

The Latest Advances in Autism Science

Key Advances in Autism Research

By Carrol T. Longshore, MD
Metro Community Health Centers, Inc.

Over the past decade, there has been a great deal of research dedicated to understanding the underlying etiology of Autism. There have been tremendous strides in the knowledge of the genetics, neuroanatomy, neurobiology and ultimately biochemical aberrations of this disorder. Additional research in these areas will lead to more comprehensive and effective treatments. As autism is most probably a neurodevelopmental disorder, the understanding of the genetics is crucial.

Genetic abnormalities can arise from single gene disorders, copy number variants and many other chromosomal variants. It is known that the concordance rates are much higher for autism in monozygotic as opposed to dizygotic twins. Recent new techniques such as CMA's, or chromosomal microarrays, have allowed molecular investigations. Various abnormalities as well as susceptibility genes



have been found on virtually every chromosome. Most of these genes are probably involved in brain development and synaptic formation, remodeling and ultimate brain metabolism. Ultimately, a wide diversity of genetic disorders has been as-

sociated with Autism Spectrum Disorders (ASD). Some patients may in fact have cumulative genetic effects related to the load of common risk variants (Cyrille, Laurent, Cohen, Fradin, Canitano, Damaj, Odent & Tordjman, 2017).

In addition, rare genetic abnormalities may result in up to 30% of ASD cases. These genes may be inherited or occur de novo. Unlike schizophrenia, no common risk loci have been found for ASD. Discovery of rare variants of the disorder can lead to the discovery of targeted therapies intended to modulate clinical outcomes in a positive fashion. Ultimately, genetic findings will be translated into clinical treatment (Vorstman, Parr, Moreno-De-Luca, Anney, Nurnberger, & Hallmayer, 2017).

There are several interesting correlations between schizophrenia and ASD. The two disorders have similarities both with regard to their underlying neurobiology and behavioral phenotypes. There are a number of recent studies comparing E/I imbalances. These excitation-inhibition imbalances when elucidated from noninvasive imaging studies can lead to molecular treatment targets. It appears that glutamatergic and GABAergic circuit abnormalities are prominent in these illnesses. In effect there are microcircuitry abnormalities. These

see Advances on page 18

New Treatment Directions for Autism Spectrum Disorders - Neuromodulation

By Eric London, MD
Director, Autism Treatment Research
NYS Institute for Basic Research
in Developmental Disabilities

Much of our psychiatric and neurologic knowledge is based on a "lesion model." When there is an intact nervous system and something happens, such as a stroke or bleed, some tissue is destroyed and deficits may remain. In autism and related developmental disorders, instead of one discreet area being the "problem," widely distributed brain circuits are malfunctioning; often without obvious telltale signs. This is the result of abnormal early brain development and leaves the "target" of treatment hard to define.

It has been observed that in individuals with autism, the level of functioning can vary dramatically from day to day (or sometimes hour to hour). For example, many "non-verbal" individuals with autism have blurted out language that their parents were unaware they were capable



Eric London, MD

of. At certain times, individuals with autism appear to learn rapidly while on other days they struggle to learn. Interestingly, when individuals with autism spike a fever, it's been observed that function may

improve. We would not expect to see this with a stroke victim, for example. If a stroke victim lost the use of a leg, we would not see the leg function return for a day and then go away again. The variability seen in autism, in contrast, leads to a hypothesis that brain circuitry is relatively intact but that something prevents their optimal functioning at times (and, perhaps, most of the time). When a person is very tired, that would not be the time for him to attempt a very difficult task and so we wait until we are at a more optimal physiologic state to undertake that task. In a similar way, the concept for autism treatment would be to aim at improving the physiologic environment in which the brain is functioning. This is done naturalistically, by promoting adequate sleep, good food and an environment in which stress is minimized. For many years, behaviorists understood that creating an environment that was not over-stimulating would facilitate better learning. To improve treatments for individuals with autism, researchers and clinicians need to take this concept another step further.

A key sign of autism pathology is the deficit in tolerating and adjusting to change in the environment. The formal diagnosis refers to this as "a rigid adherence to sameness" which explains repetitive behaviors and behaviors seen during environmental changes. Social deficits might likewise be explained by the fact that social skills are based on the need to change the script constantly in response to the person with whom you are interacting. While we do not yet have a full understanding of this problem, one rather attractive hypothesis is that "neuromodulators" responsible for helping the brain adjust to the environment are not functioning adequately.

There is a neurochemical called noradrenalin (also named norepinephrine) which functions primarily as a neuromodulator. That is, it doesn't really send messages from neuron to neuron but rather acts as a *modulator* of the functions of neurons and circuits - turning them on or off, changing the volume, etc. One might conceptualize it as an orchestra conductor

see New Treatment on page 20

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Table of Contents

The Latest Advances in Autism Science

- 1 [Key Advances in Autism Research](#)
- 1 [New Treatment Directions for ASDs - Neuromodulation](#)
- 4 [Research Steps in Establishing Music Therapy as an Effective Treatment for Children on the Spectrum](#)
- 6 [2017 National Autism Indicators Report: 27% of Adults with Autism Using Disability Services Have No Work](#)
- 11 [What Kind of Research Can Guide the Growth of ASD Services?](#)
- 17 [Parental Age Ups Rate of New Mutations Passed to Children](#)
- 19 [NIH-Funded Study Suggests Neuroimaging Technique May Help Predict Autism Among High-Risk Infants](#)

Supporting Individuals with Autism

- 12 [Building the Skills for School Readiness](#)
- 15 [Overcoming Anxiety and Fear in Children and Teens](#)
- 14 [The Lighter Side of the Spectrum: A Vulnerable Child](#)
- 16 [Employing Theater Arts to Enhance the Lives of Individuals with Autism Spectrum Disorders](#)

Supporting Autism Professionals

- 13 [Supporting Employee Professional Development Activities: An Example from a Mid-Size Human-Service Organization](#)

Autism Spectrum NewsDesk

- 8 [New York Institute of Technology's Vocational Independence Program Has Relocated to the NYIT Old Westbury Campus](#)
- 9 [Autism Science Foundation Announces Expansion of the Autism Sisters Project - 3 New Grants Awarded](#)
- 10 [NIH Awards \\$100 Million for Autism Centers of Excellence](#)

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Research Steps in Establishing Music Therapy as an Effective Treatment for Children on the Spectrum

By Alan Turry, DA, MT-BC, LCAT
Managing Director
Nordoff-Robbins Center for
Music Therapy at NYU Steinhardt

Music engages people. Autism advocates have recognized for years that engaging in music making can bring positive benefits to children with autism. The established profession of music therapy, which began in 1950 and currently has over 6,500 board certified music therapists throughout the United States has provided evidence-based treatment for a myriad of people including children on the spectrum. Here at the Nordoff-Robbins Center for Music Therapy at New York University's Steinhardt School, we have been engaging children on the spectrum in music therapy since 1989.

Recently a team of International researchers published a clinical trial examining the effectiveness of improvisational music therapy in reducing symptoms for children with autism (<http://jamanetwork.com/journals/jama/article-abstract/2647867>). Though the findings were disappointing, the path to validating that improvisation is a bona fide evidence-based treatment for children on the spectrum has clearly begun. Early



Alan Turry, DA, MT-BC, LCAT

outcomes studies on recognized treatment modalities often fail to find treatment effects. Early outcome studies in all health fields are typically one-size-fits-all treatment that proceed under the assumption that all therapists, all patients/clients and all therapeutic relationships are created equally. These studies seldom find positive results because the gains of successful therapeutic relationships are negated by the unsuccessful ones. Given that fact, the

finding in this study is *not unusual*. Second generation studies are more able to answer the question: "What treatment-specific benefits occur for which groups of patients under what conditions?"

To take the next step in the research process to establish improvisation as an evidence-based treatment intervention, music therapy researchers need to look carefully at this first generation study to understand the results. From the vantage point of years of clinical experience utilizing improvisation in the tradition of Paul Nordoff and Clive Robbins, who are considered the founding fathers of improvisational music therapy for children on the spectrum, here is my detailed perspective.

Despite its scope and strong experimental design, there were clear limitations with the study which the authors themselves acknowledge. A diagnostic tool (ADOS) was used as the outcome measure rather than an instrument that measures change in functioning or quality of life outcomes. Though the clinical interventions of the therapist were described in this study (synchronizing, mirroring, grounding), there was no discussion of how these interventions were created musically. It is impossible to assess the quality of the music created by the therapist and how effective the musical experience was in engaging the participants in this study.

The ability to listen and respond musically with sensitivity and clinical intention is a specialized skill set. It takes time and experience for music therapists to learn to improvise effectively in clinical sessions. The therapists who participated in the study varied greatly in their years of experience and training. No information was given regarding the quality of the music making or improvisational abilities of the therapists, nor specific training in improvisation, the amount of time they had already been utilizing improvisation in their practice, previous experience working with autistic children, or what kind of supervisory supports they were receiving before becoming part of the treatment team.

The authors of the study also point out study limitations in looking solely at symptom reduction. We agree with the authors that symptom reduction may not be a sensitive or appropriate outcome measure. Functional abilities are more important than reduction of symptom severity and the authors point out that this study only addresses the latter. It was a serious omission that functional gains and improved quality of life were not measured.

There were other limitations as well. The children varied greatly in terms of functioning, particularly around expressive

see *Music Therapy* on page 21

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27% of Adults with Autism Who Use State Disability Services Have No Work or Other Activities - 2017 National Autism Indicators Report

By Frank Otto
A.J. Drexel Autism Institute

A quarter of adults with autism who use developmental disability services are not working or participating in other structured activities during the day, with only 14 percent holding a paying job in the community, according to the A.J. Drexel Autism Institute.

Since 2015, the Institute has produced a National Autism Indicators Report. The past two reports showed that adults with autism have difficulty transitioning into jobs. This year's version, "National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood," delved into the lives and needs of adults with autism who use developmental disability services — an estimated 111,000 nationwide.

"Billions are spent each year on services for people on the autism spectrum," said Paul Shattuck, PhD, associate professor in Drexel's Dornsife School of Public Health and director of the Autism Institute's Life Course Outcomes program, which produces the annual reports. "Relatively little is spent trying to understand the types and amount of services people need, as well as the services they actually end up getting or the outcomes of them.

At a glance — Outcomes of adults with ASD (18-64 years) who received DD services



National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2017. <http://ow.ly/cS4130t0hdA>

This latest National Autism Indicators Report continues our tradition of publishing dashboard-like statistics about how life is turning out across the course of these people's lives."

For the third year of the report, Anne Roux, a research scientist on Shattuck's team, led a group that looked at data from 3,500 adults who used developmental dis-

ability services and took the 2014-15 National Core Indicators Adult Consumer Survey. This is a survey used by some states to monitor the effectiveness of their services.

In addition to the distressing information on lack of work and activities for most recipients the research team found that 25 percent did not believe they were getting the full services they needed.

"This dovetails with our team's earlier reports on the 'services cliff' that transition-age youth encounter when they leave special education but have difficulty accessing services they may need to become employed, continue their education, or live more independently," Roux said.

Families Shouldering Much of the Care

Although respondents indicated that they are using, on average, six different developmental disability services, the report showed that "families are shouldering a lot of care," according to Roux.

Just under half of the survey-takers lived with their parents or relatives, and the majority (81%) had been there an extended time, at least five years. Of this population, 38 percent received no paid, in-home supports.

Reported rates of mental health conditions were high in the survey respondents. Over half had at least one of the measured conditions, like anxiety or mood disorders, and use of psychotropic drugs (six in 10 respondents) was higher than in the population who used developmental disability services but didn't have autism.

