

The Importance of Scientific Research

The Future of Autism Genetics Should Learn From Its Past

By Michael Ronemus, PhD
SFARI.org

Last month in November of 2014, my colleagues and I published two large studies that sequenced the genes or **exomes** of thousands of families with a history of autism^{1,2}. These studies identified several dozen “**high-confidence**” autism genes that show spontaneous, harmful mutations in multiple affected (and unrelated) individuals.

Picking the ripest of these low-hanging fruits — through ‘brute-force’ genomics and discovery of spontaneous, or *de novo*, mutations — has brought us much closer to understanding the genetics of autism than we were just five years ago. But to optimize what we can learn, our studies must be informed by what we have already discovered. We certainly need many more sequences from more families with autism. But these sequences need to be of the right kind.

When large-scale genomic analysis be-



gan on cohorts of people with autism, we hoped — and expected — to discover many, if not most, of the underlying genes. We have undoubtedly found many, and

perhaps even most, using the broadest criteria for an autism gene.

We can now put forth a statistically sound estimate of the overall genetic con-

tribution of *de novo* mutations of different categories to autism. (These categories include loss-of-function mutations — which prevent full protein production — and missense variants, which have a less clear effect on protein function³.) There is little doubt that this approach remains the most powerful weapon in today’s arsenal — not just for autism spectrum disorders, but other neuropsychiatric and sporadic genetic disorders as well.

But we still cannot pinpoint the causal mutations for many cases of autism because the genomic background noise remains high: More than half of even the most damaging single hits to a protein are present in an individual by chance and are not linked to autism. Given this, it is not always clear what to tell clinicians and genetic counselors who are on the front line and wish to make use of these data.

So what is the future of family-based genomic studies of autism, with detection of *de novo* mutations as the central focus?

see Genetics on page 20

Evidence-Based Reading Intervention Practices for Students with ASD

By Tamara Sterling, MS, CCC-SLP, TSSLD
Speech-Language Pathologist

Reading proficiency is a skill that is necessary to function in society. Yet, low reading scores during the school years continue to be a persistent trend in the U.S. The Annie E. Casey Foundation (2014) reports that 66% of U.S. students are not reading proficiently and are not prepared for future success. The No Child Left Behind Act of 2001 and The Individual with Disabilities Education Act (IDEA) of 2004 mandate high academic standard opportunities and evidence-based practice (EBP) instruction for all student — including students with autism spectrum disorders (ASD). Students with ASD are increasingly being incorporated in general education classrooms where there is a strong emphasis on reading proficiency (Lanter & Watson, 2008). Reading instruction has been given relatively little focus in EBP analysis with regard to students with ASD (Spector 2011).

The research is evolving and shows that there are proven methods of reading interventions for students with ASD. This paper will explore the evidence-based practices for reading intervention (sight word and reading comprehension instruction) in students with ASD.

The reading profile of students with ASD is heterogeneous (Nation, Clarke, Wright, & Williams, 2006). It is the general consensus that students with ASD are great readers because of their ability to decode due to their unique rote abilities. Caution should be taken with this generalization because of the varying degrees of cognitive and linguistic skills seen in students with ASD and because word reading does not always indicate that meaning is being stemmed from the printed text. When students’ decoding skills far exceed their reading comprehension skills, they are described as having hyperlexia. These students have a compulsive preoccupation with reading and an early onset of precocious word reading skill that is unparalleled to their reading comprehen-

sion (Lanter & Watson, 2008). Children with hyperlexia are often diagnosed with ASD or may present with characteristics of ASD (Nation, 1999). On the other hand, decoding words can also be challenging to students with ASD. Nation et al., (2006) found that decoding impairment was more prevalent in students with ASD than in the general population.

Historically, students with ASD are disqualified from reading programs because of erroneous beliefs that they cannot cognitively access the curriculum. Today, federal laws mandate schools to use EBP to teach reading to all students. Evidence-based reading interventions assist students with ASD to become proficient readers. The current best evidence, research-proven reading instruction for students with ASD, that should guide clinical and academic practice, are sight word instruction and reading comprehension intervention.

Sight Word Instruction - Sight word instruction is beneficial for students with ASD (Spector 2010). It is useful in fostering a

sense of accomplishment and motivation in learning to read (Broun 2004 as cited in Spector 2010). It is a more accessible starting point intervention than phonics-based approaches for students with ASD who have challenges with abstract, auditory-based concepts (Broun & Oelwein, 2007 as cited in Spector 2010). Reading programs usually incorporate sight word instruction for high utility words that are not decodable. Sight word instruction benefits students with ASD because its mastery enables them to execute functional tasks such as reading grocery lists, menu items, directions, recipes, and environmental signs (Browder & Xin, 1998 as cited in Spector 2010).

Spector (2010) examined the evidence on sight word instruction as a means of teaching student with ASD to read printed words. The results showed the following as research-proven reading instruction for students with ASD: *Visual supports* — Students were required to match food logos,

see Reading on page 21

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It Takes Brains to Solve Autism

By Carol Koch
Director of Special Projects
Autism Science Foundation

If you have autism or are a family member of someone with autism, you now have a unique opportunity to contribute to important research that can lead to better understanding and treatment of autism. Last year, the Simons Foundation and Autism Speaks announced the establishment and funding of a new collaboration among leading research institutions devoted to advancing brain research. In May 2014, the *Autism BrainNet*, along with its public outreach program *It Takes Brains*, was formally launched and is urging people, whether or not affected by autism, to register for brain tissue donation.

There is a severe shortage of brain tissue for research. Brain tissue must be retrieved within 24 hours of a donor's death, and brain tissue donation is a separate process from organ donation. Because it has been so difficult for researchers to procure brain tissue without advance registration, *It Takes Brains* seeks to make the public, especially families affected by autism, aware of the promise of brain research and the critical need for people to register to donate brain tissue. The *It Takes Brains* website (www.takesbrains.org) provides detailed information about registration and donation. The *It Takes Brains* initiative is being



directed by the Autism Science Foundation, the MIND Institute of the University of California at Davis, Autism Speaks, and the Simons Foundation's Autism Research Initiative (SFARI).

A primary message of *It Takes Brains* is that people who register for brain donation are "Superheroes" in the mission to understand and treat autism. *It Takes Brains* profiles the Matthews family of New York, a family of five that includes a child with autism. Even though the Matthews family

is coping with autism every day, they have registered with *Autism BrainNet* because they want to help future generations benefit from brain research. In order to obtain optimal research results, the *Autism BrainNet* needs to study brain tissue from donors with autism, from donors who are parents or siblings of people with autism, and also from donors who are unrelated to anyone with autism.

The *Autism BrainNet* is currently comprised of the MIND Institute of the Uni-

versity of California at Davis, The Icahn School of Medicine at Mount Sinai in New York, The University of Texas Southwestern Medical School, and Harvard University/Beth Israel Deaconess Medical Center. There are plans to add sites for brain research across the US and internationally. *Autism BrainNet* was formed because postmortem studies on brain tissue represent the best way for researchers to gain a deeper understanding of autism on the genetic, cellular, and molecular levels. While imaging techniques like MRIs give scientists some information, the only way to fully understand the differences in brain structure and functioning for people with autism is to examine the whole brain after death. The people behind *Autism BrainNet* understand that brain donation is a difficult subject for many and takes courage to discuss, but want the public to understand that brain research is the most promising way by which scientific research can lead to improvements in the quality of life for those on the autism spectrum.

All individuals and families affected by autism need to discuss and plan for the future. While many families discuss wills, trusts, guardianships, and vocational and living arrangements, *It Takes Brains* is urging people who support autism research to take a step further and consider registering with the *Autism BrainNet* now, as a way of

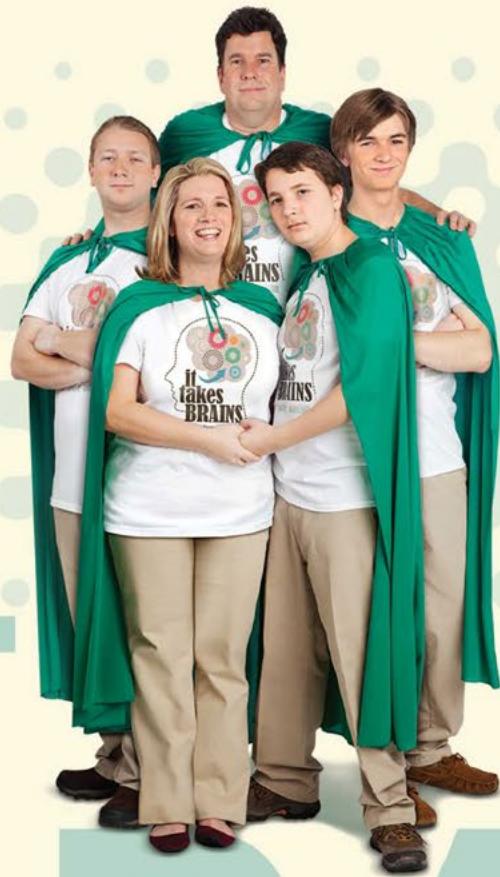
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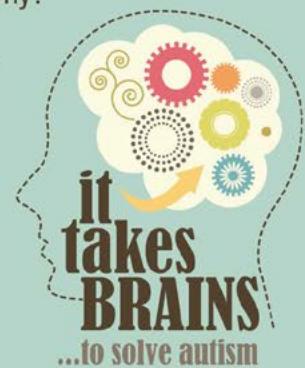
IT TAKES BRAINS TO SOLVE AUTISM

The Matthews never saw themselves as a “super” family, yet when they bonded together to support their autistic son Casey, they were indeed super. And now the Matthews and families like them around the world are being looked upon as super heroes. Why?

They have all been united by one brave and heroic act...pledging to donate the brain tissue of their sons and daughters for when they are sadly no longer with us. It's difficult to think about, but the reality is that brain tissue is urgently needed for the scientific research that will help thousands of people with autism.

Join forces with the Matthews and other super hero families to help ensure a brighter future for all. Because it takes brains to solve autism.

Visit **TakesBrains.org** to learn more and see how your entire family can help build a better tomorrow.



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Changes in Scores of Genes Contribute to Autism Risk

By The Mount Sinai Hospital at
The Mount Sinai School of Medicine

Small differences in as many as a thousand genes contribute to risk for autism, according to a study led by Mount Sinai researchers and the Autism Sequencing Consortium (ASC), and published on October 29th, 2014 in the journal *Nature*.

The new study examined data on several types of rare, genetic differences in more than 14,000 DNA samples from parents, affected children, and unrelated individuals - by far the largest number to date - to dramatically expand the list of genes identified with autism spectrum disorder (ASD).

Most of the genes that contribute to autism remain unknown, but the current study increases the number of definitive autism genes almost fourfold to 33, compared to the 9 genes most closely tied to risk in recent years by similar studies in several labs. It also identified more than 70 additional, likely ASD genes. Each of these genes is mutated in more than 5 percent of individuals with autism, signifying a large, relative contribution to risk for a complex genetic disease.

By casting a wider net, a research team from 37 institutions found that previously unsuspected sets of genes may be involved in ASD risk, including some that control how nerve networks form in the brain.



Joseph D. Buxbaum, PhD

Occurring in one out of 68 children in the U.S., ASD affects a person's social interactions, including communication, as well as behaviors with varying levels of severity.

"The steps we added to our analysis over past studies provide the most complete theoretical picture to date of how many genetic changes pile up to affect the brains of children with autism," said Joseph D. Buxbaum, PhD, Professor of Psychiatry, Neuroscience and Genetics and Genomic

Sciences at the Icahn School of Medicine at Mount Sinai and Director of the Seaver Autism Center. Dr. Buxbaum is senior author for the *Nature* study, together with Mark J. Daly, PhD, co-director of the Program in Medical and Population Genetics at the Broad Institute of MIT and Harvard. "Beyond autism, we think this work will yield insights into what makes us social beings," Dr. Buxbaum said.

"While we have very strong findings in these genetic analyses, newfound genetic discoveries must next be moved into molecular, cell and animal studies to realize future benefits for families," added Dr. Buxbaum. "A study like this creates an industry for years to come, with labs worldwide checking the brain changes linked to each new genetic finding, and searching for drugs to counter them."

