

AUTISM SPECTRUM NEWS™

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SUMMER 2012

INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

VOL. 5 NO. 1

Vital Supports and Services in the Community

Comprehensive Approach to Working With Individuals With Autism

By Nancy Weiss, MS, CCC/SLP
Speech Language Pathologist
Fay J. Lindner Center for Autism

Families and individuals with Autism Spectrum Disorders receive an endless bombardment of information pertaining to various therapies and approaches to address their complex needs. Navigating these therapies can be extremely confusing and for many it has become something comparable to a full time job. Given the unique needs of individuals with ASDs, when seeking services and support, it is essential to work with professionals that specialize in the area of Autism Spectrum Disorders.

For over 10 years, the Fay J. Lindner Center for Autism and Developmental Disabilities has been a provider of services for children and adults with Autism and other Developmental Disabilities. The Lindner Center is a center of excellence that provides comprehensive assessment, treatment, school consultation, psychopharmacology, advocacy and resource information for the tri-state area and nationally.



Individuals with autism and other developmental disabilities experience impairments across a range of areas including cognitive, social, communication, adaptive, affective, and behavioral; these areas

must be assessed in order to determine a successful treatment plan. Each individual's treatment plan needs to be tailored to address his or her unique social, behavioral, language, and academic difficulties.

The success of the Lindner Center lies in our unique collaborative approach which is utilized throughout all of the programs which is combined with highly trained and respected specialists in psychiatry, psychology, and speech language pathology.

The services provided at the Lindner Center include:

Diagnostic Testing - The Center's team meets prior to each assessment to review the individual's history and to plan and individualize an effective assessment strategy. Our team includes: psychologists, psychiatrists, and speech-language pathologists. Our team is highly trained in the use of the gold standard diagnostic instruments including the ADOS and the ADI-R, but state-of-the art assessment tools are used for all the evaluation options.

Psychopharmacology - The Lindner Center's Board Certified Psychiatrists in Child, Adolescent and Adult Psychiatry specialize in working with individuals with autism and other developmental

see Comprehensive on page 18

Finding and Evaluating Empirically-Based Interventions

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

Parents are often overwhelmed with a mountain of information regarding treatments for various symptoms of autism spectrum disorders or their co-morbid disorders. Some publications claim to reverse or even cure autism. Some of these publications and advertisements are well written, logical, based upon theory, and can have intuitive appeal. In desperation parents will try the interventions that offer a glimmer of hope. At best, they have wasted their time, money, and effort. At worst, the interventions could potentially be harmful and, in extreme cases, fatal. How can parents and even treatment providers determine if an intervention is effective?

Empirically-based interventions are those interventions that are based upon research. Empirical simply means observable. The empirical practice movement that is currently shaping the thinking in the social sciences and in education has its roots in medicine. The phrase "empirical practice" can be used interchangeably with "evidence-based practice." A practitioner uses an intervention with a client based upon evidence that the intervention is effective for a particular problem facing that population. Physicians will either conduct research to determine if a particular drug regimen is effective in ameliorating certain symptoms or will read the professional literature to see if using the drug has worked to treat the symptom presented by the patient.

Physicians who turn to the professional literature read peer reviewed journals. Peer reviewed journals are those that have an editorial board who delegate the reading of

manuscripts to a panel of experts who read the manuscript without knowing who wrote the article. The panel of experts reviews the methodology of the research, the analysis of the data, and the conclusions. By reviewing the manuscript in a "blind review" (i.e., without knowing the identity of the author), the article is approved by the merits of the research alone. The reviewers are not biased by the reputation (or lack thereof) of the author. In the social sciences and education there are hundreds, if not thousands, of peer reviewed journals that are available at the local library or online. In the field of autism one example of a peer reviewed journal with a double blind review process (i.e., the reviewers and the authors do not learn each other's identities) is the *Journal of Autism and Developmental Disorders*.

By reading the original research from a peer reviewed journal, parents and treatment providers are going to the original

source material. This is a crucial step. The popular press (e.g. newspapers and magazines) will pick up recently released research that is newsworthy. However, these types of publications attempt to translate the research into easily understandable language for mass audiences. Unfortunately, sometimes the interpretation of the results can be misleading or overly simplified. The classic example of this is when a publication states that the latest research "proves" that an intervention is effective or writes that a treatment is "clinically proven effective." Research scientists generally do not speak or write in sweepingly global terms. The language they use is more circumscribed and is couched in probabilistic terms. They write and speak of the odds or the percentage of individuals that will experience reduced symptoms when using an intervention.

see Evaluating on page 18

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Autism Spectrum News 2012/2013 Theme and Deadline Calendar