There were some inconsistencies that the research team discovered between the survey results and past published findings.

see Adults on page 21

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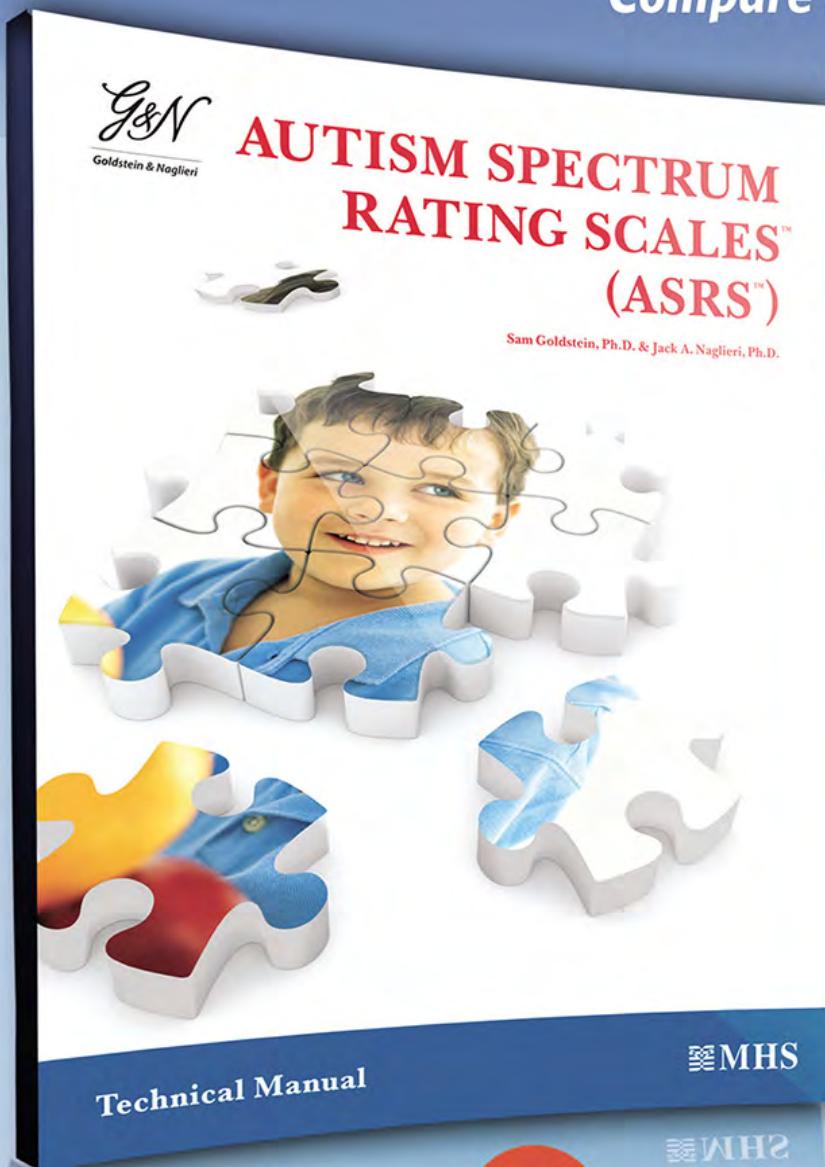
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AUTISM SPECTRUM NEWS DESK

New York Institute of Technology's Vocational Independence Program Has Relocated to the NYIT Old Westbury Campus

By The New York Institute of Technology
Vocational Independence Program
(NYIT/VIP)

It is with great excitement that we share New York Institute of Technology's (NYIT) official announcement: The Vocational Independence Program has relocated to the NYIT Old Westbury campus, located on Long Island's historic North Shore.

The NYIT Vocational Independence Program (NYIT/VIP) will continue to deliver top-quality transition programming as we have since 1987. It will continue to provide a wide array of community-based work experiences, opportunities to engage in credit coursework at NYIT, a comprehensive Executive Functioning, Independent Living and Social/Communication curricula and a robust and individualized system of student support. It has always been the goal to have NYIT/VIP students truly integrated in daily college life. Relocating to Old Westbury has allowed us to realize this goal.



**NYIT/VIP students enjoying the new Old Westbury campus
and all of the amenities and services it has to offer**

The majority of the NYIT/VIP curriculum will be delivered in classrooms located throughout the NYIT Old West-

bury campus. NYIT/VIP students will now enjoy all the services and amenities that the Old Westbury campus offers its

students, including such things as: NYIT libraries, student run clubs and activities, athletic and other campus events, academic resources and other student services. NYIT/VIP has its own residence hall, exclusive to our students, within the residential village.

NYIT/VIP has an 80 percent post-graduation employment rate for the 2017 class. More than a third of the graduating class was hired directly out of VIP-sponsored internships with major corporations in New York, New Jersey, and Washington, DC. VIP offers continuous counseling to our 1,000 plus graduates. Recently, we have placed students in internships in several major hotel chains, retail stores such as Modell's and Marshalls, local restaurants and corporate kitchens, animal hospitals, and other local businesses.

For more information and to schedule a tour of the New York Institute of Technology's Vocational Independence Program on the Old Westbury Campus, visit us at www.nyit.edu/vip or email Walter Mayer at wmayer@nyit.edu.



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AUTISM SPECTRUM NEWS DESK

Autism Science Foundation Announces Expansion of the Autism Sisters Project 3 New Grants Awarded to Search for the Female Protective Effect

By The Autism Science Foundation

The Autism Science Foundation (ASF), a not-for-profit organization dedicated to catalyzing innovative autism research, announced the launch of three new multi-year research grants to expand the [Autism Sisters Project](#) at the University of California at San Francisco (UCSF) and the Broad Institute in Cambridge, MA. The Autism Sisters Project is an ASF initiative that explores the Female Protective Effect by studying autism families with an undiagnosed sister. Multiple lines of scientific evidence now show that females with an autistic sibling may have protective or resilience factors to autism.

For years, scientists have reported higher autism prevalence in males, but the reason for this gender discrepancy isn't fully understood. One potential explanation is the presence of protective factors in females that may be genetic, epigenetic, environmental, or a combination of these. Research has shown that some females carry



Researchers participating in the Autism Sisters Project met to plan and discuss study designs

genetic deletions or duplications that are known causes of autism, yet these girls do not exhibit clinical symptoms of autism.

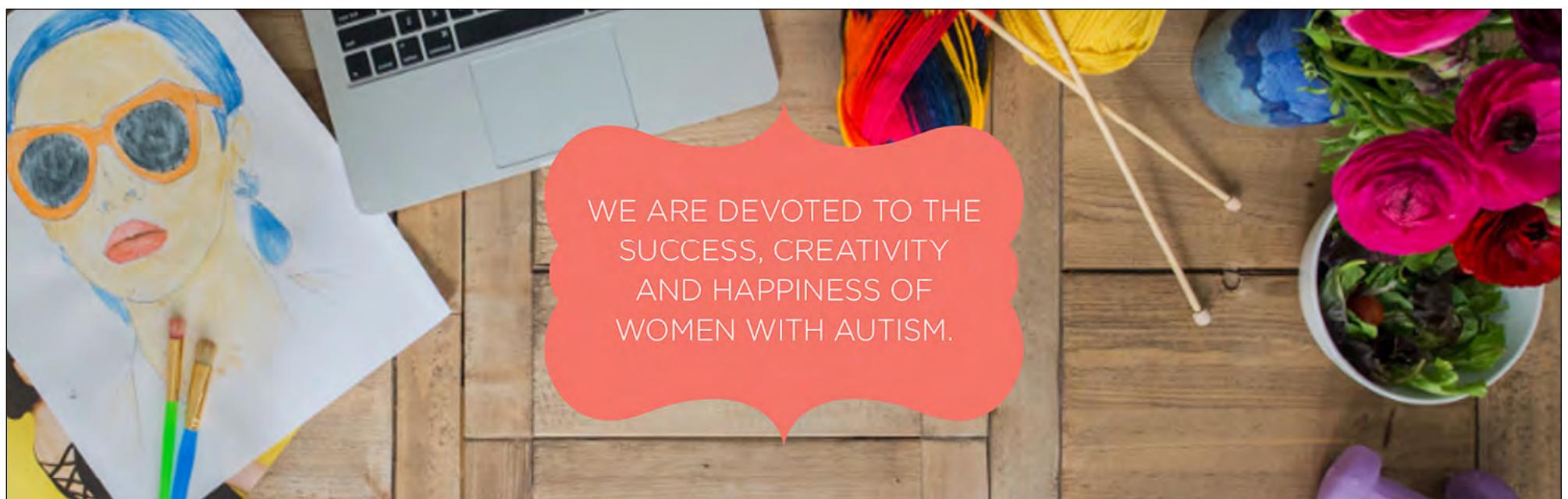
Other studies have pointed to the presence of a higher genetic "load" for females to reach the autism threshold, compared to

males. As a group, girls with autism tend to exhibit more severe symptoms and tend to be diagnosed later. These initial findings warrant a focused study of unaffected sisters of individuals with autism to try to identify this potential protective effect.

The three new research efforts funded by ASF will utilize data collected from families where a sister in the family does not have a diagnosis of ASD. Scientists will analyze thousands of families to understand the association between sex, phenotype and genetic mutation in all family members. Lead researchers will be Drs. Somer Bishop, assistant professor, and Stephan Sanders, associate professor at UCSF, and Dr. Elise Robinson, assistant professor at the Harvard T.H. Chan School of Public Health and an associate member of the Broad Institute of MIT and Harvard.

"We are excited to support this important work, which will help scientists understand not only risk factors, but also resilience factors in autism behaviors, as well as autism features in females," says Alycia

see Sisters Project on page 23



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- The expertise of a friendly staff person
- A community

AUTISM SPECTRUM NEWS DESK

NIH Awards Nearly \$100 Million for Autism Centers of Excellence Program

By The National Institutes of Health

The National Institutes of Health has awarded nine research grants totaling nearly \$100 million over the next five years for the [Autism Centers of Excellence \(ACE\)](#), a program that supports large research projects aimed at understanding and developing interventions for autism spectrum disorder (ASD). The ACE program was created in 2007 from the consolidation of previous programs. Grants have been awarded every five years, and 2017 marks the third cycle of ACE grants.

ASD is a complex neurological and developmental disorder that begins early in life and affects how a person acts, learns and interacts with others.

“Autism spectrum disorder has myriad environmental, genetic, neurological and behavioral components,” said Diana W. Bianchi, MD, director of NIH’s Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), 1 of 5 institutes funding the ACE program. “These awards will allow



Diana W. Bianchi, MD
Director, National Institute of Child Health and Human Development

us to understand how autism differs in girls versus boys, to develop earlier methods of

screening, and to improve treatments based on specific symptoms.”

In addition to NICHD, the NIH institutes that support ACE are the National Institute on Deafness and Other Communication Disorders, the National Institute of Environmental Health Sciences, the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke.

The ACE awards seek to build on discoveries of the last 10 years by supporting innovative, multi-disciplinary research that promises to yield interventions and services for people with ASD. According to the Centers for Disease Control and Prevention, [about 1 in 68 children](#) has been diagnosed with the condition.

The awards will support research at individual centers or at research networks (which involve multiple institutions) dedicated to the study of ASD.

2017 Center Grants

University of California, Davis
Improving ASD Treatments Based on Symptoms, Features

David G. Amaral, PhD, and colleagues will continue their efforts to classify children into different subgroups, based on their symptoms, behavioral characteristics and genetic features and will attempt to develop behavioral and drug interventions appropriate for each subtype. The researchers have found that, by age 3, about 15 percent of boys with ASD have brains that are unusually large relative to the size of their bodies. These boys have a higher rate of regression, or loss of social and communications skills, and are more likely to have an intellectual disability. In contrast, at age 3, only 3 percent of girls with ASD had disproportionately large brains. The researchers plan to follow these children through childhood to determine if the structure of their brains differ from those of typically developing children.

University of California, Los Angeles
Tracing ASD Symptoms to Their Origins

Susan Bookheimer, PhD, and colleagues will continue their efforts to look for clues

See NIH Awards on page 20

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What Kind of Research Can Guide the Growth of ASD Services?

By Peter Doehring, PhD
Director
ASD Roadmap

Most of my 25-year career in ASD has centered on providing services. Throughout that time, I have tried to draw straight lines from research findings to practice, and show how science benefits children with ASD. On the way, I learned is that not all research is equally relevant to service professionals and agencies seeking guidance in helping their students, patients, and clients achieve better lives right now.

Research that evaluates the effectiveness of specific practices is directly relevant because it orients those providing services towards proven interventions. In an outcome research study, a treatment is delivered to people with and/or without ASD under conditions that allow us to attribute any observed improvements to the treatment itself. Ideally, the treatment is delivered to the same kind of people who will participate in the programs we want to improve, and in a manner mimicking real-world conditions.

Several groups have defined objective and rigorous criteria for the amount and quality of outcome research needed to establish a practice as evidence-based (National Autism Center, 2015; Cox et al,



Peter Doehring, PhD

2013; Reichow, Doehring, Cicchetti, & Volkmar, 2011). Each of these groups now includes the single subject experimental designs common to applied behavior analysis in these reviews, dramatically expanding the research that can be used to establish a given practice as evidence-based. These evidence-based practices or EBPs can be prioritized when designing a program for one person or deciding what practices professionals should be trained to deliver.