For the first time, the study authors were able to assess the effects of both inherited genetic differences and those that happen spontaneously in the sperm and eggs that go on to form human embryos. While small, rare genetic differences in the top 107 genes were found to confer a relatively large jump in a person's risk, many more changes in other genes add smaller amounts of risk. According to the authors, the interplay between gene variations, both common and rare, holds the key to understanding autism. Along these lines, the team, by looking at how many times variations occurred in each of the 107 genes,

was able to predict that small differences in about 1,000 genes will eventually be found to increase autism risk.

Assembling by far the largest autism study to date, the international research team collected and analyzed data from 3,871 autism cases, 2,270 sets of mothers, fathers and their affected children, and additional control samples. This was achieved through the Autism Sequencing Consortium (ASC), originally funded by the Beatrice and Samuel A. Seaver Foundation and the Seaver Autism Center within the Icahn School of Medicine at Mount Sinai. The ASC is a multiple Principal Investigator grant funded by the National Institute of Mental Health (NIMH), with additional support from the National Human Genome Research Institute (NHGRI). In addition to Drs. Buxbaum and Daly, the PIs are Drs. Bernie Devlin (University of Pittsburgh School of Medicine)/Kathryn Roeder (Carnegie Mellon University), and Matthew State (University of California, San Francisco). Dr. Buxbaum is the communicating PI.

The consortium shares patient data because no single lab has enough to identify obscure genetic patterns scattered across thousands of genomes. The ASC continues to add patients because so far the number of risk genes found has steadily increased with the number of patients studied. Its

see Risk on page 20



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The Daniel Jordan Fiddle Foundation Announces Groundbreaking Initiatives at Yale School of Medicine and University of Miami CARD

By Linda Walder Fiddle
 Founder and Executive Director
 The Daniel Jordan Fiddle Foundation

The Daniel Jordan Fiddle Foundation (DJFF), the nation's first not-for-profit organization to focus exclusively on adults living with autism, has launched two groundbreaking initiatives designed to enrich the lives of autistic individuals throughout their lifespan.

With endowment gifts of \$100,000 each to two of the nation's leading universities, DJFF is helping to ensure that a laser focus will be placed on providing the best lives possible for adults affected by autism for generations to come.

First, DJFF partnered with Yale University Medical School's Center for Translational Developmental Neuroscience <http://childstudycenter.yale.edu/research/index.aspx> to establish the nation's first-ever research fund specifically dedicated to study adults and how aging impacts autism.

The Daniel Jordan Fiddle Foundation Adult Autism Research Fund will be led by Roger J. Jou, MD, PhD, who is a leading autism researcher, and one of the few physician-scientists in the nation who has dedicated his career to the research and care of adults living with autism.

"Autism is a life-long condition, most of



Linda J. Walder, Founder and Executive Director of The Daniel Jordan Fiddle Foundation with Dr. Michael Alessandri, Executive Director of the University of Miami Center for Autism and Related Disabilities

which is spent in adulthood," says Dr. Jou. "Our partnership with The Daniel Jordan Fiddle Foundation represents an expansion of our commitment to include adults of all ages living with autism."

Linda J. Walder, Founder and Executive Director of The Daniel Jordan Fiddle Foundation reports that this groundbreaking research fund will endure in perpetuity and ensure that vital research continues to

focus on how autism affects individuals throughout their lifespan.

Says Linda Walder, "Currently there is virtually no research being done relating to adults and autism, so this collaboration with Yale will lead the nation and, hopefully, provide much needed insights that will medically benefit individuals and that will enhance their daily lives."

Dr. Jou reports that key areas of research will include late adulthood given the risk of comorbidities. Depression and dementia will be two key areas of focus, given their increased risk in other developmental disabilities.

DJFF's second gift of \$100,000 established a new endowment fund at the University of Miami's Center for Autism and Related Disabilities (CARD) that will spearhead the further development of their world-renowned programs and enable the establishment of much-needed new programs and services for adults. With the establishment of this fund, CARD's adult and transition services will be aligned under the name **The Daniel Jordan Fiddle Foundation Transition and Adult Programs**.

Says Walder, "We are thrilled to collaborate with CARD's executive director Dr. Michael Alessandri, a visionary in the field of autism for over 25 years who has created

see Fiddle on page 23

This is what success looks like...



This is what an adult living with autism looks like!

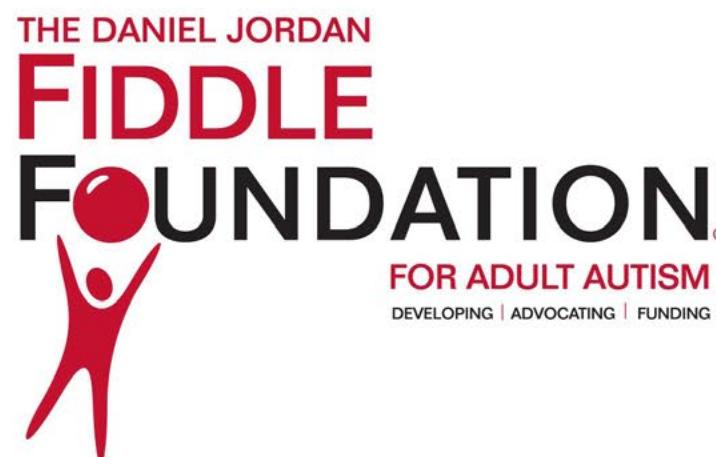
Building successful futures for adults living with autism takes innovative program development, advocacy, funding – and a belief in their strengths, talents and promise.

The Daniel Jordan Fiddle Foundation Signature Programs provide the blueprints that create opportunities for the diverse population of adults living with autism to build rewarding futures.

To learn more about
 The Daniel Jordan Fiddle Foundation
 visit: www.djfiddlefoundation.org

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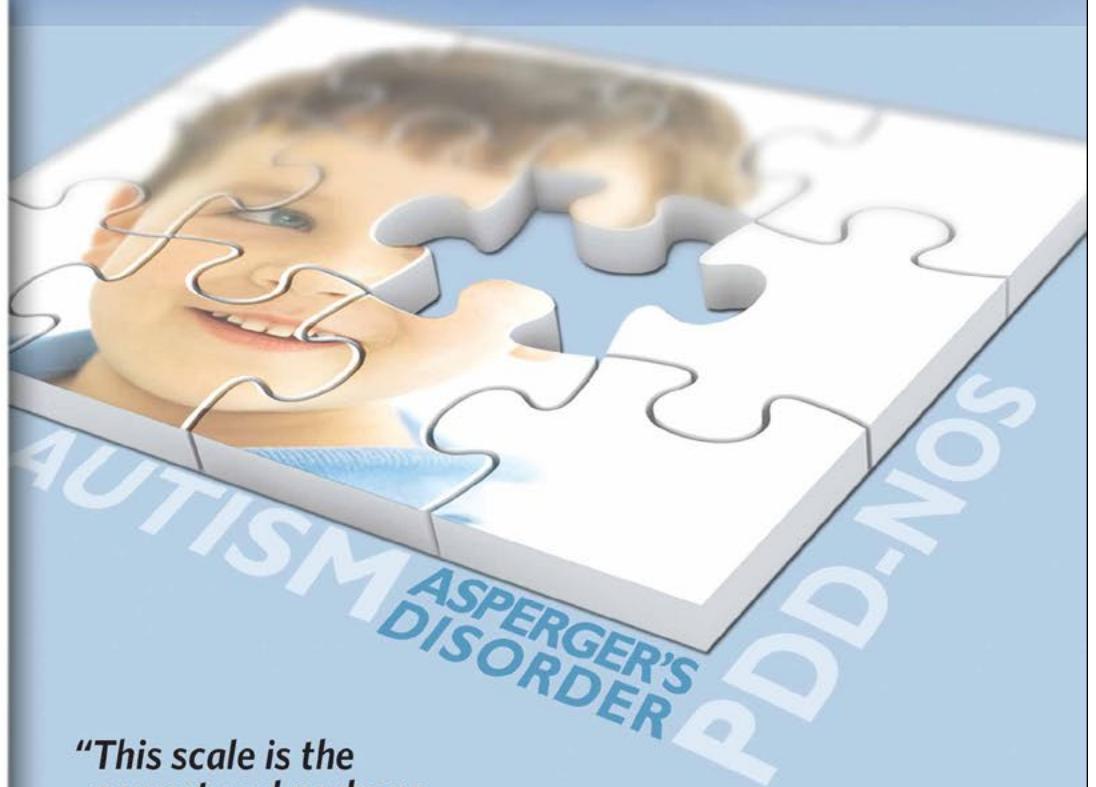
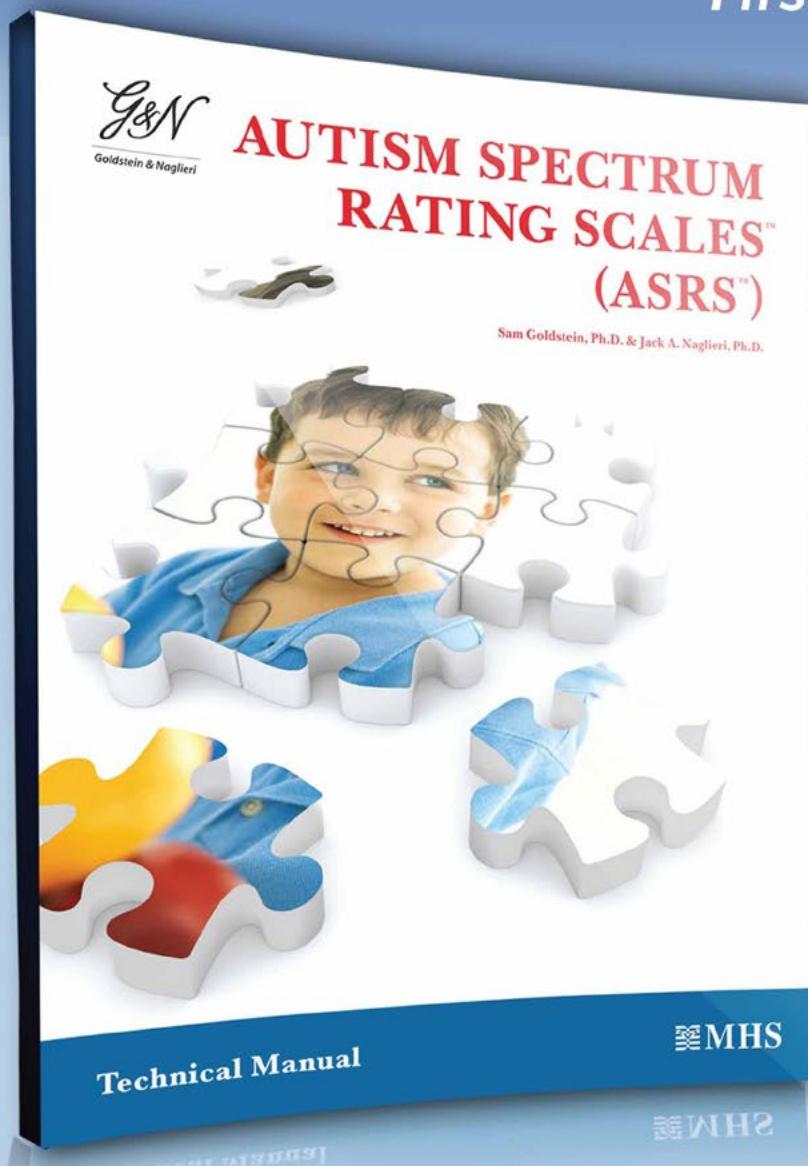
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-Kirsh, Aimee A. Assessment With Aimee, The Ohio School Psychologist, Volume 55, Number 2.

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President Obama Signs ABLÉ Act

Major Victory for Persons with Disabilities and Their Families

By The National Disability Institute

On December 19, 2014, President Barack Obama signed into law the Achieving Better Life Expectancy (ABLE) Act. First introduced in 2006, and subsequent sessions of Congress, the ABLÉ Act will allow people with disabilities (with an age of onset up to 26 years old) and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life.

