms.com/30-best-childrens-books-about-the-autism-spectrum/](http://www.appliedbehavioranalysisprograms.com/30-best-childrens-books-about-the-autism-spectrum/)

### Kohl's Autism Awareness Community Hub

This site operated by Children's Specialized Hospital provides a comprehensive variety of videos, resources, educational programs, and apps offering helpful tips and resources related to dealing with challenging behaviors, safety, inclusion, school, recreation, healthcare, and many other areas. Many of the resources are in Spanish as well as English. To learn more, visit [www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)

For more information, contact Jill Harris at [jharris@childrens-specialized.org](mailto:jharris@childrens-specialized.org), phone 908-301-2525 or [www.childrens-specialized.org/autism](http://www.childrens-specialized.org/autism).

### Evaluation from page 27

was previously encouraged for this purpose (Cunningham, 2012; Matson, 2007). In response to the need for a measure of treatment response that adequately captures changes in social communication in ASD, the Brief Observation of Social Communication Change (BOSCC; Grzadzinski et al., 2016) has been recently developed and validated based on 56 minimally verbal children with ASD, ages 1-5. The BOSCC is currently being used to assess short term changes in social communication skills in the Early Intervention program offered at CADB. Currently, we have noticed changes over a 6-month period across cognitive, language, adaptive functioning, social communication and

RBRs and are looking to validate those changes using the BOSCC (Vibert et al., under review).

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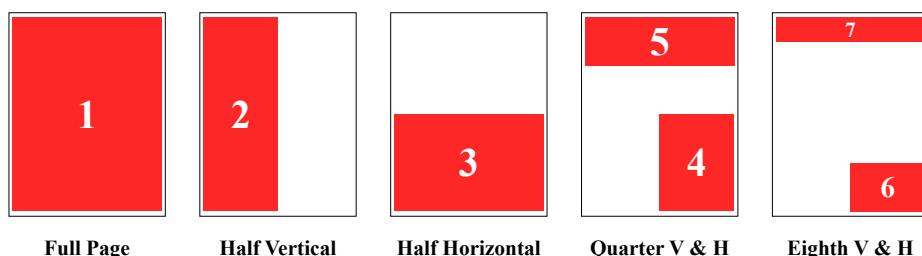
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