Consider systematic reviews that have established that a specific technique like differential reinforcement (or DR) is an EBP for decreasing challenging behav-

iors like aggression or self-injury (Savage & AFIRM, 2017). With this knowledge, a professional can confidently design a whole program of services around DR and related EBPs for challenging behavior. The same body of outcome research can suggest answers to specific questions critical to practice, like how to select the best candidates for DR, how intensively DR must be delivered, and how quickly progress might be seen. These answers can also guide decisions about the kinds of professionals needed to design and deliver a program using DR, and the funding needed to do all this. When these same reviews fail to find similar support for other popular techniques like sensory integration (National Autism Center, 2015; Reichow, Doehring, Cicchetti, & Volkmar, 2011), professionals can consider these findings when establishing treatment priorities. As noted by Dr. Sam Odom, Director of the Frank Porter Graham Child Development Institute at the University of North Carolina, "the challenge has been to develop materials, such as the AFIRM modules, that will help the practitioner choose practices wisely and implement them with fidelity."

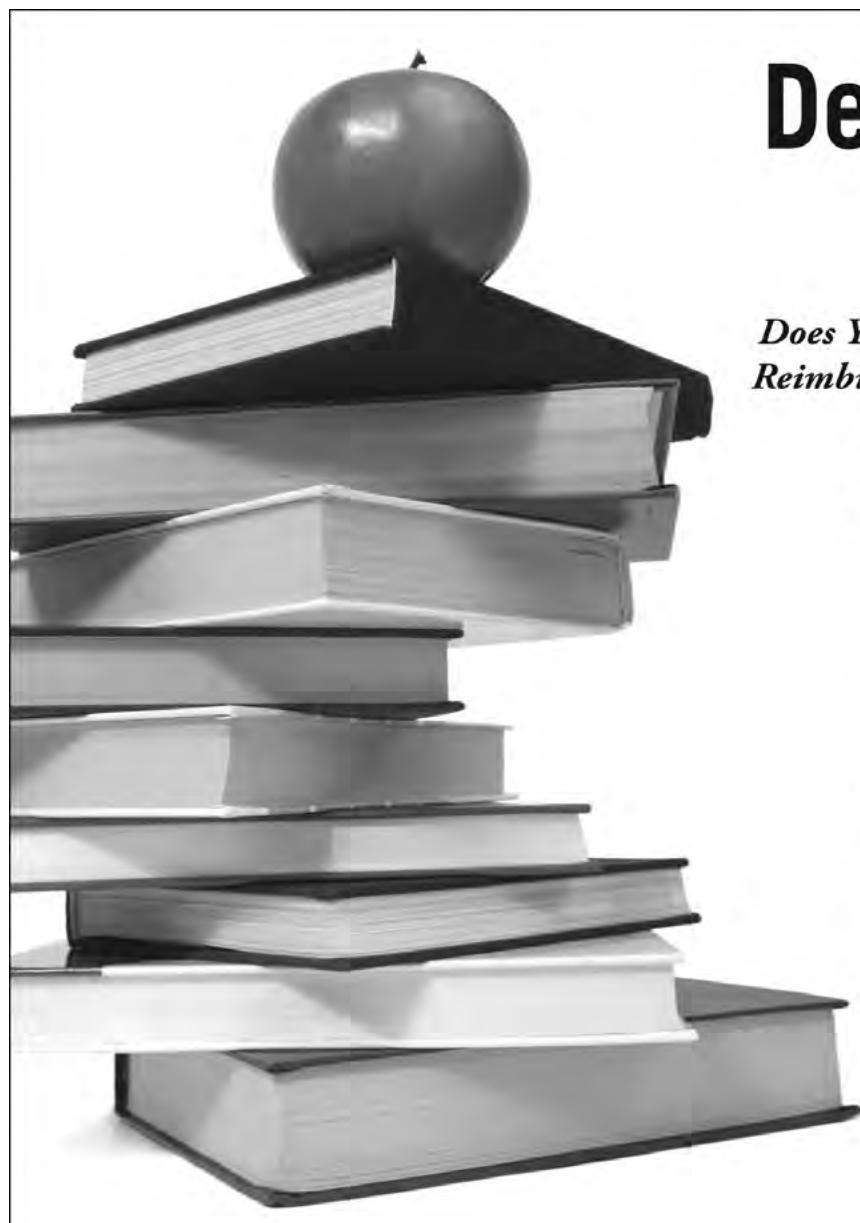
For now, the impact of these EBP reviews is limited: they might establish what treatments are effective and what progress we should expect, but they do not always tell us what outcomes are important to overall success in life. Programs established solely around very specific EBPs

can therefore still miss important life outcomes, and there are many important outcomes for which no EBPs have been established. So practitioners must always carefully identify individualized goals, track progress, and look beyond the available outcome research when there is no response to an EBP or there is simply no EBP available. As noted by Dr. Brian Reichow, Associate Professor in the School of Special Education at the University of Florida, "This is especially important when considering the research literature for individuals with ASD, given the heterogeneity of individuals with ASD and the need to identify and utilize effective treatments at the individual level."

Research that identifies gaps in desired services and quality of life for people with ASD is directly relevant because it orients those setting service-related policy towards areas of critical need. In this kind of research, a population of people with ASD is surveyed with respect to the services they received, the needs they have, and/or the outcomes they achieved. This kind of research can guide decisions about services at every level of delivery.

Consider research that consistently identifies delays in diagnosis for children from underrepresented groups (Dickerson et al, 2017). Using these findings, a service professional might re-assess potential barriers

see ASD Services on page 24



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Building the Skills for School Readiness

By Laura Bonfante, BCBA
Center Manager
Autism Home Support Services

Parents get excited about school starting in the fall and all the new adventures their children will have. They also know starting school can be a shock for first-time students. Getting up early and out the door, a day of sitting still, lining up and switching activities on a schedule isn't easy for young kids.

Parents with children on the spectrum are just as excited for their kids to start preschool or kindergarten. Yet most recognize that the adjustment may be more difficult. School behaviors that are hard for many young children can be even more challenging for kids with autism – especially when all of those behaviors take place in a single day.

A growing number of parents are preparing in advance with therapy designed specifically to help their children make an effective transition to school and build the foundation for future social and academic success. Known as “classroom-readiness groups” or “early learners groups,” these use Applied Behavior Analysis (ABA) to help young children learn the behaviors they'll need to adjust to school and be ready to learn.



Classroom Readiness groups help children learn to focus on a task

ABA has been proven to be the most effective method for teaching age-appropriate skills to children with ASD (Granpeesheh, Tarbox, & Dixon, 2009). The only autism treatment that has been endorsed by the U.S. Surgeon General (1998) and the American Association of Pediatrics, ABA uses positive reinforcement, teaching in small steps and repeated practice to help children develop behavior, language, social skills and other aptitudes (Fani-Panagiotou, 2015).

School Behaviors up Close

The tendency to assume children do things at certain ages – such as starting kindergarten at age 5 – can lead us to overlook the complex behaviors associated with taking those steps.

Going to school requires a host of skills (Pruett, 2017). A child must be able to separate from her parents, follow directions, sit still long enough to focus on a task, and start and stop activities, all

while being in close proximity to peers and teachers.

Each of these involves a number of discrete behaviors. For example, something as simple as standing in line consists of component skills such as following directions, referencing/imitating peer behavior, being aware of personal space and body awareness.

Parents whose children are on the spectrum often hope the school will teach these skills. Preschool and kindergarten undoubtedly focus on classroom behaviors, but often not enough for children with ASD. Further, general classroom teachers usually don't have time to provide the guidance and repeated practice that the one or two children in class who are on the spectrum need to absorb school behaviors.

While not specifically analyzing “school readiness” behaviors, Eldevik and colleagues (2011) found that children receiving ABA-based intervention in a preschool setting made significantly more gains in both intellectual and adaptive functioning skills when compared to children receiving the standard, eclectic approach in a similar setting. Classroom-readiness provides specialized guidance and 20 to 40 hours of therapy each week to teach kids with autism age-appropriate skills they'll need to succeed in school.

see Readiness on page 23



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Supporting Employee Professional Development Activities: An Example from a Mid-Size Human-Service Organization

By Shawn P. Quigley, PhD, BCBA-D
and Mary Jane Weiss, PhD, BCBA-D
Melmark

Individuals credentialed as Board Certified Behavior Analysts (BCBA) are required to obtain 32 hours of continuing education every two years. The purpose of the continuing education “is to ensure certificants engage in activities that will expand and maintain their behavior-analytic skills” (see <https://bach.com/continuing-education/>). According to Code 1.03 Maintaining Competence through Professional Development, professional development is also an ethical obligation for behavior analysts (BACB, 2014). Carr and Briggs (2010) also indicate the Association for Behavior Analysis International (ABAI) position statements regarding effective treatment and education support the need for behavior analysts to participate in continuing education activities.

Reading scholarly literature is a continuing education activity that may sustain or expand competence. Carr and Briggs (2010) evaluated three tasks for maintaining contact with the literature: searching the literature, accessing journal content, and contacting the contemporary literature. The purpose of this article is to discuss how a mid-size human service organ-



Shawn P. Quigley, PhD, BCBA-D

ization has conceptualized supporting the professional development of its employees. Some of the practices are developed in response to Carr and Briggs, and others are based upon the experiences of the authors and practices at the organization. Melmark recognizes that every employee has opportunity for professional development, even those without a credential. However, the strategies discussed in this article are in-



Mary Jane Weiss, PhD, BCBA-D

tended for individuals who already possess a credential associated with a master's degree or higher.

Searching and Contacting Scholarly Literature

Each of the subheadings below describe a process for searching and accessing scholarly literature for employees. Some

of the strategies are restricted by job duties due to resource constraints or other factors (e.g., affiliation with a university). Additionally, some tasks are cost prohibitive to provide to every employee (i.e., access to electronic database) and are limited to individuals with clinical responsibilities that can be enhanced with additional resources. The process of searching and accessing often overlap; therefore, the processes have some similarity.

Searching the literature - All employees are provided an algorithm for searching the literature. 1) Internet search engines are used first for searching the literature. 2) The organization maintains hard copies of previously purchased journals. The journals can be hand searched or an electronic search on the journal website can be performed. 3) BCBA's can access an electronic database and journal subscriptions via their online portal. Similar features might be available through other credentials too. 4) Employees might access search engines via alumni association benefits or if they are currently enrolled in a university. 5) Some employees are provided access to an electronic database (i.e., PsycARTICLES®) and can search materials through that resource. 6) Any individual can request

see *Development on page 25*

PARTICIPANTS NEEDED FOR GENETIC STUDY OF ASPERGER SYNDROME/ASD



What is the purpose of this research?

The goal of this study is to identify genes that contribute to autism spectrum disorder (ASD) and autism-related traits.

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What will I be asked to do?

Participants will be asked to:

- Complete online questionnaires about family history and social skills and behaviors
- Provide a blood sample for genetic testing
- Wear a sleep/activity tracker similar to a Fitbit
- Attend a study visit run by research staff at the University of Pennsylvania for more detailed assessments (optional)

What are the benefits of taking part in this study?

There are no direct medical benefits as a result of participating in this research study. However, your participation could help us better diagnose and treat ASD in the future. Participants will be compensated \$100 for their time.

How do I get involved?

For any questions or to participate in the study please contact:

Leat Perez

Research Coordinator

Phone: 267-542-1717

Email: aspe@uphs.upenn.edu

Website: www.aspe.med.upenn.edu



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

By Carrie Cariello

A Vulnerable Child

When my son Jack was about four years old, I lost him in the mall. I was pulling a sweater on over my clothes to see if it would fit, and in the three seconds it took for me to poke my head through the fabric, he was gone.

One minute, he was there, standing right in front of me with his overalls and his sticky hands from the lollipop he'd gotten when we'd stopped at the bank, and the next minute he was nowhere to be found.