"Today marks a new day in our country's understanding and support of people with disabilities and their families," Michael Morris, National Disability Institute (NDI) Executive Director, said. "A major victory for the disability community, ABLÉ, for the very first time in our country's policy on disability, recognizes that there are added costs to living with a disability." He continued. "For far too long, federally imposed asset limits to remain eligible for critical public benefits have served as a roadblock toward greater financial independence for the millions of individuals living with a disability."

NDI has long championed the ABLÉ Act as a critical strategy to providing a pathway to a better economic future for all people with disabilities. As the nation's



first nonprofit dedicated to improving the financial health and future of all people with disabilities, the organization has extensively documented and called attention to the daily reality and extra expenses associated with living with a disability, and the challenges of navigating the complex web of government rules to maintain public benefits eligibility.

In recognition of this unprecedented legislation, NDI has created a list of 10 items

about ABLÉ accounts that individuals with disabilities and their families should know:

ABLE Accounts: 10 Things You Must Know

1. What is an ABLÉ account?

ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, will be created

as a result of the passage of the ABLÉ Act of 2014. Income earned by the accounts would not be taxed. Contributions to the account made by any person (the account beneficiary, family and friends) would not be tax deductible.

2. Why the need for ABLÉ accounts?

Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than \$2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor. For the first time in public policy, the ABLÉ Act recognizes the extra and significant costs of living with a disability. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare.

For the first time, eligible individuals

see ABLÉ Act on page 23

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Naturalistic Intervention in Classrooms: A Look at Classroom Pivotal Response Teaching

By Sarah Vejnaska, BA,
Janice Chan, MA, BCBA,
Sarah Rieth, PhD, BCBA-D,
Jessica Suhrheinrich, PhD, and
Aubyn Stahmer, PhD, BCBA-D

Classroom Pivotal Response Teaching, or CPRT, is a naturalistic behavioral intervention designed for classrooms serving students with autism spectrum disorder (ASD). CPRT was created by modifying an evidence-based practice called Pivotal Response Training (PRT), which strives to improve learning in children with ASD through increasing their motivation. PRT is naturalistic in that it is intended to be used in natural learning environments (places and activities that are part of a child's daily routine), and behavioral in that it is based on the principles of applied behavior analysis (ABA). ABA involves modifying antecedents (what occurs before a behavior, such as an instruction) and consequences (the result of behavior, such as feedback from the teacher or access to an item or activity) to produce changes in behavior. Naturalistic behavioral strategies such as PRT have strong research support and are recommended for improving learning in children with ASD (National Standards Project, 2009; Odom, Collet-Klingenberg, Rogers,



& Hatton, 2010). However, due to their complexity, often the use of these strategies in community settings can be challenging.

Research conducted in Southern California indicates that over 70% of teachers use PRT strategies in their classrooms, but they also report modifying the procedures to work better for their individual settings (Stahmer, 2007). As researchers, we felt it important to better understand the modifications teachers were making to the pro-

cedure to ensure the intervention remained effective after alteration. We also wished to create a protocol for use of the strategies in the classroom to provide guidance for teachers on how to use PRT in a way that fit with their environment. To meet these goals, a team of researchers, teachers, and school administrators collaborated to: (1) gain a clear picture of the adaptations necessary to make PRT meet the demands facing special education teachers; (2) test the

effectiveness of the adaptations; and (3) develop a manualized program to help teachers use the intervention (Stahmer, Collings, & Palinkas, 2005). Based on teacher feedback, the original procedures of PRT were systematically adapted to give more information on how to use PRT with groups of children, target specific IEP goals using PRT strategies, and train classroom assistants to use PRT. Teachers also requested adaptation of some components they found difficult to use in groups, and adaptations were tested in a research setting (Reed, Stahmer, Schreibman, & Suhrheinrich, in press; Reed, Stahmer, Suhrheinrich, & Schreibman, 2013; Rieth et al., 2013). These modifications were made by teachers and for teachers to form a novel classroom intervention known as CPRT (Stahmer, Suhrheinrich, Reed, Bolduc, & Schreibman, 2011).

CPRT is supported by years of research conducted on the components of PRT. CPRT involves eight critical components, each of which is also part of PRT and adapted for classroom use. The components are:

Antecedent Components

1. Gain Student Attention: The teacher gains the student's attention before asking him to say or do something.

see CPRT on page 26

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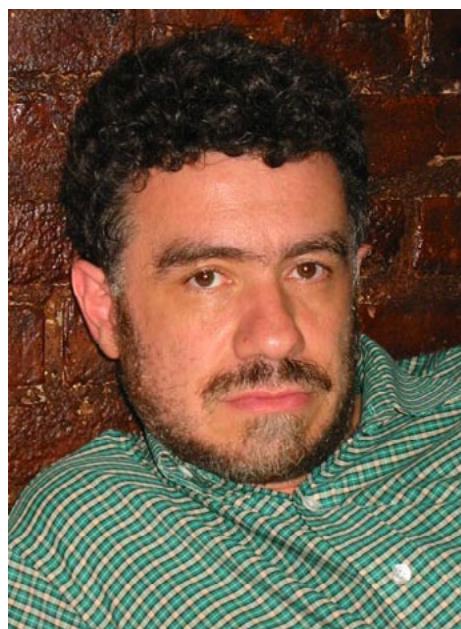
Autism and Science: A View From Across the Neural Divide

Karl Wittig, PE
 NYC Regional Facilitator
 and Board Member
 GRASP

I am writing this because I am in the somewhat unusual position of not only being on the autism spectrum and fairly involved in the autism community, but also of coming from a scientific background, even if not in the field of autism (I am a retired electronics engineer with degrees in physics, electrical engineering, and computer science who had a career in research and development laboratories). As such, I am a great believer in the value of scientific research to the autism community.

I should begin by noting that the very discovery of autism as a neuropsychological condition came about only as a result of modern science, originally through the work of Leo Kanner (1943) and Hans Asperger (1944, more recently rediscovered by Lorna Wing), and its subsequent understanding only because of the efforts of countless scientific and medical researchers.

Although I had suspected that I might have some form of autism for the preceding ten years, I did not finally self-diagnose until August of 2000 at the age of 44. I was able to do this because, when I examined the criteria for Asperger Syndrome, I found that I readily met virtually all of them and,



Karl Wittig, PE

when I looked at lists of the typical traits of affected individuals (which I should note were generally more specific than vague), I saw that a very high percentage of these applied to me – much too high for it to have been a coincidence. Nevertheless, I understood that this was entirely subjective and so I consulted a specialist who could confirm my suspicions and ascertain that I was not just “kidding myself”. As it happens, I also had very strong evidence from

my childhood (my mother had kept a diary of my early development which described numerous classic autistic traits). This made straightforward and confident what might otherwise have been a difficult and tenuous diagnosis, given my advanced age. In short, I tried to approach this in as scientific a manner as I was able to at the time.

I responded to my diagnosis by learning as much about Asperger Syndrome and autism as I could, reading every book, article, and website that I could find on the subject and attending every conference and lecture that I could get to. When I learned that Temple Grandin had participated in scientific studies of autism, mainly involving brain imaging, I realized that this was something that I wanted to do (given my own scientific background). Consequently, when the opportunity to be in such a study presented itself, I immediately volunteered. I have since been in one study at the Seaver Center for Autism of Mount Sinai Hospital and two at the Child Study Center of New York University. I am also participating in the Autism BrainNet initiative that encourages people on the spectrum to posthumously donate brain tissue, which is in very short supply, for autism research purposes.

Current scientific research in autism primarily takes place in the areas of genetics/genomics and of neuroscience/psychology. Although it has not yet led to comprehensive explanations of either the nature or cause of autism, a great amount of knowl-

edge has been gained and significant advances in understanding have been made. Although not a specialist, I frequently attend conferences and lectures about autism science and have enough of a layperson's background to grasp the essence if not understand all the details of such talks. More importantly, I am often able to appreciate the significance of what is being discussed to those of us on the spectrum. As much promise as this research may have for fundamental understanding, we in the autism community nevertheless need to be concerned about things that have a more immediate impact on the lives of those who are affected by autism.

The true significance and value of current basic research will in many cases not be fully known until well into the future. What is of direct value in the present is the knowledge that autism, in its various forms, has a scientific basis and explanation even if it is only partly understood. This can help us in the areas of awareness, accommodation, and acceptance (what I refer to as the three A's) of autism by our local communities and by society in general. We need to promote greater awareness that individuals with autism face certain challenges due to a condition that they were born with, better understanding of how to accommodate these challenges, and acceptance of the fact that we are as much

see *Neural Divide* on page 22

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Paving the Road to Success

Debra Solomon, BS
Life and Career Coach
Spectrum Strategies

There is increasing interest in helping talented individuals on the Autism Spectrum become more fully engaged in the typical world of work, and establish true independence and self-sufficiency. Autism Speaks has promoted a tool kit for employers, adults on the spectrum and their families, to think about these issues. However, individuals need more experiential opportunities to develop, generalize and maintain the skills to succeed at work and flourish in life.

Raul Jimenez and Amy Greenberg of New Frontiers in Learning stated, "As future employers continue to become educated on disability in the workplace, vocational advocates and coaches can provide a crucial and highly empowering service in aiding, organizing and acclimating individuals with Autism Spectrum Disorders (ASD) to the world of work (Autism Spectrum News)." That model is exactly what inspired Life and Career coach, Debra Solomon, to start Spectrum Strategies, a coaching service designed to help young adults create a road map for a successful future. According to the Journal of the American Academy of Child & Adolescent Psychiatry, in 2013, a reported 53.4% of young adults with ASD have ever



Debra Solomon, BS

worked for pay within the first eight years after graduating high school. Through a four-series workshop, Spectrum Strategies provides these individuals with the tools and guidance necessary to help them create their own road map to a successful and autonomous future.

The workshop is for men and women, ages 18 to 30, and includes both personal and professional training, with a focus on four key strategies for life; *A Typical Day in Your Life*, *Making Your Life More Pro-*

ductive, *Managing Your Life* and *Fit for Life*. Each module will be for a period of three weeks.

Developing confidence in any one area of life will lead to confidence and success in another. As stated by the Center on the Developing Child at Harvard University, "When children have opportunities to develop executive function and self-regulation skills, individuals and society experience lifelong benefits. These skills are crucial for learning and development. They also enable positive behavior and allow us to make healthy choices for ourselves and our families." Participants of the workshop practice these skills in an environment that will both improve and promote positive results in their personal, academic and professional lives.

To help establish this desired level of social confidence, each training session begins with an activity that connects with the particular lesson of that module. For example, as many are often hesitant to share their thoughts aloud, participants anonymously submit the challenges they have experienced. The group then works together to address these key areas of function.

The first module, *A Typical Day in Your Life*, works with participants to develop time management and organizational skills to outline daily responsibilities and improve overall productivity. Attendees write down a typical day in their lives and

work together to organize each day, and brainstorm areas for improvement. For example, by going to bed earlier each night, and waking up at an appropriate time each morning, participants establish a concrete foundation for a more productive day. Such enables the group to develop the necessary time management and organizational skills, and carry-on these tools into their everyday lives, even as daily responsibilities may change.

As part of *Making Your Life More Productive*, participants identify future goals whether they are to attend college, or be hired for a job. The module helps to discover areas of strengths and challenges, as well as areas of interests to better leverage their abilities, and improve the necessary skills to achieve their goals. For example, those wishing to attend post-graduate education practice the application process, and work to establish a potential major, or trade. Those looking for employment learn the steps needed to complete a job application and resume. Participants then engage in role-playing during which, they are asked typical interview questions, which develop key interview skills. Appropriate dress, eye contact, body language and verbal communication are all addressed.

Managing Your Life is a module in which the group discusses the topic of budgeting.

see Success on page 24



Debra Solomon is pleased to announce that she will be offering, through Spectrum Services, a series of four Independence Workshops beginning in the winter of 2015. Each module of the series will focus on a variety of skills ranging from time management and organizational skills, to self-advocacy to managing life and work, and will continue Saturdays for a period of 3 weeks each.

Workshops will focus on strategies for life:

A Typical Day in Your Life – Managing time and daily responsibilities

Making your Life More Productive – Planning your life path and developing productive steps to meet your goals

Managing Your Life – Coping with the nitty-gritty of everyday life management

Fit For Life – Improving your skills to handle personal and professional roles and the daily challenges of school and career

After an intake appointment, participants will be offered a chance to participate in individual modules or the whole series.