Fall 2012 Issue:

"The Importance of Early Intervention Following Diagnosis"

Deadline: September 5, 2012

Winter 2013 Issue:

"Exploring Educational Challenges and Opportunities"

Deadline: December 5, 2012

Spring 2013 Issue:

"Maintaining Skills During Summer Vacation"

Deadline: March 5, 2013

Summer 2013 Issue:

"Supportive Housing for Adults with Autism"

Deadline: June 5, 2013

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AUTISM SPECTRUM NEWS DESK

Most Children with ASD Diagnosed After Age Five Use Multiple Services and Medications

By The National Institute of Mental Health (NIMH)

Fewer than one out of five school-aged children with special health care needs were diagnosed with autism spectrum disorder (ASD) by age 2, according to new data from an NIMH-funded study. These diagnoses were made by a variety of health care providers, and most children in the study used multiple health care services (such as speech or language therapy) and multiple medications.

Background

Identifying ASD at an early age allows children to start treatment sooner, which can improve their later development and learning, and may also reduce a child's need for specialized services or treatments later in life.

To determine the experiences of school-aged children with special health care



needs, Lisa Colpe, PhD, MPH, and Bev Pringle, PhD, of the NIMH Division of Services and Intervention Research, col-

laborated with colleagues who conducted more than 4,000 telephone interviews with parents or guardians of a child be-

tween the ages of 6-17 who had a confirmed diagnosis of ASD, intellectual disability, and/or developmental delay.

These survey interviews were a part of the Pathways to Diagnosis and Services Study, sponsored by NIMH using funds available from the American Recovery and Reinvestment Act of 2009 (Recovery Act). Additional collaborators on this project include the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) and the Maternal and Child Health Bureau at the Health Resources and Services Administration (HRSA).

Results of the Study

Key findings include:

- The median age when school aged children with special health care needs and ASD were first identified as having ASD was 5 years.

see Diagnosed on page 32

Autism Symposium Unites Families and Professionals in Discussion on Life Transitions

By The Weill Cornell Autism Research Program

Today, more children than ever are growing up with an Autism Spectrum Disorder (ASD), facing day-to-day transitions as well as major life transitions in school, work and home environments.

In the field of academic medicine, autism researchers continue to tackle unanswered questions about the causes of ASDs, the most appropriate way to diagnose the condition, and the most effective therapies. They are joined by numerous parents, educators, service providers, and autism advocates in their commitment to improving current understanding of ASDs, and in particular, the lives of affected individuals and their families.

On Friday, May 11th, the Weill Cornell Autism Research Program (WCARP) brought together all these stakeholders in its 2012 Autism Symposium, "Growing Up With Autism: Life Transitions." The all-day Symposium, co-sponsored by the Clinical and Translational Science Center (CTSC), took place at the Uris Auditorium and Griffis Faculty Club of Weill Cornell Medical College (WCMC) and was attended by nearly 200 individuals.

A survey of participants at the symposium revealed the diversity of roles held



Dr. Catherine Lord, Director of the Center for Autism and the Developing Brain, Reflects on "Rethinking Autism Diagnoses" at the May 11 Autism Symposium.

Photo Courtesy of New York-Presbyterian/Weill Cornell Medical Center, photographer Amelia Panico.

by those in attendance. When respondents could select all of their relevant affiliations, 28% identified as school professionals, 27% identified as parents, and 23% identified as clinicians (including MDs, Occupational Therapists, Speech Language Pathologists, and Physical