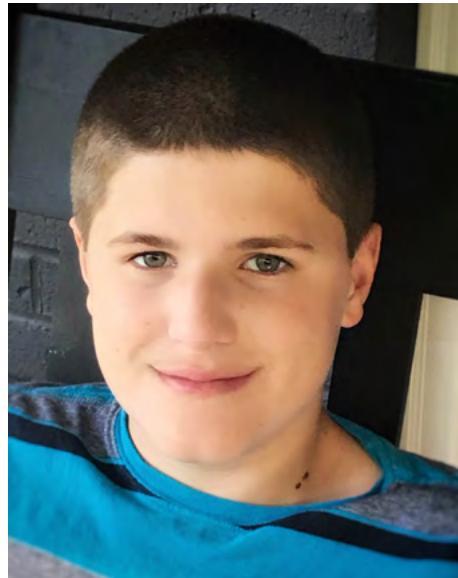
When Jack was four, he couldn't say his own name, but he could start a car.

He didn't know his phone number, or his address, but he knew how to walk out of the doors and into the wide, open parking lot.

He had autism.

He was gone for about eight minutes. When I say this was the most terrifying eight minutes of my life, I am lying, because the word terrifying doesn't begin to describe it. My heart was in my ears and I was sweating and I felt like my head might spin off of my shoulders.

I knew he could be anywhere. I knew firsthand the way a [silent child](#) could slip under the radar—through the door, and into the



Jack Cariello

sunset. I knew, because I'd seen him do it.

Now Jack is thirteen. He still has autism. This makes him very vulnerable in ways most people can't imagine.

For one thing, he can't talk when he's under stress. He literally cannot form the words in his brain and make them travel to his mouth and out into the air. He cannot ask for help.

He is a boy who won't make it out of a

burning building unless someone is right there with him. He will not shout that the water is too deep and he can't touch the bottom, or that a strange person tried to touch him in places no one should touch him.

I worry all the time.

I worry if there's ever a fire in the grocery store and he's standing at the Redbox—he stands at the Redbox every single time we go to the grocery store, and even if I've warned him we aren't renting a movie this time, he still likes to push the buttons and search through the new releases—but if he's standing there while I wait to check out and there's a fire and I can see him and I can't get to him, I know he will never get out on his own.

He'll put his hands over his ears and he will stand completely still, like he's made of stone. He might scream.

I'm scared one day he's going to get run over in a parking lot. I have to [hold his hand](#)—can you even imagine? A boy taller than me and I have to hold his hand when we walk into a store?

The thing is, he has no concept of cars coming and going. He's lost to his own thoughts about strawberry frosting and the latest Disney movie and who even knows what else. He assumes someone will always see him.

He's vulnerable.

He loves popcorn with lots of butter and he says *tick-tock-tick-tock* whenever I put the blinker on in the car. He sleeps with exactly six pillows.

Every year on December 5th, he goes into the basement and brings up the big red boots we bought at Target, and he puts them in the exact same spot by the fireplace. He does this to remind us about [Santa](#).

He is a teenager. He is so painfully naive, it makes my heart ache.

I'm not saying he's dumb—not at all. He's pure, and unguarded, and real. He believes people are good and the earth is round and that cars cost exactly one hundred dollars.

You will never meet another person like him in your life. I guess you could say he's like a like painting full of color and light - a curious mix of red and blue and green that, at first glance, looks like a big old mess.

But then you step back, and you look again. You see each color separately. You look down at your feet and you look up once more, and you realize it is more than a painting. It is a tapestry, and it tells a story about a boy.

see [Vulnerable](#) on [page 16](#)



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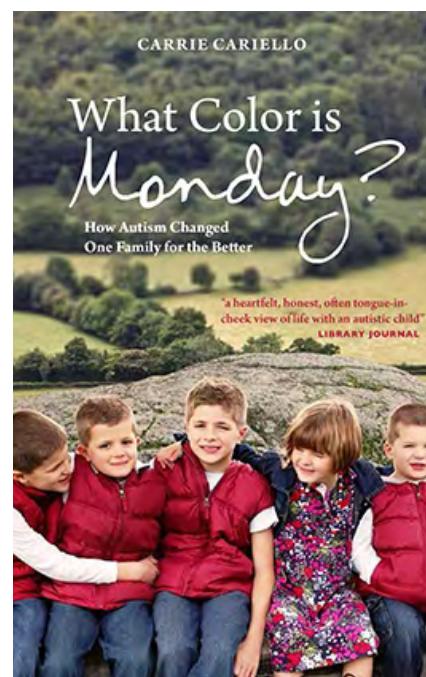
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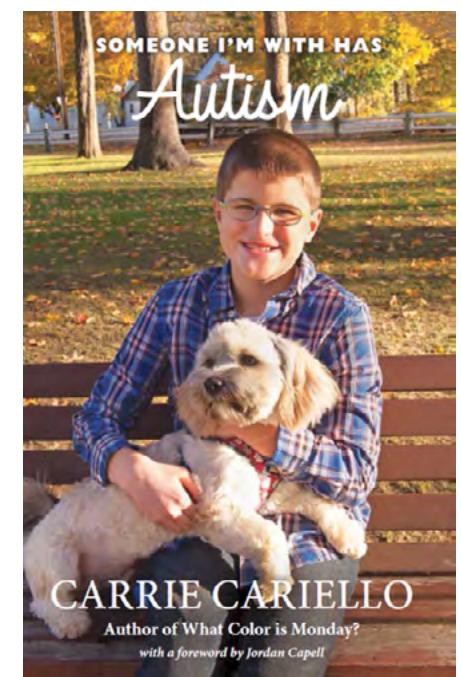


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Overcoming Anxiety and Fear in Children and Teens

By **Jed Baker, PhD**
 Director
 Social Skills Training Project

Study after study has shown that if you can get anxious individuals to gradually face their fears (a treatment called gradual exposure), their anxiety will decrease, and they will no longer be controlled by their fear. That is the science of treatment, to gradually face fears. But how do you get someone with overwhelming anxiety to do that? The art of treatment is figuring out what to do to persuade someone to gradually face fears. In my book *Overcoming Anxiety in Children and Teens* (Baker, 2015), I spell out some of the steps involved in helping young people face their fears. All the steps are appropriate for verbal clients, yet steps 3 and 5 can be used effectively for those clients with less language capability.

Step 1: Motivating Clients to Want to Address Anxiety

Therapy can be threatening, especially if you are being forced into it by others. There is an unspoken message that something is *wrong* with you that needs to be fixed. For verbal clients, I prefer to begin therapy with what is *right* about them to help them see their value and feel optimistic about the future. From this position of



Jed Baker, PhD

strength, we can talk about challenges that get in the way (like anxiety symptoms).

I start by explaining that everyone has a profile of strengths and challenges. Begin by making a list of their strengths (at least 7) and a smaller list of challenges (3 and under). Strengths include any special knowledge, traits, and characteristics they possess. Strengths are things that lead to successful careers and relationships. Challenges are things that can get in the way of reaching those goals. We do not need to totally overcome challenges like anxiety; we just need to get to the point where they are no longer in the way.

Step 2: Learning About Alarm System

All of us have an alarm system to help us survive in the face of perceived danger. When a significant threat is detected, we are wired to react automatically with an intense emotional response to fight, flee, or freeze as if our lives depended on it. Daniel Goleman, in his book titled *Emotional Intelligence*, refers to these moments as a state of being “hijacked by emotions.” It is as if the emotion center (the limbic system) has taken over the rest of the brain so that we don’t have easy access to our reasoning ability. This quick, non-thinking response certainly has survival value. When walking down the street, if a car suddenly veers off the road into your direction, this is not a time to reflect. You must move quickly to a safer place. This is a TRUE ALARM. Yet in a world where perceived threats may not always be life threatening, the fight, flight, or freeze response can lead to FALSE ALARMS, causing us to become emotionally reactive when no actual danger is present. Some of us may inherit a more sensitive alarm system that can set off many FALSE ALARMS.

Step 3: Identifying Fears: Creating a Fear Ladder

This is crucial since treatment will focus on gradual exposure to the very things that are feared. In *Overcoming Anxiety in*

Children and Teens (Baker, 2015), I cover some of the major anxiety disorders for children and teens including: simple phobias, social phobia, selective mutism, separation anxiety, school phobia, panic disorder, generalized anxiety disorder, somatic symptom disorder and illness anxiety disorder, obsessive compulsive disorder, and other common fears like perfectionism, fear of loud environments, and medical procedure phobias.

Create the “Fear Ladder”

For each type of fear, make a list of situations from least fearful to most fearful. Then the child can gradually face those fears. For example, my clients who are afraid of arranging a get-together with a peer might break up the task into smaller steps (“rungs on the ladder”). The first step might be just say “Hi” at lunch. At another time, find out which video games they both like, then another time ask for a phone number in case they want to talk about video games, and then ask the peer if he or she wants to hang out to play video games. Finally, have the get-together.

Reward Facing Each Fear on the Ladder

There are two broad categories of rewards for facing fears: *intrinsic* rewards

see *Anxiety on page 26*

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Employing Theater Arts to Enhance the Lives of Individuals with ASD

By Aubrie Therrien
and Sam Goldstein, PhD

The EPIC Players Inclusion Company is a theater based group in New York City, founded by Aubrie Therrien. EPIC's goals include redefining the face of theater arts, creating employment opportunities for actors with Autism Spectrum Disorder, and providing the local community with an active theater experience. EPIC Players promotes positive peer interaction at the same time as helping cast members with ASD sharpen their communication skills and improve their overall self-esteem and confidence. EPIC (Empower, Perform, Include and Create) provides neuroinclusive theatrical opportunities and an inclusive social resource for performing artists living with developmental disabilities. Actors with disabilities, such as Autism Spectrum Disorder, seek to express and represent themselves, while expanding their social awareness. EPIC provides actors with inclusive social opportunities and resources, in addition to helping them develop their talents on stage and screen.

Supported by caring community partnerships, EPIC combines social skill building, performing arts, and job training to provide the community with an active theater experience. Cast member, Ben Dworken, an actor living with ASD, asserts: "EPIC helped



Aubrie Therrien

me do better as an actor, helped me connect more with outside theater companies, and I earned friendships out of it." This year EPIC successfully produced three main stage performances with neuroinclusive casts comprised of actors both on and off the autism spectrum. All cast members receive training in professional stagecraft and etiquette, as well as a stipend for their participation.

EPIC is a strong advocate in helping members find work outside the organization. Recently, the producers of *Good Time* hired EPIC's actors to perform in the film's



Sam Goldstein, PhD

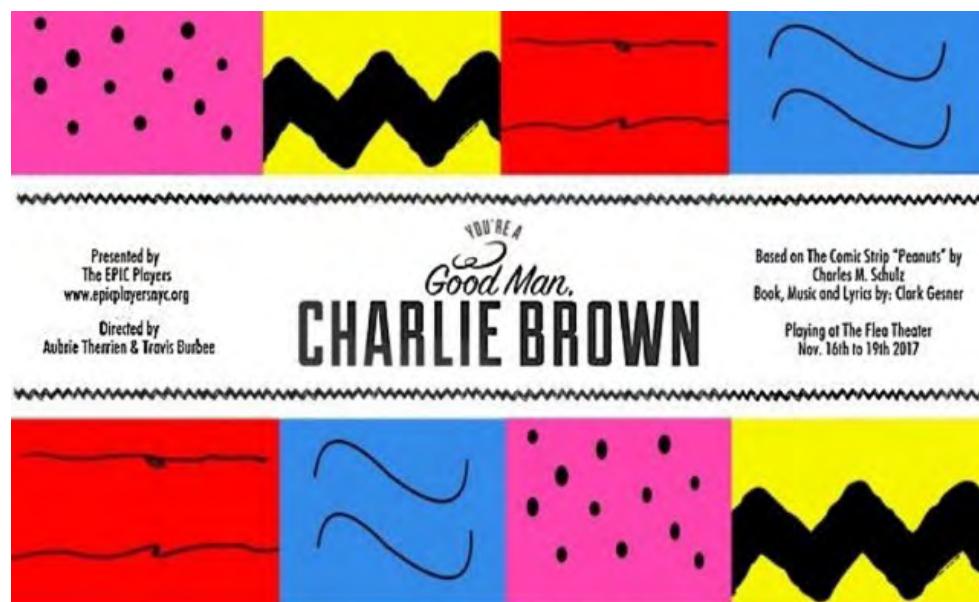
final scene. Participating players earned feature film credits for their resumes and industry compensation. Samantha Elison, a 26-year-old actress living with autism, talks about her first season with the company: "EPIC really helped me accomplish my personal and professional goals. It really helped me learn and grow as a person, improve my communication as a professional performing artist. EPIC also really helped me become a better direction taker, more trustworthy towards others as a person, and more flexible with getting

and receiving clarification and reassurance from a director."