To inquire about details, including fees and schedule, please contact Debra Solomon at debra@spectrumroadmap.com or 516-510-7637.

For more information on Debra Solomon's coaching practice, please visit www.spectrumroadmap.com.

Autism Spectrum News Honors Leaders at New York City Event

Staff Writer
Autism Spectrum News

The speaker at the lectern began his remarks. “Good evening everyone, I am Dr. Jorge Petit. I am honored to be Chairman of the Board of Mental Health News Education, Inc., publishers of Autism Spectrum News and Behavioral Health News. Welcome to our Second Annual Autism Leadership Awards event.”

The Autism Spectrum News Second Annual Leadership Event honored two outstanding leaders of the autism science community, Joseph D. Buxbaum, PhD, Director of the Seaver Autism Center at the Icahn School of Medicine at Mount Sinai Hospital, and Alison Singer, MBA, President of the Autism Science Foundation.

Dr. Buxbaum is the G. Harold and Leila Y. Mathers Professor of Psychiatry, Neuroscience, and genetic and genomic Sciences, the Head of The Laboratory of Molecular Neuropsychiatry, and the Vice Chair for Research in the Department of Psychiatry at Mount Sinai. Dr. Buxbaum is the Director of the Seaver Autism Center, and his research focuses on using techniques of molecular genetics and neurobiology to identify, and ultimately characterize, genes that contribute to autism susceptibility. His laboratory has identified common and rare genetic variants that underlie autism spectrum disorders and has developed model systems in which novel therapeutics can be tested. In addition, Dr. Buxbaum has taken a lead in several international consortia, most recently the Autism Sequencing Consortium aimed at sequencing 20,000 exomes, dedicated to advancing research in autism



Event Honorees
Joseph D. Buxbaum, PhD
and Alison Singer, MBA

spectrum disorders. Dr. Buxbaum is the author of more than 200 publications, and he is co-editor-in-chief of the journal *Molecular Autism* (www.molecularautism.com).

Alison Singer is Co-Founder and President of the Autism Science Foundation, a non-profit organization dedicated to funding autism research and supporting the needs of families raising children with autism. As the mother of a child with autism and legal guardian of her adult brother with autism, she is a natural advocate. Since 2007, Singer has served on the national Interagency Autism Coordinating Committee (IACC) which is charged with

writing a strategic plan to guide federal spending for autism research. Within the IACC, she served as co-chair of the safety subcommittee and currently sits on the subcommittees for Strategic Plan Review and Services. Singer also currently serves on the executive board of the Yale Child Study Center, on the external advisory board of the Marcus Autism Center at Emory University, and on the external advisory board of the CDC’s Center for Birth Defects and Developmental Disabilities. In 2012, the American Academy of Pediatrics named her an “autism champion.” Alison currently chairs the International Society for Autism Research public relations committee and is a member of the IMFAR program committee and community advisory committee. Prior to founding the Autism Science Foundation in 2009, she served as Executive Vice President of Autism Speaks and as a Vice President at NBC. She graduated magna cum laude from Yale University with a BA in Economics and has an MBA from Harvard Business School.

The Autism Spectrum News Annual Leadership event was held at the corporate office of EmblemHealth in Lower Manhattan, who donated space for the event. According to Dr. Petit, “We are indeed grateful to EmblemHealth for their generosity in donating space for our event.”

The honorees each received the Autism Spectrum News Beacon of Hope Award. Dr. Buxbaum received the Beacon of Hope Award in Scientific Research, “In recognition of his vital research in genetics and neurobiology that has led to an increased understanding of the cause and treatment of autism spectrum disorders.” Mrs. Singer received the Beacon of Hope Award in Ad-

vocacy and Philanthropy, “In recognition of her tireless efforts to advocate for families touched by autism and her dedication to unlocking the mysteries of autism by funding vital scientific research.”

According to David Minot, Associate Director of Mental Health News Education, Inc., and Publisher of Autism Spectrum News, “We are so proud of this year’s honorees for the incredible work they do to better the lives of individuals and families struggling with autism spectrum disorders, and for their work in advancing the science which may one day unlock the mysteries behind the causes of these disorders.”

Mr. Minot went on to praise his dedicated 2014 Autism Spectrum News Leadership Event Committee who worked with him to put on this year’s successful event. “I want to give a special thanks to the members of our event committee, without whom this event would not have been possible. They are: Susan M. Cortilet-Jones, a member of the ASN Editorial Board, Judith R. Omidvaran, a member of the ASN Editorial Board and the MHNE Board of Directors, Theresa Pirraglia, a member of the ASN Editorial Board and the MHNE Board of Directors, Patricia Rowan, a member of the ASN Editorial Board, and Dianne Zager, a member of the ASN Editorial Board and the MHNE Board of Directors. I would also like to give a very special thank you to Thomas Hwang, a young man on the spectrum who provided us with his wonderful piano playing for the event. Finally, I would like to thank all of our generous sponsors, donors, honorees, guests and volunteers for making the Autism Spectrum News Second Annual Leadership Reception a tremendous success!”

Photo Gallery of Attendees at Our Leadership Event

Staff Writer
Autism Spectrum News

We would like to thank everyone who attended our Annual Leadership Event. We tried to take photos of everyone, but may have missed a few of you who were there. Here is an index of the photographs taken at the event that are shown on page 15.

#1 David Minot, BA, Associate Director, Mental Health News Education, Inc. (MHNE) and Publisher of Autism Spectrum News, Joseph D. Buxbaum, PhD, Director of the Seaver Autism Center Icahn School of Medicine at Mount Sinai Hospital, and Ira Minot, LMSW, Founder and Executive Director, MHNE

#2 Alex Kolevzon, MD, Associate Professor of Psychiatry and Pediatrics, Clinical Director, Seaver Autism Center at Mount Sinai, who presented the award to Alison Singer, MBA, President of the Autism Science Foundation

#3 Joseph D. Buxbaum, PhD, and his

daughter Adina Buxbaum, PhD, Postdoctoral Research Fellow, Albert Einstein College of Medicine who presented the award to her father

#4 David Minot, BA, Alison Singer, MBA, and Ira Minot, LMSW

#5 David Minot, BA, and Judy Omidvaran, MHNE Board Member and ASN Editorial Board Member

#6 David Minot, BA, and Constance Brown-Bellamy, MPA, MHNE Board Member

#7 Lois Perlman and Barry Perlman, MD, MHNE Board Vice-Chairman

#8 Alan Eskenazi, MA, CPHQ, CASAC, MHNE Board Member and David Minot, BA

#9 Naomi Weinstein, MPH, MHNE Board Member and Jorge Petit, MD, MHNE Board Chairman

#10 Ira Minot, LMSW, and Former Chairman, Peter Campanelli, PsyD, Child Psychologist, McSilver Institute for Poverty, Policy, & Research

#11 Alan Trager, LCSW, MHNE Board Member and Jorge Petit, MD

#12 Susan Cortilet-Jones, MS, LMHC, ASN Editorial Board Member and David Minot

#13 Patricia Rowan, LMSW, ASN Editorial Board Member and Mary Zingaro, Parent Advocate

#14 Carey Zuckerman, ASN Editorial Board Member and Judy Omidvaran

#15 Peter Campanelli, PsyD, Barbara Lindner, Director, Behavioral Health Services Line, NY Presb. Hospital & Stuart Linder

#16 Danielle Halpern, PsyD, Assistant Clinical Professor of Psychiatry and Director of Psychology Training, Seaver Autism Center at Mount Sinai, Joseph D. Buxbaum, PhD, & Michelle Gorenstein-Holtzman, PsyD Assistant Professor of Psychiatry and Director of Community Outreach, Seaver Autism Center at Mount Sinai

#17 Alex Kolevzon, MD and Alison Singer

#18 Paul Novello, LCSW, Clinical Services Director, ValueOptions and Ira Minot

#19 Thomas Hwang, the event’s piano player and his mother Maria Hwang

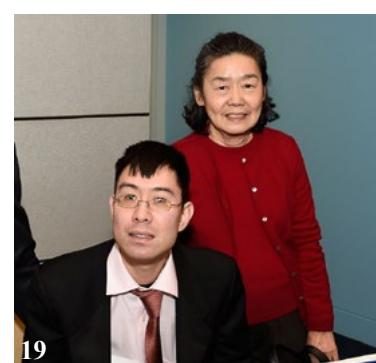
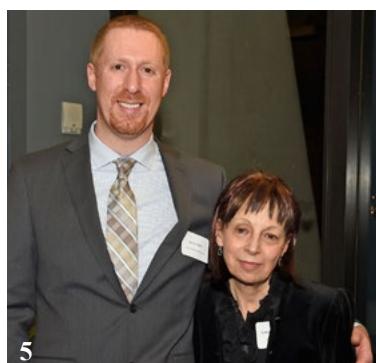
#20 Representing ValueOptions: David Glazier, VP, Stephen Ferrante, Director of Quality Management, Sarah Metter, Manager of Provider Relations and Alexander Serviss, Account Executive

#21 Ross Cooper, Director, Digital & Planning, GNF Marketing, and representing the Autism Science Foundation: Alycia Halladay, PhD, Chief Science Officer, Meredith Gilmer, Community Relations Associate, Casey Gold, Operations Manager, and Alison Singer, MBA, President

#22 Representing Serviced for the Under-Served: Elizabeth McKee, BCBA, Coordinator of Applied Behavior Analysis Services, William Shea, Behavior Intervention Specialist, Jessica Feldman, Manager of Practice Innovation, and Jesse Feldman

#23 Representing Services for the Under-Served: Amanda Duva, Registered Behavior Technician, Bessie Whitfield-Vick, Behavior Intervention Specialist, and Nevila Cerriku, Behavior Intervention Specialist

Autism Spectrum News Honors Leaders at New York City Event





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Autism a Major Theme at YAI 2015 Conference May 4-7 in New York City

By The YAI Network

Autism will be a major topic at YAI's 2015 Conference, "Living, Loving, Working and Learning," on May 4-7, at the New York Hilton Midtown, 1335 Avenue of the Americas.

The conference will feature more expanded workshops on autism, providing attendees with access to hands-on training and leading experts.

Among this year's autism workshops are:

- I Have Asperger's ... He Has Autism! Making a Romance Work
- A Musical Curriculum for Individuals with ASD
- Using Creative Arts Therapies with Middle School Children with Autism Spectrum Disorders
- Bullying and Children with ASD
- Practical iPad-Based Social Skills for Children with ASD

- Autism Support Team: A Model that Works!
- Targeting Play Skill Development in Preschool Autism Intervention
- Using Art to Enhance Literacy-Learning in Students with Autism
- Education of an Aspie: College Through My Eyes
- Preparing School-Age Students with Autism for Success in Adulthood
- Using Schedules and Other Visual Supports to Teach Skills and Promote Independence in Individuals with Autism

To request a conference brochure, visit yai.org/conference2015. Questions? Contact Abbe Wittenberg, Conference Manager, at 212-273-6472 or abbe.wittenberg@yai.org.

To reserve your hotel room at a discounted conference rate, visit our [personalized YAI group](http://personalized.yai.org) page (<https://aws.passkey.com/event/12157142/owner/6708/home>) or call 212-586-7000 and mention group code: YAI. The deadline for the discount is April 13, 2015.

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Evaluating the Ability of Learners with Autism to Work in Small Groups

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

Learners with autism do well with one on one instruction, and this is widely known. However, the provision of one-to-one instruction on a long-term basis is not efficient or realistic. Funding streams, particularly in adulthood, do not support this level of staffing. Furthermore, the ability to follow instructions delivered to a group is essential to successful integration in school, vocational and community settings.

In our clinical work at Melmark, we have found that this issue is a challenging one for educational teams. Often, there are diverse opinions about a student's readiness for group instruction. Educational team members and parents often have strong opinions about readiness for group instruction or about the need for continued individualized instruction.

Concerns about behavioral regression and about a slowed rate of acquisition often result in long-term provision of individual instruction. This is understandable, as established skills need to be maintained. Furthermore, learners with developmental delays and slowed skill acquisition need more intensive instruction to learn. Worry over loss of skills and a slowed rate of skill



Helena Maguire, MS, BCBA

development often results in long-term reliance on a 1:1 instructional ratio.