One audience member who reviewed EPIC's first neuroinclusive performance wrote this: "By random happenstance I happened to find myself at your opening night performance of *Dog Sees God*. I was not sure what to expect but I wanted to let you all know that I was blown away. The amount of talent and professionalism that I witnessed on that stage was truly magical. Every actor gave their heart and soul in every scene and it really showed. I have never seen such a wonderfully supportive and coherent ensemble. It has been awhile since I experienced a group of actors enjoying what they were doing as much as this cast. I am so thankful to have been there and I can't wait to see what else is in store for all."

The performing arts offer some of the strongest forms of social and behavioral development that exist today. The opportunity to perform in a neuro-diverse cast (actors with and without ASD) not only helps establish the social communication and acting skills of those with ASD, but also goes a very long way to help those without ASD better understand the condition. The need to address apparent inequities of disabilities representation in mainstream arts was noted at the National Summit on Careers in the Arts with People

see *Theater Arts* on page 24



Vulnerable from page 14

There so much about the real world he doesn't understand.

He cannot begin to grasp the concept of a hurricane marching over a small island, or how a shooter's keen eye scans an unprotected crowd, or the way a bully sizes up the easiest target.

He's never been to a concert. Oh, sure, he knows all about them—he knows a lot of people get together and sing the lyrics to their favorite songs at the top of their lungs, swaying in time to the rhythm of the heavy beat.

But my vulnerable child has no idea what it means to stockpile ammunition, or collect weapons, or break windows in a ho-

tel room for the clearest shot on a beautiful autumn night.

Autism is without cure, and this vulnerable boy will one day grow to a vulnerable man—a man others will prey upon, and try to scam.

A man who may stand stock-still, and watch as the flames edge closer and closer.

As much as I long to, I know I cannot always be there for him. I cannot always stand in between him and disaster.

Can you see? Can you see how important it is for me to tell his story? I have to tell you about the mall and the popcorn and the pillows. I have to tell you about the color and the tapestry and I have to make you feel as though you know my Jack-a-boo, so that one day, you might help me.

Will you help me?

Will you help me keep him safe?

Will you peer into the blaze of hatred, and behold the beauty of a complicated child?

Will you show compassion for the unusual, and mercy for compromised?

Will you think before you speak, and breathe before you act, and always look behind you when you put your car in reverse in a parking lot?

Will you listen for those who have no voice?

And if the fire alarm goes off in the grocery store, and you see a boy standing all alone with his hands clapped over his ears, will you lead him out the door?

With his hand in yours, please, run. Run from the heat as if you are outrunning the sun.

I need you.

Mom. For the concert. In Las Vegas. Did they stop dancing. When he shot them.

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

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

Parental Age Ups Rate of New Mutations Passed to Children

By Alla Katsnelson
SPECTRUM

Men and women both transmit an increasing number of new mutations to their children as they age, according to a study published recently in *Nature* (Jónsson H. et al., 2017). The finding is based on an analysis of whole genomes from nearly 5,000 people. The increase in these ‘de novo’ mutations may explain why older parents are more likely to have a child with a condition such as autism.

Men accumulate de novo mutations four times faster than women, the researchers found. However, in about 10 percent of the genome, mutations accumulate twice as quickly as elsewhere, and appear at an equal rate in both women and men.

“The majority of the contribution still comes from the father, particularly when the father is in an older age range,” says lead investigator **Kári Stefánsson**, chief executive of deCODE Genetics. “But the mutation rate is not equal across the genome, so we have to make sure we do not generalize too much.”

The new study builds on earlier work by deCODE Genetics, a company based in Reykjavik, Iceland. In 2012, the researchers reported that the rate at which people acquire mutations and pass them down to their children **increases sharply**



with age in men but stays level in women. Those findings were based on whole-genome sequences from just 78 individuals and their parents.

The findings provide one possible explanation for the increased risk of autism among children born to older parents. But it is still unclear how much of the risk the increased mutation rate explains, says **Daniel Weinberger**, professor of psychiatry, neurology and neuroscience at Johns Hopkins University in Baltimore, who was not involved in the study. “We just don’t know the answer to that,” Weinberger says.

“Some of it probably is, but it’s very possible that most of it isn’t.”

Mounting Mutations

Stefánsson and his team analyzed the whole-genome sequences of 1,548 Icelanders, their parents and, in 225 cases, at least one child — providing three generations of genomes in those cases. The researchers identified 108,778 de novo mutations in these intergenerational genomes and were able to determine the parent of origin for 42,961 of them.

They found that mothers gain an average of 0.37 de novo mutations each year; fathers, by contrast, gain an average of 1.51 de novo mutations.

Maternal de novo mutations are especially concentrated in hotspots that comprise about 10 percent of the genome. In those regions, the mutation rate is equal between mothers and fathers. Based on their previous work, the researchers say, the maternal mutations seem to occur as errors in the repair of DNA breaks.

Similar mutational hotspots also exist in the chimpanzee genome and to a lesser extent in the gorilla genome, but not in the orangutan genome. These three primates are increasingly more distant from humans on the evolutionary tree, pointing to an evolutionarily conserved system for introducing variation into the human genome.

“The de novo mutation rate in this part of the genome is almost twice what it is in the rest of the genome because of this big contribution from mothers,” Stefánsson says.

The results suggest that the accumulation of mutations from the mother and from the father occur through different underlying mechanisms, says **Stephan Sanders**, assistant professor of psychiatry at the University of California, San Francisco, who was not involved in the study.

Previous studies have identified hotspots in the genome in which mutations accrue

see *Parental Age* on page 26



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Advances from page 1

local modulations may have a widespread effect on the overall cortical dysfunction with major functional abnormalities. The possible implications of this research are very exciting with regard to future treatments. (Foss-Feig, Adkinson, Ji, Yang, Srihari, McPartland, Krystal, Murray & Anticevic, 2017).

Another recent line of research is quite intriguing as there appears to be a connection between ASD and FMRP genes. This gene codes for a protein named Fragile X Mental Retardation 1. This protein is ubiquitous in the brain and plays an important role in transcription and synaptic formation. Various correlation studies have associated the FMRP gene with other psychiatric illnesses although the role of mitochondrial, synaptic, glial, or synaptic pathways in ASD cannot be ruled out. Perhaps a better understanding of ASD and other psychiatric disorders will be better achieved in the future as a result of this exploration (Arija, Dieleman, Smit, Verhage, Verhulst, Polderman & Posthuma, 2017).

Additionally, there is a recent line of research in that there may be a connection between the possible up or down regulation of GABA receptors, excitatory receptors involving glutamate, as well as neuromodulators including serotonin, dopamine and acetylcholine. This can disrupt circuits in the basal ganglia which may lead to system wide abnormalities resulting in behavioral problems similar to those observed in autism. Further research as related to autism is needed (Subramanian, Brandenburg, Orsati, Soghomonian, Hussman & Blatt, 2017).



Carrol T. Longshore, MD

There is a significant body of knowledge to suggest that ASD is accompanied by problems of brain development with issues with resultant connectivity issues. As the macroscopic changes evident in the brain are readily apparent, there is much less information about the cellular and molecular abnormalities related to this morphology. Further research is hoped to clarify these phenomenon in relation to autism (Ecker, Schmeisser, Loth & Murphy, 2017). There are a number of neuroanatomical issues that have been determined through the noninvasive brain imaging studies. There are abnormalities within the neural systems and circuitry comprising the social circuitry. Involved

structures are the amygdala, basal ganglia and the prefrontal cortex. Problems with the amygdala and nucleus accumbens appear to be particularly important in the pathogenesis of ASD as they relate to response to cues.

With regard to specific neurotransmitters, there is a good deal of evidence supporting the role of serotonin in the pathophysiology of ASD. This relates particularly to the differentiation, migration and proliferation in cells that are innervated by serotonin. There is also some evidence that glutamate levels may also be increased but this has been difficult to quantify as there is a conversion of glutamate to GABA. A more recent discovery has been the discovery of Oxytocin in the regulation of social behavior. Oxytocin has been found to be important in serotonin signaling pathways. Further elucidation of this information hopefully will lead to a better understanding and treatment of ASD (Fernandez, Mollinedo-Gajate & Penagarikano, 2017).

Current treatment of ASD involves a combination of psychological behavioral methods as well psychopharmacology. Treatment individualization requires multiple disciplines to arrive at the most useful treatment plan. The goal of these treatments is to improve functional abilities as well as social skills, communication and language. To accomplish this, there has to be coordination of services and advocacy for patients. Early intensive behavioral intervention is important. Some behavioral approaches may alter behavioral development as well as brain development as we know occurs with psychotherapy. (Pouske & Kamp-Becker, 2016).

There are some useful approaches to treat ASD patients with psychopharmacology but clinical applications are expected to become more diverse as research is applied to clinical symptoms. Currently in the U.S., there are only two medications with FDA approval for the treatment of the core symptoms of ASD. These are risperidone and aripiprazole. Recent meta-analysis data confirms this finding. In addition, there is some indication that NAC, clonidine, methylphenidate and tianeptine, a tricyclic antidepressant, may have some efficacy. Risperidone and aripiprazole can have associated somnolence as well as weight gain as adverse side effects. Citalopram and venlafaxine showed small effect sizes and naltrexone had a small effect size as well. Valproate had mixed results and recent studies involving the use of oxytocin hopefully will lead to further treatment protocols (Fung, Mahajan, Nozzolillo, Bernal, Krasner, Jo, Coury, Whitaker, Veenstra-Vanderweele & Hardan, 2016).

Continued research is hoped to lead to new treatments, both behavioral psychopharmacological which will be based on advances in the understanding of the pathophysiology and neural and molecular mechanisms of ASD. The current research projects will lead to a better future life for individuals with ASD.

Dr. Longshore is Senior Psychiatrist, Metro Community Health Centers and Medical Director, NY START, Brooklyn/Staten Island. For more information, please visit <http://www.mchcnyc.org>.

Metro Community Health Centers, Inc. (MCHC), recognized by the National Committee of Quality Assurance as a Level 3

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Neuroimaging Technique May Help Predict Autism Among High-Risk Infants

Brain Patterns Precede Behavioral Symptoms of Autism, NIH-Funded Study Suggests

By The National Institutes of Health

Functional connectivity magnetic resonance imaging (fcMRI) may predict which high-risk, 6-month old infants will develop autism spectrum disorder by age 2 years, according to a study funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the National Institute of Mental Health (NIMH), two components of the National Institutes of Health. The study is published in the June 7, 2017, issue of *Science Translational Medicine*.

Autism affects roughly 1 out of every 68 children in the United States. Siblings of children diagnosed with autism are at higher risk of developing the disorder. Although early diagnosis and intervention can help improve outcomes for children with autism, there currently is no method to diagnose the disease before children show symptoms.

“Previous findings suggest that brain-related changes occur in autism before behavioral symptoms emerge,” said Diana Bianchi, MD, NICHD Director. “If future studies confirm these results, detecting brain differences may enable physicians to diagnose and treat autism earlier than they do today.”

In the current study, a research team led by NIH-funded investigators at the University of North Carolina at Chapel Hill and Washington University School



Joshua Gordon, MD, PhD
Director, National Institute
of Mental Health (NIMH)

of Medicine in St. Louis focused on the brain’s functional connectivity—how regions of the brain work together during different tasks and during rest. Using fcMRI, the researchers scanned 59 high-risk, 6-month-old infants while they slept naturally. The children were deemed high-risk because they have older siblings with autism. At age 2 years, 11 of the 59 infants in this group were diagnosed with autism.

The researchers used a computer-based technology called machine learning, which trains itself to look for differences that can separate the neuroimaging results into two groups — autism or non-autism — and predict future diagnoses. One analysis predicted each infant’s future diagnosis by using the other 58 infants’ data to train the computer program. This method identified 82 percent of the infants who would go on to have autism (9 out of 11), and it correctly identified all of the infants who did not develop autism. In another analysis that tested how well the results could apply to other cases, the computer program predicted diagnoses for groups of 10 infants, at an accuracy rate of 93 percent.

“Although the findings are early-stage, the study suggests that in the future, neuroimaging may be a useful tool to diagnose autism or help health care providers evaluate a child’s risk of developing the disorder,” said Joshua Gordon, M.D., Ph.D., NIMH Director.

Overall, the team found 974 functional connections in the brains of 6-month-olds that were associated with autism-related behaviors. The authors propose that a single neuroimaging scan may accurately predict autism among high-risk infants, but caution that the findings need to be replicated in a larger group.

About the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

NICHD conducts and supports research in the United States and throughout the world on fetal, infant and child development; maternal, child and family health; reproductive biology and population issues; and medical rehabilitation. For more information, visit [NICHD’s website](http://NICHD's website).

About the National Institutes of Health (NIH)

NIH, the nation’s medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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New Treatment from page 1

whose job it is to quiet down the wind instruments so that the violins can play the melody. Later, he must bring in other instruments perhaps at high volumes to create the desired effect.

I am proposing that, in individuals with autism, the noradrenergic system is dysregulated and does not perform its function well. The chronic non-performance of this function leads to more permanent deficits as children develop. The clearest example of this is that the noradrenergic system is needed both to focus attention as well as to change focus. When we are out in the world we may be in a “wide-scanning” mode; for our ancestors that meant looking for predators or prey. Then when we encounter something, like food in a tree, we need to figure out how to access the food which requires attention, focus, and perhaps learning a novel task. Once we’ve eaten the food then we go back to scanning the environment to see what may come next (perhaps to find water or a female). Each one of these transitions requires the noradrenergic system to initiate the switch. If the noradrenergic system does not do its job at that time, there will be no switching of circuits and the person will continue in his current mode. Or conversely if the noradrenergic system fires at the wrong time the switch will take place prematurely in the middle of the task.

Aside from attention, there are many other examples of how the circuitry needs to be switched for adequate functioning. Behaviorists have noted for a long time

that children with autism can perform much better when given “prompts.” Often a small touch in the right direction enables the student to perform a complex task that they could not seem to perform without it. In fact, the behavioral literature is voluminous on how to fade prompts as prompting is so effective. It is very likely that the function of prompting is to stimulate the appropriate circuitry because the noradrenergic stimulation has failed to do so at that time. Other functions dependent on the noradrenergic modulation include language acquisition, sleep, arousal levels when awake, memory formation and the ability to discard memories, learning consolidation, and autonomic functioning which goes hand in hand with our emotions and behavior. Put another way, the noradrenergic modulation - or the dysfunction thereof - can explain many of the deficits seen in autism.

The use of noradrenergic medications is not new in psychiatry or even for autism. Clonidine and guanfacine work on this system in short or long acting forms and are commonly used for individuals on the autism spectrum. All of the medications used for ADHD are adrenergic. A medication which is less commonly used, however, but which has shown more promise is propranolol (brand name: Inderal). David Beversdorf and his group at the University of Missouri have used small single doses of propranolol on high functioning individuals with autism spectrum disorders. They have shown improved cognitive functioning in many different testing paradigms. I have used large doses of propranolol for

individuals with autism who have severe symptoms of aggression and/or self-abusive behaviors. About 85% of those individuals with whom I have used this medication have gotten “much better” or “very much better” and these were individuals who failed on an average of over six other medications (with some having tried up to 12 medications). I recently received grant funding and will soon begin a double-blind, placebo-controlled trial with propranolol for patients with severe aggression or self-abuse. This type of rigorous study is necessary to demonstrate the findings which I have observed in my clinical practice.

Psychiatric medications, as currently available, are a blunt instrument to address brain pathology. When administering a medication orally we need to deal with the reality that it will not be selective to the circuitry that we are interested in “fixing.” It is not that there is too much or too little noradrenalin; rather that is not well regulated and that does not do its job at the times that it is needed. Better ways of administering treatments need to be ascertained. Techniques such as deep relaxation or meditation do regulate the adrenergic system; however, my experience is that the effect does not last long so that in a few minutes the dysregulation is back. Experienced meditators may be able to overcome this but I would not be optimistic about individuals on the autism spectrum becoming expert at these techniques. Electrophysiologic methods deserve attention, such as Transcranial Magnetic Stimulation, which is being used by Manny Casanova’s research team in South Carolina. Deep brain stimulation

is now being used successfully for obsessive compulsive disorder and Parkinson’s disease. This would allow for specifically stimulating important circuits; however, the electrodes need to be implanted surgically which limits the practicality of designing research for this modality. Vagal stimulation has potential and is used for epilepsy. Up until recently, surgical implantation was needed. However, there are now external vagal stimulators which are being tested for various disorders and only require holding the device against the skin.

Forty years ago, the best evidence-based treatments for Autism Spectrum Disorders was applied behavioral analysis and anti-psychotic medications. Today’s best treatments are similar with some refinement but no breakthroughs have occurred. I believe that improved treatments targeting more sophisticated goals are likely to prove successful. With these prospective treatments “on the shelf,” what is needed is the careful study of these new modalities to provide the scientific evidence for their application to those who are in need of them.

For almost 50 years, the Institute for Basic Research in Developmental Disabilities (IBR) has been serving New Yorkers with developmental disabilities, initially through research alone, and currently through an integrated program of research, service, and education. Discoveries made in the Institute’s laboratories help save lives and improve the quality of life of people who have developmental disabilities, from premature infants to the elderly. For more information, visit <https://opwdd.ny.gov/ibr/>.

NIH Awards from page 10

into the nature of different subtypes of ASD by looking at areas of functioning often affected by the condition: sensorimotor processing, or how individuals process information from their senses; social motivation, the need to interact with others and be accepted by them; and social communication, the ability to use language and gestures for interactions with others. They will also test a medication to see if it can improve social functioning.

Yale University, New Haven, Connecticut
Examining Development of Functional Brain Connections

Katarzyna Chawarska, PhD, and colleagues will investigate brain connections in fetuses and newborns to identify early indicators of ASD. They will also determine if boys and girls with ASD differ in their brain circuitry, with the aim of improving diagnosis and treatment. In addition, they will evaluate an intervention to improve social functioning in children at high risk for ASD.

Duke University, Durham, North Carolina
Understanding and Potentially Treating ASD-ADHD Combination

An estimated 40 to 60 percent of people with ASD have attention deficit hyperactivity disorder (ADHD), which encompasses such symptoms as difficulty paying attention, problems controlling behavior and hyperactivity. Co-investigators Geraldine Dawson, PhD, and Scott Kollins, PhD, aim to learn how ADHD may influence the di-

agnosis and treatment of autism and plan to observe children who have ASD alone, ASD and ADHD, and ADHD alone and compare them to typically developing children. They will also test whether the stimulant medication used to treat ADHD will help children with both conditions.

Emory University, Atlanta
Studying Social Interaction to Identify the Early Signs of ASD

Ami Klin, PhD, and colleagues will conduct studies on diagnosing autism early and developing the earliest possible interventions. The center will follow hundreds of infants from birth to 30 months, including those at high risk for ASD. They will study infant social interactions through measures of visual, vocal and brain development. Previously, the group showed that, when looking at videos of people speaking, infants who were later diagnosed with ASD had eye movements that differed from those of typically developing infants. More recently, the group found a genetic basis for those eye movements. When the children are 6 months of age, the researchers will test an intervention that will be easy for care givers to administer and tailored to each infant’s individual characteristics.

2017 Network Grants

George Washington Univ., Washington, D.C.
Investigating How ASD Differs Between Boys and Girls

Girls are diagnosed with ASD much less frequently than boys. Kevin Pelphrey, PhD, and network colleagues will follow chil-

dren through adolescence and into adulthood to understand differences in ASD risk between boys and girls and in how they each respond to interventions. They will also collaborate with self-advocates with ASD to understand how well their findings reflect real-life experiences. Together, they aim to uncover information that will help males and females living with ASD better manage the transition to adulthood.

University of North Carolina, Chapel Hill
Tracking Brain Development, Behavior as ASD Progresses

Joseph Piven, MD, and network colleagues previously compiled detailed information on brain development and behavior for 300 children at high risk for ASD and 100 children at low risk. The researchers found that brain growth of infants later diagnosed with ASD differed from that of typically developing children. With the new award, the researchers will follow these children through ages 7 to 10 years to determine how their brains change as they grow and the potential effects of ASD on learning and social development. Based on what they learn, they aim to develop interventions tailored to school-age children with ASD.

Drexel University, Philadelphia
Evaluating Autism Screening for All Toddlers

Should every toddler be screened for ASD? Diana L. Robins, PhD, and network colleagues will conduct a randomized, controlled trial of 8,000 toddlers to determine if screening lowers the average age of ASD

diagnosis, leads to earlier interventions and improves outcomes. Participating children from network clinics either will be evaluated at 18 months of age or be part of a group which will receive standard pediatric care. All children not screened at 18 months will be screened at 48 months and all children who are diagnosed with ASD will receive one year of behavioral therapy.

Florida State University, Tallahassee
Testing Parent Coaching, Home Intervention for Toddlers

Amy Wetherby, PhD, and network colleagues will test a two-part intervention designed to empower parents of children with ASD. The researchers will offer parents **Problem Solving Education**, a six-session intervention to help them access the services their children need and to adapt to caring for a child with special needs. Parents will also receive training in **Early Social Interaction**, which teaches them to support their children’s communication and social skills in everyday routines, activities and settings.

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NIH, the nation’s medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Music Therapy from page 4

language and cognitive abilities. It is possible that baseline symptom level was related to treatment response. For example, it is possible that children with intact speech or higher levels of cognitive functioning responded differently to the intervention than children with limited speech, or limited cognitive functioning. Subgroup analyses are essential in investigating response to autism treatments, given the heterogeneity of the population. One-size-fits all approaches are particularly limited in autism spectrum research.

Another problem related to controlling the intervention was the different numbers of sessions participants received, and that participants missed. It appears as if half of the scheduled music therapy sessions were not given. In fact, there was no discussion at all of the impact of missed sessions as a clinical variable.

The authors do acknowledge that the lack of consistency and implementation between different music therapists in different locations might have had an effect on the overall measurement of the music therapy intervention. It also acknowledges the total length of the study (5 months) as probably being too short.

The problem of testing a low-quality behavioral intervention in a large, well-designed outcome study which is not then followed by second generation studies can have major negative impacts on a field. This was the case in the ADHD literature, when in 1999 The Multimodal Study tested stimulant medication against a weak behavioral intervention. Because stimulant medication outperformed the limited behavioral intervention, and because second generation large clinical trial studies did not follow, the field was influenced for decades in believing medication was a superior treatment. It is vital that second

generation studies are fielded to provide a more in-depth perspective on high-quality interventions.

The most problematic element of the study under discussion was the lack of therapy process measures. Engagement is a key ingredient for the success of any therapy. Research shows that the more engaged a client is, the more benefits he or she is likely to achieve. We know from clinical experience that increased musical engagement results in increased attention, awareness, responsiveness, organization, and flexibility in music therapy participants.

Yet this study did not measure musical engagement. It did not determine *how many* of the participants became significantly more engaged with music making in the sessions. We do not know how clients became more engaged. We do not know how much their level of engagement increased. It could be that some participants did become more engaged and some did not. Gains by those who did become more engaged and benefitted from the intervention may not have been detected when combined in the overall analysis with those that did not. Without looking at engagement, the researchers undertaking this study were, in our view, taking a *black box* approach to the intervention that they were investigating.

To summarize, we do not know anything about the quality of the musical and improvisational skill of the therapists, the quality of the music making interventions of the therapists, how many clients showed increased engagement with the music making, and whether those clients who did show increased engagement in music making made functional or quality of life gains outside in other settings. We do not even know if clients who increased engagement with music making showed reduced symptoms.

To address the need for a sensitive empirical therapy process measure, we are working at the Nordoff-Robbins Center to develop an empirically-validated process measure. Process measure data is needed to answer the question of what gains in musical engagement can be realistically expected for what groups under what conditions. This in turn drives research design; for example, treatment conditions need to be at the quality and duration of time needed to allow gains to emerge.

From our perspective, we want to know which groups of children on the spectrum increase their social connection with the primary people in their lives - family members, teachers, peers - when they increase their engagement with music during treatment in Nordoff-Robbins music therapy. This is the next step that needs to be researched, and we need to construct the best method to measure this.

Paul Nordoff and Clive Robbins are recognized as pioneers of the clinical intervention and study of improvisation (Nordoff and Robbins 2007) in clinical music therapy. Broadly speaking, they focused on the fundamental research question "How are the therapist and client engaged in music making?" In their holistic case studies, they asked and found a variety of answers to the question "How does increased musical engagement lead to overall improvement in the child's life?" Their core question and findings continue to provide the foundation of our ongoing research at the Center.