Prolonging this ratio beyond the instructional need, however, may be counter-productive. Some learners may become dependent on this level of support, and it may impede their ability to transition to settings with less rich instructional ratios. One of our primary obligations is to ensure that we prepare learners for next (and ultimate) settings. Future settings do not generally provide such rich instructional ratios. A student who requires such support as an adolescent or adult learner may have fewer



Mary Jane Weiss, PhD, BCBA-D

settings available to them.

From a clinical and research perspective, it is important to identify any learner's capacity for group instruction. There are few guidelines about how to assess such capacity. While there is agreement on the importance of reduced staffing and independent responding, there is a need for explicit tools for assessing a learner's ability to demonstrate and learn skills in a group setting.

Prior Research

Fading intensive staffing is essential to



Frank L. Bird, MEd, BCBA

the promotion of independence and the successful transitioning of our students to less restrictive settings or into adult programs. Although research has indicated that individualized instructional arrangements are highly effective with individuals with autism who display challenging behavior, the resources necessary to provide intensive staffing to all students are rare (Kamps & Walker, 1990). Not only is intensive staffing often unrealistic, some research indicates that 1:1 instructional formats hinder

see *Evaluating on page 25*

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Understanding Treatment Effect Scores in Behavioral Therapy Research

By **Monica E. Carr**
Doctoral Researcher
Monash University
Melbourne, Australia



Monica E. Carr

Current prevalence estimates released by the Center for Disease Control (CDC) suggest that one in 68 children in the United States may have Autism Spectrum Disorder (ASD) (CDC MMWR, 2014). The core impairments that characterize autism - social and communicative functioning and the presence of restricted, repetitive and stereotyped interests and behaviors - are reportedly experienced to varying degrees into adulthood (Roth, Gillis, & DiGennaro Reed, 2013). Support systems have been slow in adapting to the needs of transition aged youth with ASD and many adults on the spectrum have been described as socially isolated, economically unproductive, and financially disadvantaged (Howlin, 2008; Geller & Greenberg, 2010).

While there are a wide variety of potential treatments available for supporting individuals with ASD, a long history of failed treatments and fads has been reported (Food and Drug Administration, Consumer Health Information, 2014). In their report, the FDA warned that a number of companies may face legal action should they continue to promote false or misleading claims about products and therapies

that claim to treat or cure autism. In particular chelation therapy, hyperbaric oxygen therapy, miracle mineral solution, detoxifying clay baths, coconut kefir and other probiotic products were listed.

A combination of genetic makeup and lived experiences contribute to a unique personal profile of strengths and deficits for those on the autism spectrum, and a focus on individuality is essential when identifying treatment options. Applied Behavior Analysis (ABA) based treatments are endorsed by the U.S. Surgeon General and the New York State Department of Health.

While many children have the benefit of accessing ABA-based early intervention programs, others who face a life time of autism related challenges may grapple with little to no funding for support services. For some, geographic isolation may impact the ability to access support services while for others socio-economic factors may mean that families in under-funded communities may struggle with limited access to support services.

Accordingly, the ability for parents, teachers and clinicians alike to access and interpret scientifically robust information on evidence based treatments is essential. Researchers working in a behavioral therapy paradigm often utilize Single-Case Design (SCD) methodology as these designs make it possible to draw scientifically valid conclusions (Baer, Wolf, & Risley, 1968). SCD research is of particular importance to the autism community as these research designs are highly suitable for accommodating the unique characteristics of individuals on the spectrum. Treatment packages can be developed for older students and adults in addition to younger children.

The What Works Clearinghouse (WWC) was formed under the Education Sciences Reform Act (2002) to address the concerns of Evidence-Based Practice (EBP) and empirically-supported treatment that may enable federal and state governments to invest in educational, clinical and social practices that are scientifically valid

(Horner, Swaminathan, Sugai, & Smolkowski, 2012). The WWC Procedures and Standards Handbook describe quality assessment procedures for both group design and SCD research (Kratochwill et al., 2013). Methodology for determining strength of treatment effects in group design research is well established, however for SCD research the most appropriate approach to determine treatment effect is surrounded by ongoing debate.

The current WWC SCD pilot guidelines recommend that a treatment may be considered evidence based if a set of studies have met the minimum 5-3-20 rule:

- At least five SCD studies document experimental control;
- The five studies were drawn from at least three different research teams/locations, and;
- The five studies document effects for at least 20 different participants.

Currently, the WWC panel has cautioned against calculating a treatment effect score for SCD research until a greater consensus on a best method is reached. In the interim, visual analysis has been suggested as the preferred method to evaluate treatment effects. However, a treatment effect score

see Scores on page 24



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

By Carrie Cariello

A Boy and His Dog

Allow me to introduce myself. My name is **Wolfie**.

I am half Bichon and half Shih-Tzu, also known as a Teddy Bear Dog or a Zuchon. I am sixteen and a half pounds and I barely stand a foot off the floor, but do not let my size fool you. I may be small, but I am mighty.

I've been with my family for five months now. Everyone keeps saying the Easter Bunny brought me as a surprise.

But I remember the two biggest people in the family—the mom and the dad people—came to pick me up in a conference center off the highway in a small town called Portsmouth. We drove around for hours and then snuck home because they said *the kids* were finally asleep. I never did see a bunny.

For the first two weeks I was in my new home, I tried this strategy:

Pee on couch. Look adorable.

Poop on rug. Appear irresistible.

Pee on floor. Tilt head to one side with cutest expression possible.

This went on for a while until the dad



Jack with his dog Wolfie

guy said I was on something called *thin ice* and I'd better get house trained soon. He had just stepped in one of my puddles wearing only his socks.

He pretends he doesn't like me, this dad. But I'm not fooled by him. When it's late at night and all the small people have gone

to bed and the mom is upstairs reading, he sits on the big red couch and he calls to me in a quiet voice.

"*Wolf, come on boy, come sit with me.*"

I sit next to him and we watch shows that the mom doesn't like; baseball and politics and something weird called *The First 48*. But I can tell by the absentminded way he rubs my foot that he's only half-listening to the television. Instead he's thinking about his patients and his children and tax returns and healthcare and insurance.

There are a lot of people in this house. Seven. Two big people and five kids. One time a man came and delivered some food in a brown paper bag that smelled delicious. When he stepped into the kitchen and saw all the kids at the counter, he asked if we were having a birthday party.

The round boy laughed and shouted, "Yes! It my birthday! Let's sing HAPPY BIRTHDAY TO ME! *Happy birthday to me!*" until the mom said, "Okay, Henry, we heard you. Eat your egg roll."

This **Henry** boy is the smallest, but he isn't too small. Life is very, very exciting for him, and he is very loud about it all. He fills up every room with his chatter and his laughter and his drawings, and he is squishy and delicious and curious and smart. He is so alive, you can almost see his heart beating through his favorite Batman shirt.

There are all these boys and only one little **girl**. When you look at her you just think about the color pink. She is sweetness and light and airy and calm, like the most delicate wafer cookie you hold on your tongue until it melts.

But she works very hard. She is the first one awake to take me out in the morning, even before I ask, and all day long she is trying to do things for other people; pack their snacks or sweep the floor or straighten the playroom.

Her mother worries and the Dad guy hopes if he tells her how beautiful and smart and sweet she is, she will believe it forever and never listen if someone accuses her of being fat or ugly or stupid or worthless.

I'm not worried, because this pink girl is so very strong.

There is a very big boy, a boy who stands taller than the mom's shoulder. He wears glasses. They call him a *tween* sometimes, and I don't know what that means but it seems to annoy him.

He and the mom can really get each other going laughing. They both like the same jokes. But there is a strain that I don't think was there before. It feels new.

It feels like the beginning of something

see *Dog on page 21*

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... a positive perspective on the challenges of raising a child with autism ...
The strength of Carrie and Joe and the love that they abundantly share for each other and their family are incredibly inspiring. —Dana Finkle, The Deep Roots Foundation for Autism

what color is Monday?

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Genetics from page 1

Where to Look

The good news is that we have truly begun to narrow the search. Put simply, we have a much better idea of where to look than we used to. The cost of sequencing continues to drop, and sequencing the entire genome is rapidly becoming a financially viable option.

These data will enrich the existing dataset by uncovering genomic regions that were not accessible using previous methods^{4,5}. Dropping costs will also allow us to sequence large numbers of gene candidates in large populations, as was done previously for smaller gene sets⁶.

However, in some ways our current approach may be reaching its limit. For example, the types of mutations highlighted in our two studies are more rare in males with autism who have intelligence quotients (IQs) above 90, and the genes affected largely do not overlap with the genes mutated in females or in males with autism who have IQs of 90 or below.

This suggests that another, **relatively unexplored type of risk** — such as common

variants — perhaps with greater environmental contribution, may lead to autism in this group.

It's also possible that we have already found the most important genetic contributors to autism. Simply extending the current discovery paradigm along existing lines might yield diminishing returns, despite the many candidate genes already identified.

There is legitimate reason to question whether groups containing a large proportion of high-functioning males will be informative, at least in the near term. Genetic efforts may be most effective if directed toward females and lower-IQ males with autism, who are the most likely to carry harmful mutations.

We also need to know where not to look. Almost all families in one well-characterized group, called the **Simons Simplex Collection**, include at least one unaffected sibling. (The collection is funded by the Simons Foundation, SFARI.org's parent organization.)

This allowed us to do statistical analyses to calculate the overall likelihood of mutations being found in an individual by chance. It also allowed us to exclude genes that are mutated in unaffected sib-

lings. Without these data, the conclusions we reached would have been far murkier.

We can refine our analysis by applying statistical models to integrate information in inherited variation and studies that compare data from cases and controls with the existing *de novo* data. Data from people with other disorders are also an essential piece of the puzzle.

It is important to remember that these models need to account for the unique features of autism spectrum disorders. This includes well-established characteristics such as the high male-to-female gender ratio and the implication that females serve as carriers **due to a protective effect**.

It also includes more recent observations: for example, the lack of overlap in gene targets between males of high and low IQs and the finding that females have more deleterious mutations in genes expressed during embryonic development than would be expected by chance.

As a final note, the new studies also highlight the contribution of *de novo* 'missense' mutations, which have less clear effects on protein function. This relationship between strongly inactivating variants (harmful) and moderately inactivating

variants (missense) needs to be understood at the functional level. In many respects, the real fun is just beginning.

This article was originally published on SFARI.org and is reprinted with permission. You may view the original article, published 9 December 2014, at <http://sfari.org/news-and-opinion/viewpoint/2014/future-of-autism-genetics-should-learn-from-its-past>.

Michael Ronemus is research assistant professor at Cold Spring Harbor Laboratory in New York. News and Opinion articles on SFARI.org are editorially independent of the Simons Foundation.

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many investigators share samples, data, and ideas without first publishing them in medical journals, a unique level of collaboration that is accelerating discovery.

“The genetics underlying ASD are highly complex and having access to large sample sizes is essential to rooting out the many genetic mutations involved, and the biological mechanisms implicated by those mutations,” said Dr. Daly, also founding chief of the Analytic and Translational Genetics Unit at Massachusetts General Hospital. “This sort of study cannot be done without the collaboration and cooperation we relied on across the consortium.”

Surprise Links

The *Nature* study points to three pathways required for healthy development where variations in genes were linked to greater autism risk, in some cases confirming past study results. Among the surprises was a newfound association between autism risk and variations in genes that control “chromatin remodeling.”

As part of the organization of genetic material within cell nuclei, DNA forms a complex with proteins called histones to become chromatin. Long chains of DNA wrap around histone “spools” that unwind with the right signal. The unwinding makes stretches of genetic instructions accessible to the machinery that builds proteins, which comprise bodily structures and signals.

One group of genes newly linked to autism, for instance, codes for an enzyme that regulates histones by attaching or removing methyl groups to one of their building blocks, lysine amino acids. By doing so,

the enzyme influences when specific genes are turned on or off, and the study results support the theory that such mechanisms may be altered in autism, such that developing brain cells may not mature, divide, or migrate the same way.

Other variations linked to autism by the study were in genes that govern synapses, the spaces between nerve cells in pathways that “decide” whether signals travel onward. Nerve cells must be able to execute well-timed maneuvers, such as allowing charged particles to build up or rush out of them, to pass on nerve signals normally. A third set of genes linked to risk by the study regulate basic steps that turn genes into proteins. For a protein to be built based on genetic code, the code must be translated into related molecules (transcription) and cut up and rebuilt (spliced) into the core instructions for protein building.

Study researchers reached their conclusions with the help of new DNA sequencing techniques, which determine the order of the letters (bases) making up the genetic code to reveal rare variations, some linked to disease risk. The current study employed whole exome sequencing, which is a less expensive, more focused version of whole genome sequencing. By looking at only the protein-coding part of genes, exome sequencing precisely identifies small changes in the gene code that in turn affect specific spots in a resulting protein.

The study results also revolve around genetic mutations. Changes occur in our genetic code at a steady rate thanks to the error-prone processes that copy the code and other factors, and despite mechanisms bent on weeding out faulty code. Part of evolution, changes in the order of the “letters” (base pairs) making up the in-

structions encoded in DNA are called mutations, with some inherited and others occurring when the egg or sperm are formed (de novo mutations).

Past studies looking at genetic autism risk focused only on de novo mutations that caused any key protein to stop working (loss-of-function mutations). The current study looked at both inherited and de novo loss-of-function mutations, along with de novo “missense” mutations in affected children and their parents. Where loss-of-function mutations are blunt, causing the resultant protein to stop working, missense mutations may make a protein work slightly less well. Being more common and subtle, they are harder to spot, but the current study shows that they make a sizeable contribution to ASD risk.

The new study was also the first to compare the rate of different classes of mutations between girls with ASD and boys with ASD. Feminine genetics somehow protect girls from ASD, so comparing mutations between girls and boys enabled the authors to estimate the risk associated with different kinds of mutations. Using this approach, the study authors found mutations that came with a more than 20-fold increase in risk for autism.

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Along with Dr. Buxbaum, researchers from several teams within the Icahn School of Medicine at Mount Sinai played a role in this landmark *Nature* study and in the ASC, including teams within the departments of Psychiatry, Genetics and Genomic Sciences, Pediatrics, Pharmacology and Systems

Therapeutics, Preventive Medicine Pharmacology and Systems Therapeutics, and Neuroscience, along with researchers from the Friedman Brain Institute, the Mindich Child Health and Development Institute, and the Icahn Institute for Genomics & Multiscale Biology.

Playing vital roles in the study were researchers from leading universities worldwide, along with the National Institutes of Mental Health, the Wellcome Trust Sanger Institute and National Health Service Trust Fund in the United Kingdom. For a complete list of authors and institutions, please see the *Nature* study text.

About The Autism Sequencing Consortium

Founded in 2010 by Dr. Buxbaum, the Autism Sequencing Consortium (ASC) is an international group of scientists who share ASD samples and genetic data. All shared data and analysis is hosted at Mount Sinai on a supercomputer called Minerva designed by Mount Sinai faculty, which enables joint analysis of large-scale data from many groups. The ASC is supported by a multiple Principal Investigator (MPI) grant funded by the National Institute of Mental Health (NIMH), with additional support from the National Human Genome Research Institute (NHGRI). The MPIs at the four lead sites are Drs. Joseph D. Buxbaum (Icahn School of Medicine at Mount Sinai), Mark J. Daly (Broad Institute of MIT and Harvard), Bernie Devlin and Kathryn Roeder (University of Pittsburgh School of Medicine and Carnegie Mellon University), and Matthew State (University of California, San Francisco).

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environmental signs, grocery aisle signs, and spoken words to printed words (i.e. Dolch words). *Massed trials* – students responded to each sight word in succession during flash card drills. *Differential positive reinforcement* – students were presented with sight word stimuli and were required to read each word. They were given feedback on correct and incorrect responses. They received praise, tokens, and/or food for corrected errors. *Systematic prompting* – students were given defined prompts when presented with sight word stimuli. Overall, students with ASD, even those with no prior reading instruction and limited oral language, learned to identify printed words. Sight word instruction is an evidence-based practice to teach students with ASD.

Reading Comprehension Intervention

The challenges that students with ASD have with reading comprehension can be explained by three theoretical frameworks (Gately, 2008 as cited in El Zein, Solis, Vaughn, & McCulley, 2014). One is the theory of Weak Central Coherence (WCC). It explains that students with ASD present with challenges in identifying main ideas and summarizing. The Theory of Mind (ToM) framework states that students with ASD often do not comprehend the emotion/internal states of characters in reading passages and thus are challenged with predicting character actions (Carnahan & Williamson, 2010, Colle, Baron-Cohen, Wheelwright, & Van der Lely, 2008, and Williamson, Carnahan, & Jacobs, 2009 as cited in El Zein et al., 2014). The third framework is the Executive Dysfunction Theory (EDF). It explains that students with ASD may have unique frontal lobe activity that is manifested by challenges with planning, flexibility, and self-monitoring (Pennington, et al., 1997 as cited in El Zein et al. 2014). These challenges lead to reading comprehension deficits because in order to accurately and



Tamara Sterling, MS, CCC-SLP, TSSLD

appropriately obtain meaning from reading passages, readers are required to be flexible in adapting to changes in printed text. Reading comprehension, for students with ASD, is achieved when they appropriately summarize information, retrieve and apply prior knowledge, understand social cues and character emotions, and make inferences from printed text. These are high-level reading skills and students with ASD struggle with skilled reading because of their challenges with interpretive language.

Evidence-based practice for reading comprehension intervention, for students with ASD, is increasingly becoming necessary as they are now being included in general education classrooms. El Zein et al. (2014) synthesized reading comprehension intervention studies that were conducted on students with ASD. The outcome identified interventions that increase reading comprehension. The following are effective reading comprehension interventions for students with ASD: *Direct In-*

struction (DI) program, Corrective Reading Thinking Basic: Comprehension Level A – featured use of scripts, choral student responses, cuing student responses, correction of errors, modeling and independent practice. *Peer tutoring with typically developing peers* – typically developing peers provided 1:1 tutoring sessions followed by 10 minutes of free play activities with tutees. Tutors provided task directions, modeling, and prompting. *Classwide peer tutoring (CWPT) with typically developing peers* – it featured reading in pairs, feedback from peers for oral reading, 3 minutes of reading comprehension questions (WH questions) by tutors, and error correction. *Cooperative Learning Groups (CLG) with typically developing peers* – featured teacher-directed reading instruction, peer tutoring on vocabulary words, WH question practice, and factual information game based on the story. *Story Map* – student read a passage, then used a graphic organizer Story Map as a visual map of literal story elements (characters, place, time, beginning, middle, and end). *Reciprocal questioning and scaffolding instruction using SCORE curriculum* – featured students with ASD and typically developing peers taking turns reading a story out loud and asking questions. Scaffolding instruction featured modeling, verbal prompting, and corrective feedback and taught question generation and response. SCORE curriculum features five social skills: share ideas, compliment others, offer encouragement or help, recommend changes nicely, and exercise self-control. Overall, explicit instruction, student grouping practices, graphic organizers, and strategy instruction are effective interventions for increasing reading comprehension in students with ASD.

The current best evidence reading intervention for students with ASD, that should guide clinical and academic practice, are sight word and reading comprehension intervention.

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York. She has eight years of experience working with children and adults with articulation, stuttering, language, and autism spectrum disorders. She is an ASHA Mentor and a recent recipient of v award. For more information, please email sterling.tamara20@gmail.com.

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Dog from page 19

and the end of something all at the same time. He is starting to cleave from them, to long for video games and something called an iPhone and movies that are PG-13. The mom, she knows this, and her heart is aching to make the most of the time she has left, before this tween will pack up his glasses and his gym shorts and his Nook and drive down the driveway to a faraway place called college.

I may be very close to the floor, but I see it all.

There's another big boy, just about as tall as the first boy. He also wears glasses. From behind they look like the same boy and sometimes people mix them up, but I never do.

From what I understand, I was supposed to help this boy. He has something called autism and he was very, very afraid of dogs, even little ones like me.

When the mom first brought me in from the garage where I was hiding and trying to stay very, very quiet, all of the kids squealed and laughed and clapped their hands. But he didn't. His face was all twisted up and his voice was very loud and angry-sounding.

"I DO NOT like dogs. You have ruined my life. With this dog."

I don't know anything about autism or how to help people who have it. So I just did the only thing I knew how: I waited. I waited and waited and one afternoon when no one was watching he crept over to where I was lying on the couch. With one finger he stroked my paw.

"You are. Soft."

This boy gets very, very mad. One day over the summer his temper rose until it felt like the sun was shining inside the house, the rays too hot to touch. He was screaming and hitting his head over and over again.

"No para! I will not have a PARA!"

I did not know what a para is, but the mom seemed to because she kept talking softly, telling him to take a deep breath and calm down, they would talk about it.

Then he came for her. With his fists curled into the tightest balls he charged her wordlessly. She grabbed his wrists and held them with her long fingers and said, "Enough Jack," so sharply her voice was like a knife cutting through the hot, still room.

He dropped his arms to his sides and the only sound was his whimpering, *no para*

no para no para. I barked once, twice, my voice not as sharp as hers, more like an ice cube clattering into a smooth glass.

He fell to his knees next to me and buried his fingers into the fur around my neck, where it's longest and deepest. Through his fingertips, I understood. I knew. Somehow, because of this strange thing called a *para*, the boy felt different. He felt worried and alone and disappointed.

He felt less.

There is another boy. He looks just like the dad, with dark hair and deep brown eyes that make you think of chocolate. He is all fun, this one.

But every once in a while a shadow crosses his face and his eyes get cloudy, like the rain is coming. That's when I know he needs a little extra cuddle and I just turn on my back so he can rub my soft, white belly. He rubs it until the sun shines again.

"Come on, Wolfie, run outside with me!"

A couple of weeks ago the big yellow bus started coming around again. We all walked down to the bus stop and everyone was so excited. But when the kids got on and the bus pulled away, the mom put her head on the dad guy's shoulder and said, "Oh, Joe."

Slowly the three of us walked back up the driveway. They looked down and started talking to me in a funny voice with funny words. "You a wittle doggy, wight? Just a wittle pup-pup." I felt confused.

Then I understood. Their babies were gone. Now I was the baby.

Last weekend we all went to a big field to play with a black and white ball. The mom and dad kicked it around with the kids, but the second boy said he only wanted to hold my leash and run with me.

So we did. We ran and ran through the fields together. And with each big step he took I could tell, for the moment, he was free. Free of the shame and rage and confusion and panic that follow him around all day like uninvited guests.

Running by my side through the rich green grass, he wasn't a child with autism or a fifth grader with a para or a brother who is not like the rest.

He was, quite simply, just a boy and his dog.

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

Neural Divide from page 12

a part of our society as anyone despite our unusual differences. Autism science has much to contribute in advancing all three.

Autism science has also yielded much that is of direct value to people on the spectrum. This has primarily been in the evaluation of therapies and treatments to determine which are effective and which are of no value (in some cases fraudulent). One good example of this was the discrediting of Bruno Bettelheim's theories about "refrigerator mothers" and the ineffective psychotherapies which were based on them. More recently, controlled studies have shown that traditional psychotherapies have little or no effect on people with autism – with the notable exception of cognitive behavioral therapy (CBT) which has been successfully used on many. Although, as is well known, there is no single effective treatment for autism, numerous techniques and therapies have been demonstrated to be effective in addressing some debilitating traits, deficits, and challenges of autistic individuals. Most of these are the products of scientific work in areas related to autism.

Of greatest personal interest to me as an adult on the spectrum, however, is the development of a quick, simple, and reliable method of diagnosing adults, especially older adults. Straightforward as it may be for qualified professionals to identify or diagnose a child on the autism spectrum, diagnosing an adult is an entirely different matter. This may be one of the most difficult diagnoses to perform in

all of medical science due to the great variety of coping mechanisms that individuals with autism develop to compensate for their deficits over the course of their lives. Current diagnostic practice usually involves a large battery of psychological tests, many of which are far better suited for children than adults, and interviews of childhood caregivers, who may have long forgotten much relevant information or even be deceased.