For more information, email alan.tur-ry@nyu.edu or visit <http://steinhardt.nyu.edu/music/nordoff>.

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Adults from page 6

"People reported high levels of satisfaction with where they work and live and the services they receive," Roux said. "This simply doesn't line up with the frustrations we hear from adults with autism and their family members. Many are truly dissatisfied with their quality of life and the difficulties they have finding services that

could help improve their situation."

The report is a snapshot of a segment who *are* receiving services. Roux, Shattuck, and the rest of the team know there is likely a sizable population of adults with autism who don't receive developmental disability services and really need them.

"Some states don't provide developmental disability services for adults with autism unless they also have intellectual disability,"

Roux explained. "These policies ignore the fact that many with autism are cognitively-able but still have tremendous challenges navigating the social, organizational, and communication demands of adult life."

"It's critical that we identify, evaluate and promote state policies that appropriately recognize and adequately meet the unique needs of adults with autism spectrum disorder who use, or need to use, state

developmental disability services," added Shattuck. "Without that we will continue to struggle to improve the quality of life for those who use these services."

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Readiness from page 12**Classroom Readiness up Close**

Classroom-readiness groups work with children from ages 3 to 6, when kids typically transition out of state-sponsored early intervention and start preschool or kindergarten.

These structured small groups combine individual and group exercises. ABA therapists work one-on-one with each child, implementing a treatment plan that is customized for his or her unique abilities and supervised by a Board Certified Behavior Analyst.

Throughout the day, the children gather to practice in a classroom-like environment and generalize their skills to new situations. Four to six kids will work on typical school activities such as lining up, sitting for show and tell, eating snack and following directions. The group also helps improve social skills such as taking turns, playing together, working in teams and sharing.

Another valuable feature of classroom-readiness therapy is the opportunity to define a child's most effective learning style. Does she learn behaviors most easily when she works one-on-one with an adult or in a small group setting? This information can be extremely helpful to parents, teachers and the team that is developing a child's Individual Education Plan.

To be clear, classroom readiness groups emphasize behavior, not knowledge. They don't directly teach academic subjects. The primary goal of classroom-readiness therapy is helping children become familiar with the behaviors they'll need to go to school and be ready to learn (Bene,



Individual work in a Classroom Readiness/Early Learners' group at the AHSS Autism Center in Arlington Heights, Illinois

Banda and Brown, 2014).

The Team Approach

Many parents find that it's helpful to continue classroom-readiness therapy after their child starts school. By staying in touch with the child's teachers and Individual Educational Plan team, an ABA therapist can incorporate the IEP's goals into classroom-readiness efforts. Ongoing individual and group therapy group can also sharpen the child's evolving skills and behaviors as needed.

Starting school opens new worlds for children. Children with autism often need

extra help to make the most of those opportunities. Classroom-readiness groups can be one answer, providing intensive, focused therapy to help children on the spectrum learn school behaviors and build a foundation for social and academic success.

Laura Bonfante (lbonfante@autismhomesupport.com) is a Board Certified Behavior Analyst for Autism Home Support Services (AHSS) and manages AHSS' Autism Center in Arlington Heights, Illinois. AHSS is the Midwest's largest provider of in-home ABA therapy and offers classroom readiness groups at a growing number of autism

centers across the United States. For more information, see autismhomesupport.com or call (844) 247-7222.

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Sisters Project from page 9

Halladay, chief science officer of the Autism Science Foundation. "These researchers will work with data already collected, even as work continues at Mount Sinai School of Medicine to recruit more families to add to these datasets."

Funding for Drs. Bishop, Sanders and Robinson will allow them to analyze previously collected genetic and behavioral data to study the female protective effect in autism, specifically the genetic and behavioral features of sisters of individuals with ASD. The unprecedented combination of datasets includes information from thousands of families contained in the Autism Sequencing Consortium as well as datasets such as the Autism Genetic Resource Exchange and the Baby Siblings

Research Consortium.

The Autism Sisters Project focuses on three areas:

- Data on unaffected sisters will be gathered from existing databases with rigorous behavioral phenotyping data on all family members, this funding will start in August.
- New families with a member who has autism and a female sibling without an ASD diagnosis will be recruited to the Icahn School of Medicine at Mount Sinai to donate saliva samples and participate in a full screening. A full DNA exome scan, among other analyses, will be performed on the entire family. This was funded in 2016 and the study is ongoing.

- In the future, funds will be provided to autism research sites so that sequencing and phenotyping can be expanded to include an unaffected sister in families where samples from parents and the individual diagnosed with autism have already been collected.

The Autism Science Foundation is also providing financial support to the Seaver Autism Center at Mount Sinai School of Medicine to collect information on families that have not previously participated in a genetic research study. Interested participants should contact the Seaver Autism Center at 212-241-0961 or email theseavercenter@mssm.edu.

The Hilibrand Foundation provides major financial support for the Autism Sisters Project.

To participate in the Autism Sisters Project, interested participants should contact the Seaver Autism Center at 212-241-0961 or theseavercenter@mssm.edu.

About the Autism Science Foundation

The Autism Science Foundation (ASF) is a 501(c)(3) public charity. Its mission is to support autism research by providing funding to scientists and organizations conducting autism research. ASF also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. To learn more about the Autism Science Foundation or to make a donation, visit www.autismsciencefoundation.org.

ASD Services from page 11

(like the relative lack of referrals from other providers serving families who do not speak English), and decide to offer translated versions of ASD screening instruments to these providers. Similarly, an agency leader may look for barriers built into their own organization (like the difficulties that families living in poverty might encounter in simply getting to an appointment), and create a satellite clinic with easier access to public transportation.

Research on the characteristics associated with ASD is sometimes relevant to service providers. Some research on characteristics associated with ASD has revealed some co-occurring mental health conditions that can complicate ASD and directly impact important life outcomes. This kind of research is clearly relevant to treatment. Consider the debilitating anxiety that occurs in a surprising proportion of people with ASD at some point in their lives, and that is responsive to EBPs like adapted forms of Cognitive Behavioral Therapy or CBT (National Autism Center, 2015). This kind of research can sensitize service professionals to co-occurring anxiety, and perhaps mobilize them to seek CBT. This kind of research can also help agencies to adopt policies to ensure adequate funding for treatment.

Other research studies have focused on

characteristics deemed important to theories of ASD's development, but without clear implications for intervention and/or important life outcomes. Consider one such study describing a new approach to assessing a specific aspect of social understanding that reveals differences between people with and without ASD and that suggests exciting new possibilities about how ASD emerges over development. These findings are unlikely to change the practice of most service professionals. Why? Professionals must decide each day and for each child which treatments are likely to lead to the best outcomes. Without clear guidance about implementation and outcomes, they will probably choose to focus on characteristics with a clear impact, using known, practices with proven effectiveness.

Research on the possible causes of ASD has rarely proven to be relevant to the services provided to children with ASD. Why? Because we have yet to identify any single, specific cause clearly linked to a significant proportion of cases of ASD, or any cause amenable to intervention (Doehring, 2013). To be clear, our understanding of ASD's causes has influenced services. Almost fifty years ago, for example, neurological and genetic research was used to overturn prevailing psychoanalytic theories and treatments that ascribed ASD to poor parenting. And

research refuting links between ASD's apparent rise and the MMR vaccine have been key to maintaining the high vaccination needed to ensure public health. Of course, research on ASD's causes might yet suggest new paths to intervention. But until then, such research will remain largely irrelevant to those seeking to improve outcomes now.

Taken together, these distinctions suggest a potential disconnection between the potential benefits of research and the actual outcomes experienced by people with ASD. The challenge for ASD researchers, professionals, and advocates will be to work together to close this implementation gap. As noted by Dr. Fred Volkmar, Editor in Chief of the Journal of Autism and Developmental Disorders, "Research in adults age groups is so severely limited as to be, on some topics, almost nonexistent. We know very little about the needs of adults with ASD and this research gap is a critical one to address as children with ASD move into adulthood."

For more information, email Dr. Doehring at peter@asdroadmap.org or visit <http://www.asdroadmap.org/>.

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Theater Arts from page 16

with Disabilities in 2009. The fact that artists with disabilities seek equal status in the mainstream arts community was highlighted by the Honorable Kathy Martinez, Assistant Secretary for Disability Employment Policy, U.S. Department of Labor. In her address she said:

As someone who has been a musician, it was one of the few times in my life when my disability was not a factor. As a percussionist, people reacted to how well I played and what kind of art I was producing. The Office of Disability Employment Policy understands that media is critical to the employment of people with disabilities. The arts, I believe, are one of the best ways to do it.... We need to look at the laws that really are disincentives and create incentives to make it possible for folks to work, to save money and to become part of the mainstream by promoting economic justice.

In his 2013 textbook, *Interventions for Autism Spectrum Disorders: Translating Science into Practice*, Dr. Sam Goldstein

noted that the capacity to socialize effectively, gain access to peers, and enjoy the company and interactions of others is a powerful, driving force in human development. Neurotypical children and adults deprived of this opportunity invariably struggle and often fail to thrive. An increasing volume of scientific research demonstrates the benefits of social skills and related training for ASD. It has become apparent that the treatment of Autism Spectrum Disorder extends well beyond the doctor's office or the classroom into the community. Theater arts offer an opportunity for individuals with ASD to venture into the community in a win-win relationship. EPIC's performances help the general community better understand the nature of having ASD. At the same time, actors with ASD have the opportunity to interact in a medium that we believe will foster not only the development of self-esteem, but appropriate social interaction—the latter very clearly being the primary hurdle to successful adult transition for those with ASD. EPIC hopes to quantify our initial experiences

of the benefits of theater for those with ASD through a long-term, qualitative study measuring the associative effects of theater arts, training on social skills, sense of purpose and independence in daily life activities.

It is our company's hope that—through this research—we will be able to develop social-emotional learning tools, using the performing arts to help children and adults with ASD create important life skills and find alternative employment solutions in the arts.

EPIC's next production, "You're a Good Man Charlie Brown," will feature a neuroinclusive cast of actors living with and without ASD. Performances will take place at famous The Flea Theater, The SAM Space at 20 Thomas Street in Manhattan, November 16th - 18th at 7pm and November 19th at 3pm. General Admission is \$25, VIP Reserved Tickets are \$55. **Autism Spectrum News readers will receive a 20% discount on tickets with the Code: ASN123.** Tickets can be reserved at www.epicplayersnyc.org or by calling 347-687-7610.

Aubrie Therrien, the Executive Artistic Director of The EPIC Players Inclusion Company, is an experienced non-profit professional with an MPH from New York University. She founded and currently Co-Chairs the Coalition for Disabilities in the Arts in and is a passionate advocate for increased opportunities for individuals living with ASD and other developmental disabilities on stage and screen.

Sam Goldstein, PhD, is a neuropsychologist, researcher, author and test developer. He has authored the Autism Spectrum Rating Scales and multiple trade and professional books on Autism Spectrum Disorders, including "Interventions for Autism Spectrum Disorders: Translating Science into Practice" (2013, Springer), "Assessment of Autism Spectrum Disorders - 2nd Edition" (2017, Guilford), and "Raising Resilient Children with Autism Spectrum Disorders" (2011, McGraw Hill). He is the Clinical Director of the Neurology, Learning and Behavior Center in Salt Lake City, Utah.

Development from page 13

information from the behavior analytic community via the teaching behavior analysis and ethics and applied behavior analysis listservs.

Journal access - All employees are provided an algorithm for accessing the literature. This algorithm is often completed in conjunction with searching the literature. 1) Internet search engines can locate desired literature from many sources (e.g., available online via author websites, available online through databases like PubMed Central). 2) The organization maintains hard copies of previously purchased journal issues. Previously published articles in these journals are available in hard copy. 3) BCBA's can access scholarly works via their online portal. Similar features might be available through other credentials, too. 4) Individuals might access the literature via alumni association benefits or if they are currently enrolled in a university. 5) Some employees are provided access to an electronic database (i.e., PsycARTICLES®) and can access materials through that resource. 6) Any individual can request information from the behavior analytic community via the teaching behavior analysis and ethics and applied behavior analysis listservs.