Ideally, I would like to see a test that can be done in a clinician's office to quickly determine whether a patient is on the autism spectrum and, perhaps, to what degree – I consider this to be the "holy grail" of adult autism research. Given that the prevalence of autism in the general population is currently estimated as 1 in 68, and that the dramatic increase in this figure over the past 20 years is largely attributed to improved diagnosis (i.e., the prevalence in the past was not dramatically lower), the number of undiagnosed and unidentified adult autistics is staggering. In New York City alone, there are probably around 100,000 adults on the spectrum, and the number for the U.S. is in the millions. Although many have managed to "get by" and even enjoyed some degree of success (as did I), most of them have lived entire lives with the challenges of autism but never even heard of an autism spectrum disorder, let alone known that they were on the spectrum. Scientific research offers the only hope of finding a practical means of identifying them.

Brain imaging techniques such as MRI and PET have been used in much research,

but not yet yielded any reliable method of performing a diagnosis. Also, brain scans are far too expensive for use on such a massive scale. Other neurological techniques such as transcranial magnetic stimulation (TMS) have actually shown statistically-significant results in studies at Harvard Medical School where autistic subjects responded differently from neurotypical controls. I attended a talk at which these results were described, and immediately saw their potential as a possible diagnostic method. Surprisingly, there was little interest on the part of the attendees, who were more interested in very preliminary findings related to possible therapeutic methods using this technique. To me, this is indicative of a general lack of interest in the issue of adult diagnosis. It is also indicative of the interest in finding "cures" rather than providing the accommodations and services that our community needs. Magneto-encephalography (MEG) is another method that has been used in research on response times to auditory stimuli at Children's Hospital of Philadelphia and may have some potential as a diagnostic tool.

Genetic and genomic research is another avenue that may have diagnostic potential. It is by now well-established that there is no "autism gene" – in fact, hundreds of genes have been found to be connected to autism, and estimates show that approximately 1000 genes are so connected. Given that the human genome consists of 22,000 genes, this means that as many as 5% of all genes in some way affect autism. Consequently, it will be very difficult, and most likely impractical, to effectively di-

agnose autism using genetic tests alone. This will provide some assurance to those in the autism community who fear that such a test might be used for eugenic purposes. Where such tests will have value, in conjunction with other methods, is in the early detection of autism which can in turn lead to effective interventions in small children. Such methods may also be of use in performing adult diagnoses. In addition to genetics and genomics, autism research is finding applications for epigenetics (the activation/deactivation of specific genes) and proteomics (mapping of the actual proteins that are synthesized by cells from DNA sequences with the genetic code); the latter is currently being studied at Clarkson University and other places, and has shown some promise towards future diagnostic methods.

I want to take this opportunity to encourage readers who are involved in any relevant research to consider its possible implications for adults on the autism spectrum. In particular, anything that could lead to a diagnostic method will be of great benefit to our community.

In conclusion, science is more responsible for the benefits that we all enjoy in the modern world than any other single factor. In the same manner, science offers enormous potential for addressing the issues and challenges that people living on the autism spectrum face. Let the march of scientific progress continue, especially in the area of autism.

For more information, Karl can be reached at kwittig@earthlink.net.

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Fiddle from page 8

innovative transition, employment, and recreational programs that benefit thousands of people in Florida and internationally. Together, we look forward to addressing additional needs including housing.”

CARD and The Daniel Jordan Fiddle Foundation share a joint vision of creating and expanding replicable models and opportunities for adults living with autism to have the best lives possible for generations to come.

Dr. Alessandri explains that the DJFF endowment is especially crucial since CARD's Department of Education funding does not provide for serving adults who have left high school. The executive director reports that the DJFF funding will allow CARD to explore more innovative approaches to issues such as:

- Employment, including education, training, and mentorship for families who wish to explore microenterprise as an employment path for adults living with autism.
- Community-based leisure programming, including peer-to-peer social opportunities, art programs, etc.
- Developing long-term solutions to the



Dr. Roger Jou, Dr. Kevin Pelphry, Linda J. Walder, Dr. Fred Volkmar, and Fred Fiddle at the Yale Child Study Center

challenges of full community inclusion for adults living with autism.

- Creating workshops for families geared to legal, financial, and self-advocacy initiatives.

Says Dr. Alessandri, “We are grateful to The Daniel Jordan Fiddle Foundation for its generous gift to CARD. It will help support our existing programs and help stimu-

late exploration, discussion, and action on a range of solutions for housing, employment, health care, and legal issues.”

The Daniel Jordan Fiddle Foundation was established in 2002 in honor and memory of Linda Walder's own autistic son Danny Fiddle, who passed away at age nine. Since its inception, DJFF has helped develop, advocate for, and fund innovative programs and resources for

adults living with autism, including residential programs, employment training for students in transition, health/wellness initiatives, music and art programs, hiking and equestrian activities, as well as social/relationship opportunities. The Foundation has pioneered much-needed resource materials that address critical needs and are offered free of charge to the public, including booklets on topics such as Autism and Epilepsy, Autism and Faith, a handbook for college students on the spectrum, and a pocket-size travel guide.

Linda J. Walder is a leading national advocate and has been instrumental in developing public policy that addresses the needs of all people living with autism and their families.

There are over three million individuals living with autism today. It is estimated that over the next decade, 500,000 individuals will reach the age of 21 and “age out” of government-mandated programs.

For more information about The Daniel Jordan Fiddle Foundation, visit: www.djffid-foundation.org. For information about Yale's Center for Translational Developmental Neuroscience, visit: <http://child-studycenter.yale.edu/research/index.aspx>.

To learn more about CARD and The Daniel Jordan Fiddle Foundation Transition and Adult Programs visit: www.um-card.org/adults-asd/.

ABLE Act from page 10

and families will be allowed to establish ABLE savings accounts that will not affect their eligibility for SSI, Medicaid and other public benefits. The legislation explains further that an ABLE account will, with private savings, “secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary's employment and other sources.”

3. Am I eligible for an ABLE account?

Passage of legislation is a result of a series of compromises. The final version of the ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you would still be eligible to open an ABLE account if you meet SSI criteria regarding significant functional limitations. The regulations to be written in 2015 by the Treasury Department will have to explain further the standard of proof and required medical documentation. You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have the documentation of disability that indicates age of onset before the age of 26.

4. Are there limits to how much money can be put in an ABLE account?

The total annual contributions by all participating individuals, including family and friends, is \$14,000. The amount will be adjusted annually for inflation. Under current tax law, \$14,000 is the maximum

amount that individuals can make as a gift to someone else and not pay taxes (gift tax exclusion). The total limit over time that could be made to an ABLE account will be subject to the individual state and their limit for education-related 529 savings accounts. Many states have set this limit at more than \$300,000 per plan. However, for individuals with disabilities who are recipients of SSI and Medicaid, the ABLE Act sets some further limitations. The first \$100,000 in ABLE accounts would be exempted from the SSI \$2,000 individual resource limit. If and when an ABLE account exceeds \$100,000, the beneficiary would be suspended from eligibility for SSI benefits and no longer receive that monthly income. However, the beneficiary would continue to be eligible for Medicaid. States would be able to recoup some expenses through Medicaid upon the death of the beneficiary.

5. Which expenses are allowed by ABLE accounts?

A “qualified disability expense” means any expense related to the designated beneficiary as a result of living a life with disabilities. These include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which will be further described in regulations to be developed in 2015 by the Treasury Department.

6. Where do I go to open an ABLE account?

Each state is responsible for establishing and operating an ABLE program. If a state should choose not to establish its own program, the state may choose to contract with another state to still offer its eligible individuals with significant disabilities the opportunity to open an ABLE account.

Now that President Obama has signed the ABLE Act, the Secretary of the Department of Treasury will begin to devel-

op regulations that will guide the states in terms of a) the information required to be presented to open an ABLE account; b) the documentation needed to meet the requirements of ABLE account eligibility for a person with a disability; and c) the definition details of “qualified disability expenses” and the documentation that will be needed for tax reporting.

No accounts can be established until the regulations are finalized following a public comment period on proposed rules for program implementation. States will begin to accept applications to establish ABLE accounts before the end of 2015.

7. Can I have more than one ABLE account?

No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

8. Will states offer options to invest the savings contributed to an ABLE account?

Like state 529 college savings plans, states are likely to offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.

9. How many eligible individuals and families might benefit from establishing an ABLE account?

There are 58 million individuals with disabilities in the United States. To meet the definition of significant disability required by the legislation to be eligible to establish an ABLE account, the conservative number would be approximately 10 percent of the larger group, or 5.8 million individuals

and families. Further analysis is needed to understand more fully the size of this market and more about their needs for new savings and investment products.

10. How is an ABLE account different than a special needs or pooled trust?

An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.

This article was reprinted with permission by National Disability Institute and can be found online at www.realeconomicimpact.org/News.aspx?id=460.

About National Disability Institute

National Disability Institute (NDI) is a national nonprofit organization dedicated to building a better economic future for people with disabilities. The first national organization committed exclusively to championing economic empowerment, financial education, asset development and financial stability for all persons with disabilities, NDI affects change through public education, policy development, training, technical assistance and innovative initiatives. NDI and its Real Economic Impact (REI) Network have helped more than 2.3 million people with disabilities receive nearly \$2.3 billion in tax refunds and credits. To learn more, visit www.realeconomicimpact.org. Engage with NDI on Facebook: [RealEconImpact](https://www.facebook.com/RealEconImpact) or follow NDI on Twitter: [@RealEconImpact](https://twitter.com/RealEconImpact).

Success from page 13

Whether a person lives on their own, or as part of a family, they need to practice how to shop, how to pay and how to budget. The group learns how to write a check, manage income and pay bills. By filling out a budget sheet, participants track their income, track their expenses such as food, clothes, bills and leisure, and also keep records of their spending. They learn to understand their fixed expenses and utilize key resources for saving money.

The fourth and final module is *Fit for Life*, which integrates the combined skills of time management, organization, career

and finance into each participant's every day. Individuals create a handbook that outlines a customized plan utilizing their skills for their own paths to success. For example, as one is hired and given more responsibility, their handbook acts as a guide and reminds them of the importance of establishing a routine for better life control. As a frame of reference for continuous success, individuals take the results of these experiences and remain empowered in their everyday lives beyond the Spectrum Strategies Workshop.

Debra Solomon is a New York University certified Life and Career Coach, who

helps her clients discover the personal and professional goals that best match their interests and abilities. When someone in her own family was diagnosed with an Autism Spectrum Disorder, Debra learned first-hand what it meant to guide someone through life's challenges and how important the right team of professionals can be in achieving success. Today, she utilizes her past experiences to help her clients realize their potential and develop the executive function skills needed in order to succeed in their personal lives, as well as in the professional workplace. She believes that collaboration and involvement in group interventions are essential for this development.

Scores from page 18

has previously been specified as a requirement for meta-analysis publication by the APA Taskforce on Statistical Inference (1999). In addition, the earlier statistical taskforce emphasized the importance of understanding how a given statistical measure is calculated, and how to interpret the statistic. Despite this debate, the ASD community of stakeholders require information describing evidence based best practice *immediately*. It is of critical importance to identify potential treatments that may in fact cause harm, and in the best interests of all parties to avoid selecting treatments that may be ineffective.

The Percentage of Nonoverlapping Data (PND) (Scruggs, Mastropieri, & Casto, 1987) effect size calculation has been identified as the most frequently adopted method of calculating a treatment effect score in SCD research, with a recent review of published meta-analyses reporting that this method was applied in 47 of the 84 (55%) effect sizes that were reported (Maggin, O'Keeffe, & Johnson, 2011). PND has been criticized in the literature on the grounds that it is reliant on a single extreme data point in baseline, lacks sensitivity as calculated scores approach 100%, and confidence intervals cannot be calculated. In recent years, alternate calculation methods have been developed to address these concerns.

Carr and colleagues (2014) investigated the suitability of SCD data for treatment effect calculations using examples drawn from peer-reviewed published behavior therapy research specifically for individuals diagnosed on the spectrum. Self-management was selected to represent an established treatment, and exercise to represent an emerging treatment, as described in the National Standards Report (2009). The aim of their research was twofold: first to determine if the data may be suitable for a more complex regression based treatment effect calculation; and second to compare three calculation methods that can be performed by hand. The logic behind this approach was that calculations that do not require extensive training or additional software applications to perform may mean that teachers or clinicians in underfunded communities, or remote locations, could access and interpret treatment reports with greater ease.

Risk from page 20

About the Mount Sinai Health System

The Mount Sinai Health System is an integrated health system committed to providing distinguished care, conducting transformative research, and advancing

biomedical education. Structured around seven member hospital campuses and a single medical school, the Health System has an extensive ambulatory network and a range of inpatient and outpatient services--from community-based facilities to tertiary and quaternary care.

The System includes approximately

on behalf of treatment providers or families.

For further information please contact Monica E. Carr, Doctoral Researcher, Monash University, Australia, at mebar4@student.monash.edu.

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6,600 primary and specialty care physicians, 12-minority-owned free-standing ambulatory surgery centers, over 45 ambulatory practices throughout the five boroughs of New York City, Westchester, and Long Island, as well as 31 affiliated community health centers. Physicians are affiliated with the Icahn

Evaluating from page 17

generalization of skills (Koegel, Egel, & Dunlap), eliminate the potential for observational learning (Keel & Gast 1992), and require far more instructional time than do group formats (Favell, Favell, & McGimsey, 1978).

Research in this area indicates that small group formats are as effective as (Kamps & Walker, 1990) and more efficient than (Biberdorf & Pear, 1977) one-to-one instruction, with comparable rates of challenging behavior across instructional arrangements (Kamps & Walker, 1990). Data from a study by Kamps et al (1992) indicates that individuals with a history of one-to-one instruction can successfully be transitioned to small-group formats across several curriculum areas with few problems. McDonnell et al (2006) demonstrated equivalent learning in embedded and group instructional formats for middle schoolers with developmental disabilities.

There are many questions about learning in groups that remain unanswered. Some novel work by Taylor and colleagues seeks to isolate the components of the listening response that may facilitate learning observationally in group instructional contexts. Taylor, DeQuinzio, and Stine (2012) evaluated the components of responses that may facilitate observational learning in group contexts. They found that teaching a monitoring response increased observational learning.

Challenging assumptions about the benefits of 1:1 instruction, Melton, Hansen, Mayer, and Kenyon (2013) presented data that demonstrated the superiority of group instruction for the acquisition of new skills. In their examination of seven learners with autism, they found that 4 of 7 acquired skills more rapidly when taught in a group context. The other three participants had equivalent rates of acquisition across conditions. These data are interesting, and await replication.

While the majority of past research has focused on students' ability to acquire new skills in small-group arrangements, a student's ability to maintain independent responding on mastered targets when transitioned to a dyad instructional arrangement

from individualized instruction may be a good indicator of whether or not fading staff ratios is practical at that time.

Melmark's Focus

The research team at Melmark is committed to figuring out an efficient way to address this clinical need and has designed an instructional protocol to assess a learner's performance in individual and group instruction. Initially, research focused on examining the learner's differential performance in individual and dyad learning situations with mastered skills. Ultimately, this work will be extended to examine differential acquisition of new material in group and individual learning contexts.

Perhaps the most exciting element of the protocol is that it enables educational teams to make decisions about learner readiness for group instruction on the basis of objective and individual data. The focus of the assessment will be to identify the learners' skills in core areas relevant to success in group learning environments. Variables assessed include not only the ability to learn new material, but also:

- Levels of engagement
 - Rates of challenging behavior
 - Maintenance of mastered targets in individualized and group instructional arrangements
- Successful candidates for group instruction should exhibit:
- Stable patterns of independent responding
 - Maintenance of learned skills
 - High levels of engagement
 - Low rates of challenging behavior
 - Low rates of stereotypy across conditions

The initial assessment compares differential performance of mastered skills in

individual and dyad instruction. This is an important first step, as learners need to be able to demonstrate and perform tasks when they are not provided with individual attention. Furthermore, it will provide information on whether behaviors that can interfere with tasks are more prevalent in learners with autism in individual or group environments. Finally, it will provide data on whether performance suffers in group contexts. The latter assessment compares differential acquisition of new instructional targets in individual and dyad instruction. These data are important to ascertain whether learners with autism truly need individual instruction to learn new skills.

It is hoped that such an instrument could be used to support the learner's readiness to be weaned from individual instruction and to participate in group learning. As the ability to participate in group instruction is essential for academic and vocational environments, assessing this skill is part of our clinical obligation to prepare learners with autism for their next environments.

For more information on the assessment tool described, please contact Helena Maguire at hmaguire@melmarkne.org or Mary Jane Weiss at mweiss@melmark.org.

Helena Maguire, MS, BCBA, is Senior Director of School Services at Melmark New England. Mary Jane Weiss, PhD, BCBA-D, is Executive Director of Research at Melmark. Frank L. Bird, MEd, BCBA, is Chief Clinical Officer of Melmark, Inc.

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

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Free Support Group For Families of Adults with Asperger's Syndrome and High Functioning Autism

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For more information, visit our website www.FAAHFA.com or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

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Brains from page 4

showing that they want to make a difference in the mission to solve autism. The *It Takes Brains* website covers many issues of concern to potential donors. Visitors to the site will learn, for example, that brain tissue donation does not involve any cost

to the donor's family, is permitted by most religions, and does not alter funeral arrangements or medical treatment. Further, while advance registration is encouraged, it is not required and it is not binding. In all cases, the donation process is initiated by a call to the *AutismBrainNet* hotline number immediately upon a donor's death, after

which an *Autism BrainNet* coordinator will work with medical personnel to retrieve the brain tissue and transport it to a research center. Donor families will be treated with respect and compassion, and provided with continuing support and information.

Please visit www.takesBrains.org and www.autismbrainnet.org to learn about

brain research and to register.

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CPRT from page 11

2. **Make Instructions Clear and Appropriate:** The teacher provides clear and developmentally appropriate instructions that are easy for the student to understand and are at, or just above, her developmental level.
3. **Provide a Mixture of Easy and Difficult Tasks:** Rather than consistently increasing task difficulty, the teacher provides a balance of easy and difficult tasks to maintain previously mastered skills, and to keep motivation high and frustration low.
4. **Share Control with the Student:** The teacher follows the student's lead to her choice of activities and materials, takes turns with the student, and incorporates preferred materials into activities.
5. **Use Multiple Exemplars:** The teacher presents opportunities to respond that require the student to attend to multiple aspects of the learning materials to give a correct response, and the teacher varies the form and content of cues given to students.

Consequence Components

6. **Provide Direct Reinforcement:** The teacher should provide reinforcement that is naturally or directly related to the activity or behavior.
7. **Present Contingent Consequences Immediately:** The teacher should present consequences immediately, and based on the student's response.
8. **Reinforce Appropriate Behaviors:** By rewarding not only correct responses, but also goal-directed attempts toward correct responses.

When all eight components are used within one teaching interaction, CPRT is being implemented effectively.

The effectiveness of the complete CPRT program is being tested in our current research study, which includes 108 teachers randomly assigned to receive training and coaching in CPRT. As part of the training, CPRT coaches rate how well and how consistently teachers use the components of CPRT in their classrooms. In order to meet implementation criteria, teachers must skillfully perform each component for 80% or more of the teaching interaction. Of the 58 teachers trained thus far, coaches report that 75% of teachers have met criteria for correct use of CPRT. This is an improvement from previous studies in which teachers demonstrated difficulty implementing PRT strategies consistently (Suhrheinrich et al., 2013). In addition to the ratings from the coaches, expert independent observers watch video samples of teachers working with their students to provide

unbiased ratings of teachers' CPRT use. In the project's first year, we found that teachers consistently implement antecedent components such as gaining student attention and providing clear instructions. Furthermore, teachers typically did well with session preparation and providing consequences contingently. This suggests that teachers may find training that targets the CPRT components that focus on maximizing student motivation, such as shared control strategies and providing appropriate tangible consequences (reinforcement), most useful because these are the areas that appear most challenging. By way of example, difficulties that teachers have reported with the shared control and reinforcement strategies and possible solutions to these difficulties that could be the focus of additional training are discussed below.

There are four parts to the shared control aspect of CPRT: providing choices, taking turns, following student interest, and using preferred materials and activities in the teaching interaction. Data from independent observers indicates that in one-on-one settings, shared control is crucial to cultivating student engagement. Specifically, teachers' use of turns and a greater number of choices is correlated with higher student engagement (Vejnoska, Rieth, Suhrheinrich, Wang, & Stahmer, 2015). Teachers, however, have expressed to their coaches that it is difficult to implement certain shared control strategies, such as incorporating preferred materials when students in a group had highly individualized preferences. For example, a common academic skill taught in a group setting is counting. When using CPRT, we may encourage teachers to provide pictures of students' favorite cartoon characters to count, instead of counting blocks or plastic bears. Teachers found it difficult, however, to provide character pictures catered to every student's individual preferences. One solution is to provide a choice between a limited set of popular characters such that student preference is involved in the activity but is also balanced with feasibility. Similarly, many teachers incorrectly believed that using preferred materials required the creation of novel materials rather than incorporation of existing materials and activities that are popular with students. For instance, when working on reading comprehension skills, instead of reading *The Polar Express* and utilizing materials that most students generally prefer, such as shaving cream as pretend snow, some teachers felt the need to create individualized reading comprehension activities with teacher-made stories and worksheets based on their students' favorite characters. Because of this, fewer teachers have met fidelity criteria on preferred materials in comparison to the other shared control strategies. Thus, it is worthwhile to continue to collaborate with teachers to identify which strategies are the most beneficial and what is feasible, and adjust

training accordingly.

Another example of how training can be adjusted relates to providing feedback. Recognition of appropriate student behaviors can come in the form of contingent consequences (such as verbal praise) and/or reinforcement that is tangible and directly related to the activity or behavior. Teacher struggles with implementing these consequence strategies is an area of concern. Independent observers found that though teachers excelled at providing contingent consequences (usually praise), they did not often provide tangible reinforcement in either one-on-one or group settings. This is in keeping with coaches' reports that many teachers had difficulty with determining appropriate consequence strategies for students, particularly for those who seemed intrinsically motivated to complete typical classroom activities. This implies that future training should focus on identification of which students require tangible reinforcement and maintaining teachers' implementation of tangible consequences for those students. Further analyses will explore the student characteristics that necessitate a high frequency of tangible reinforcement delivery.

Overall effectiveness of and satisfaction with the CPRT training program has been very positive. Teachers enjoy the strategies and see them working with students. The fact that teachers have difficulty implementing certain components of CPRT indicates that adapting evidence-based practices for use in the classroom is an ongoing process. The implementation issues surrounding group activities and student characteristics illustrate the need for continued partnerships between researchers and teachers to help make CPRT more useful for teachers. Additionally, further research should investigate the influence that adaptations to shared control and consequence strategies have on student engagement. Despite these growing pains, 100% of teachers who completed training reported being satisfied with the quality of training they received. Furthermore, 97% of teachers said they were satisfied with their ability to use CPRT with their students. To put it in the words of one of the teachers who completed CPRT training, "This program provides a fresh perspective on ABA as it simplifies the most effective evidence based strategies for teaching children with autism in individual and group settings and gives that to the teacher in a nice, easy to use package. CPRT would benefit teachers in all areas, including those teaching only neurotypical children!"

For more information about Classroom Pivotal Response Teaching please contact Renee Herman (858) 966-7703 x 3842 or raherman@ucsd.edu or visit www.classroomprpt.org.

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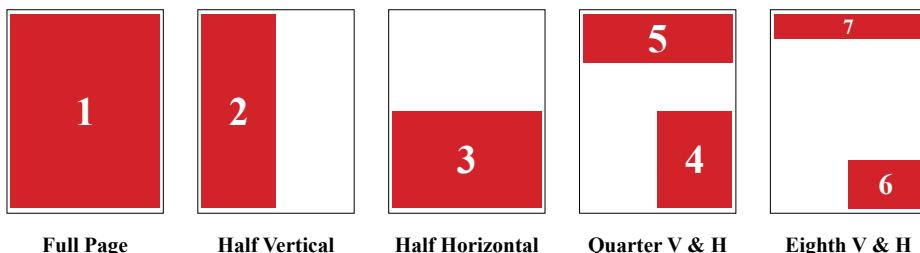
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