Library - Melmark has begun a library where scholarly books, videos, manuals, and other materials are purchased and kept. Many of the materials are related to clinical services (e.g., implementation guide for a particular intervention), job duties (e.g., evidence-based supervision), and training opportunities (e.g., textbooks for behavior analysis classes) to facilitate job performance and to minimize employee cost of

training opportunities. Materials are purchased and managed through the Professional Development Department. Access to the materials are managed in a similar manner to local or university libraries (e.g., database, sign-out, return date, fees for non-returned items).

Monthly Professional Development Meetings

Reading scholarly literature is an important aspect of professional development, but it might not always lead to application. Or, the information and practices do not readily extend beyond the professional who experienced the learning. To remove these barriers and enhance learning opportunities, Melmark has begun to plan monthly professional development meetings. The meetings have recurring themes each quarter: journal article review, treatment / research protocol review, and conference summary reviews. The journal article review meeting provides employees an opportunity to review relevant literature on a salient topic. The treatment / research protocol review is an opportunity for employees to showcase a treatment protocol or research protocol that is in place or being developed. Other employees can determine if the protocols are applicable for individuals they support, or if they are in line with research goals they are pursuing. The conference summary review allows employees an opportunity to communicate headline information about noteworthy presentations from recent conferences they attended.

Each quarter the meetings are repeated with the same themes but with different presentations from other employees. The intent is to spread information from professional development opportunities to other employees, thereby increasing their

professional development and support of individuals served. It is also hoped these meetings become a breeding ground for ideas of research and practice. The logistics of the meetings (e.g., schedule, room, circulating materials) are handled by the Professional Development Department. Most importantly though, a departmental employee coordinates each meeting with another department so responsibility of content delivery is rotated across departments throughout the year. This is intended to increase involvement and buy-in as departments choose topics that are relevant to them and across Melmark. The content of the meetings requires employees to be actively engaged in professional development opportunities (e.g., reading literature, attending conferences) and conducting research, which is another process in and of itself.

Expert Speaker Series

Every year Melmark coordinates a series of speakers known as the Expert Speaker Series. Four to six speakers a year are asked to provide a lecture-style information session for Melmark employees and community members. The topics vary based upon the needs of the organization and community, but there is typically one presentation geared toward ethical considerations and another toward effective supervision practices. These two topics are emphasized once every two years to support behavior analysts to meet the continuing education requirements in these specific areas each certification cycle.

In addition to the presentation, Melmark is exploring additional methods for increasing the professional development opportunities within these events. The speakers have provided technical assis-

tance for specific clients, evaluated program effectiveness, and are now helping create resources specific to Melmark initiatives. For example, Melmark provides the necessary supervision for individuals seeking a BCBA credential. In an effort to create a supervision curriculum, some expert speakers are helping to create learning series in a specific content area and provide the initial supervision for BCBA's to develop content knowledge and skills in the content area, thereby expanding scope of competence and ability to train others.

Shawn P. Quigley, Ph.D., BCBA-D, is Senior Director of Clinical Services and Professional Development, and Mary Jane Weiss, Ph.D., BCBA-D, is Senior Director of Research, at Melmark.

Melmark is a multi-state human service provider with premier private special education schools, professional development, training, and research centers. We are committed to enhancing the lives of individuals with autism, intellectual and developmental disabilities and their families by providing exceptional evidence-based and applied behavior analytic services to every individual, every day.

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Anxiety from page 15

and *extrinsic* rewards.

Intrinsic rewards are the naturally occurring rewards for facing fears. Feeling pride and knowing that you are able to do so much more than you used to do are intrinsic rewards of facing fears. We can help clients see the payoff of being able to break out of their patterns of avoidance. We can help them feel proud of themselves for no longer letting anxiety control them.

Extrinsic rewards refer to providing contrived reward after facing a fear. This might be something like getting to play a video game or purchasing special items as a reward for taking a step towards facing a fear. For younger kids, and those students with greater cognitive challenges who may not comprehend the intrinsic payoff of overcoming anxiety, external rewards may be especially useful to motivate change.

Step 4: Use Cognitive Behavior Therapy to Combat Worries

The basic concept of Cognitive Therapy (CBT) for anxiety is to use logic and scientific reasoning to challenge the validity of the worrisome thoughts that maintain a high state of anxiety. To simplify matters for children, Rapee *et al.* (2008) focuses on just two ways of thinking to evaluate anxious thinking: overestimating the probability of negative events and/or overestimating the consequences of those negative events. I prefer to excuse kids from copious record keeping of their anxious and alternative thoughts and instead, write a brief summary for them of ways to “Think Like a Scientist.” The essence of CBT is to behave like a scientist and collect evidence to determine the actual probability and/or consequences of anticipated negative events.

For example, Ellie was a relatively typical nine-year-old afraid of bees and wasps. She often missed out on outside play with others during the summer months because she was afraid of being stung. She had never been stung, but she had heard some people have allergies and could go into anaphylactic shock and maybe even die from a sting! Her parents had taken her to an allergist who confirmed that Ellie was not allergic to insect bites.

To help her combat her worrisome thoughts and begin to face the fear of going

outside in summer months, we created the following summary:

“Think Like a Scientist”

Feared Situation: Getting stung by a bee or wasp

Anxious Thoughts: 1) Being outdoors in the summer makes it likely to be stung.

2) Getting stung really hurts and maybe I could even die

Realistic Outcome: 1) Bees and wasps are not aggressive away from nests. Not likely to sting unless swatted, hit, or stepped on. If I avoid nests, wear shoes when walking in leaves, and do not swat, I am not likely to be stung. I can also cover up food or stay away from garbage cans where those insects gather.

2) It is not possible for me to die because I am not allergic. I can reduce the pain by immediately flicking or taking out the stinger to limit the venom and apply ice for the swelling. I have had injections before and stings are actually less painful.

By researching the actual scientific evidence of the dangers of bee and wasp stings, she was able to gradually face fears on a fear ladder, involving staying outside for increasing amounts of time with her friends.

Step 5: Using Biological and Physical Interventions to Lower Anxiety

Exercise, physical activity, and sensory soothing actions can all reduce anxiety. Studies show the positive effects of exercise on increasing confidence and reducing anxiety. Several studies show exercise to be at least as effective as antidepressant medications. It seems that aerobic exercise may have the largest effect, followed by weight training. Therefore, many experts recommend that individuals with anxiety begin a regular exercise program, particularly one that involves an aerobic component such as jogging, walking, swimming, biking, or other sports that require aerobic activity.

There are times, however, when it is not possible to be physically active, such as when confined during travel or when going to bed at night. Therefore, we need ways to

calm ourselves when our bodies are quieter. Many of the repetitive sensory movements and special interests of children with autism also serve to reduce anxiety and can be incorporated into the child’s schedule to reduce stress.

Meditation and mindfulness stress reduction embrace strategies to bring calmness to mind and body in a way that does not depend on movement. These practices involve learning to focus one’s attention to what’s happening in the moment, whether something experienced with the five senses (such as a taste, smell, sound, touch, or sight) or an internal sensation, such as the feeling of one’s breathing or even the awareness of having a particular thought. Periods of time allocated to focusing the mind on the present moment are associated with a sense of well-being and reduced anxiety.

Though “mindfulness” is considered a way of trying to live one’s life rather than a specific tool, there are some mindfulness strategies that can reduce anxiety. Progressive Muscle Relaxation, involves the tensing, and then relaxing, of the muscles of the body, one group at a time. Deep belly breathing can also induce a state of relaxation. One can find scripts for progressive muscle relaxation, deep breathing, and mindfulness guides in my book (Baker, 2015). The interested reader will find many more resources by searching for “free meditation guides” online.

Putting It All Together

Anxiety itself is not always a problem, yet when it disrupts one’s life with unnecessary worries, or causes one to avoid desired activities, then it becomes a problem. The purpose of calming strategies is to increase a sense of well-being and lower anxiety enough so that individuals no longer avoid non-dangerous situations. Here are recommendations for using the calming tools:

1. Active calming: All readers are encouraged to start an exercise program. This is cost-free; reduces anxiety; and can increase attention, memory, and learning, as well. Keeping busy with desirable activities like playing music, games, reading, and watching shows can also reduce stress. Such activities must be balanced with required activities like homework, dinner, and bedtime.

2. Quiet calming: Readers should experiment with progressive muscle relaxation, deep breathing, and mindfulness meditation to see which strategies are easier for them and which strategies reduce stress. These strategies should become part of a daily practice, for example at bedtime, upon awaking, and certainly at anxious moments (before, during, and after facing a feared situation).

3. Using CBT to challenge anxious thinking is useful for all verbal children. Learning to combat the tendency to overestimate the frequency and consequences of negative events is crucial to this process. Caregivers are encouraged to create “Think Like a Scientist” cards for their children to use as a reminder of how to combat their particular worrisome thoughts.

4. Together, caregivers and children can create the “fear ladders” to identify situations to face in an effort to gradually overcome those fears. For young children (12 and under), or those less willing to face the feared situations on the ladder, external rewards should be identified to use as incentives for confronting a situation.

5. If the strategies and lifestyle changes described above do not sufficiently reduce anxiety, consider the use of neurofeedback and/or medication to further lower anxiety. Neurofeedback is quite safe in general, yet there is a cost and time commitment that may not make it everyone’s first choice. Medications can be quite helpful, yet should not be a first choice since they carry the risk of side effects.

For more information about this article or to learn more about Dr. Jed Baker, visit www.socialskillstrainingproject.com and www.jedbaker.com.

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Parental Age from page 17

especially quickly, Sanders says. But no one has shown whether or how they have a clinical effect. Stefánsson says his team has not yet been able to identify the function of the hotspots.

Risk Assessment

Based on the new data, a 45-year-old mother and father are 5 to 10 percent more likely to have a child with autism than are a 20-year-old mother and father. But the absolute risk of autism among children born

to older parents is still small: roughly 1.5 percent for children born to parents in their 20s, and 1.58 percent for those with parents in their 40s.

“In the big picture, that is a very small effect,” Sanders says.

That’s because most of the mutations don’t hit a gene that affects autism risk, if they even hit a gene at all, Sanders says. “It’s like James Bond standing in front of a machine gun. While there are a lot of bullets flying, very few are actually hitting the target.”

The more likely explanation for how parental age contributes to autism risk —

particularly from fathers — is that, for unknown reasons, men who have children later in life tend to carry common variants that predispose their children to autism, experts say. It is also possible that the increased incidence of autism among children born to older parents is related to changes in chemical tags on the parents’ DNA, rather than in the DNA sequence, Weinberger says. “My guess is, most of the age association is not explained by de novo mutations.”

Stefánsson and his team are analyzing de novo mutations shared by siblings. The results may help researchers determine the

likelihood that the sibling of a child with a condition caused by de novo mutations will also carry the mutation.

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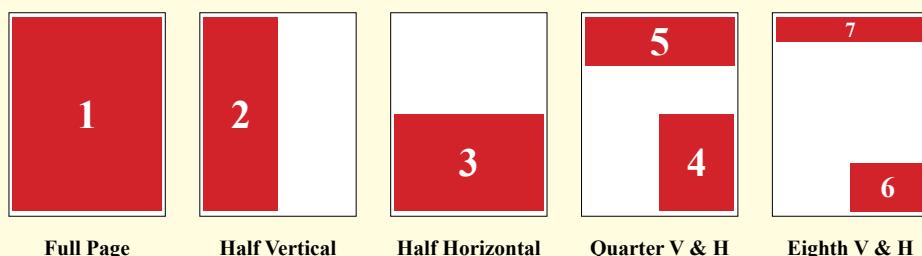
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Fall 2018 Issue - September 6, 2018



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	<u>Width</u>	<u>Height</u>
Full Page (1)	10.4	12.8
Half Vertical (2)	5.1	12.8
Half Horizontal (3)	10.4	6.4
Quarter Vertical (4)	5.1	6.4
Quarter Horizontal (5)	10.4	3.1
Eighth Vertical (6)	5.1	3.1
Eighth Horizontal (7)	10.4	1.5
Business Card (not shown)	5.1	1.5

Some see obstacles. We see outcomes.

Beacon Health Options administers Autism Spectrum Disorder services and benefits on behalf of employers, Medicaid programs, and our health plan partners under a coordinated model of care.

Our specialized autism program provides access to expert treatment and therapies for children as well as coaching support for families.

Learn how Beacon helps people live their lives to the fullest potential at beaconhealthoptions.com.