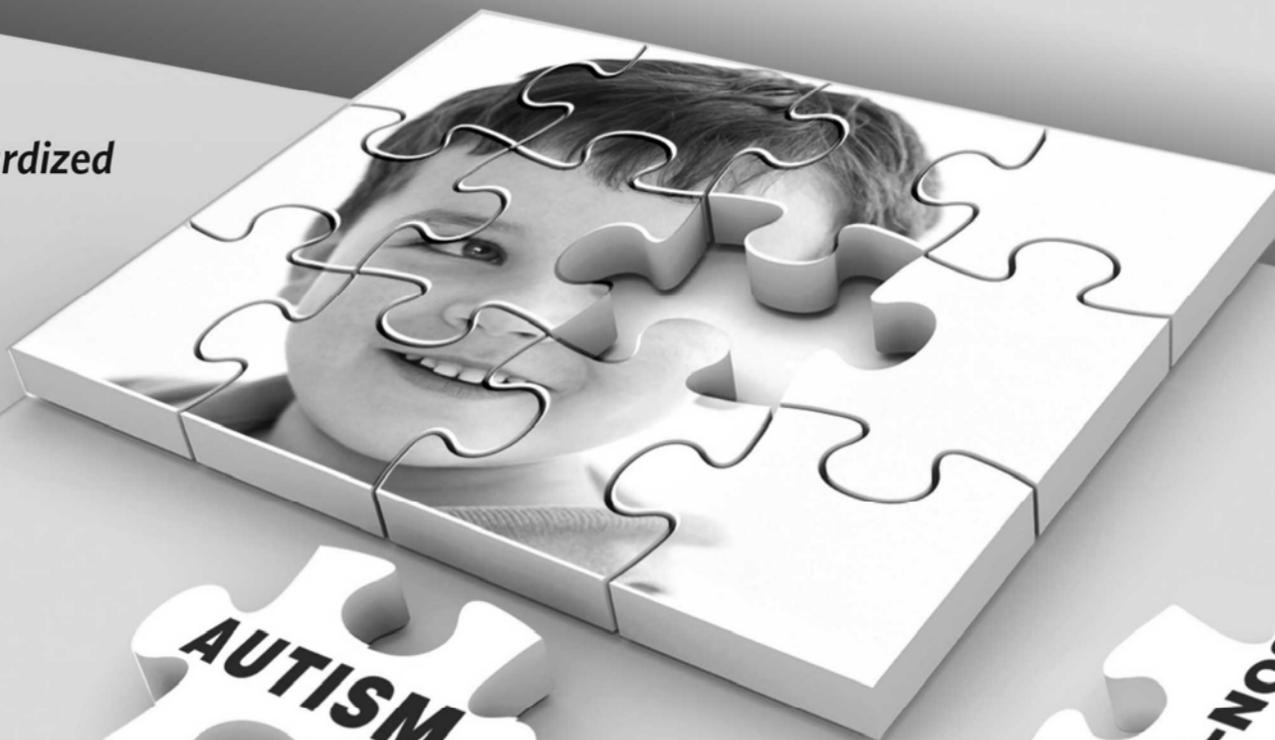
Therapists). In addition, attendees came from near and far to join in on the discussion – local participants hailed from New York, New Jersey, Connecticut, Maryland, Virginia, and Florida, while international participants represented both Sweden and Israel.

Opening remarks by Dr. Gerald Loughlin, Chairman of the Department of Pediatrics at Weill Cornell Medical College; Dr. Julianne Imperato-McGinley, Director of the Clinical and Translational Science Center at Weill Cornell Medical College; and Dr. Barry Kosofsky, Director of the Weill Cornell Autism Research Program, emphasized the timely topic of transitions and the importance of continuing research to improve scientific understanding of Autism Spectrum Disorders. "We are really in the midst of a revolution, in both diagnosis, therapy, and our understanding of this enigmatic brain disorder," stated Dr. Barry Kosofsky as he introduced the first of two panel discussions, designed to highlight a number of these current research efforts.

The program began with a Basic Science panel, featuring four WCMC researchers: Dr. John Walkup, Vice Chair in the Department of Psychiatry and Director of the Division of Child and Adolescent Psychiatry; Dr. BJ Casey, Director of the Sackler Institute for Developmental Psychobiology; Dr. Francis Lee, Professor and Vice Chair for Research in the Department of Psychiatry; and Dr. Anjali Rajadhyaksha, Associate Professor in the Division of Child Neurology. The panelists discussed progress made in research projects related to anxiety, adolescent

see Symposium on page 25

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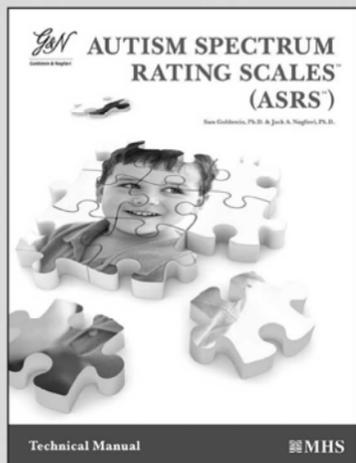
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Directing Attention Boosts Language For Young Children With Autism *Study Confirms That Pointing and Gestures to Focus Attention Improve Later Language*

By The National Institute of Mental Health (NIMH)

An intervention in which adults actively engaged the attention of preschool children with autism by pointing to toys and using other gestures to focus their attention results in a long term increase in language skills, according to researchers supported by the National Institutes of Health.

At age 8, children with autism who received therapy centered on sharing attention and play when they were 3 or 4 years old had stronger vocabularies and more advanced language skills than did children who received standard therapy. All of the children in the study attended preschool for 30 hours each week.

"Some studies have indicated that such pre-verbal interactions provide the foundation for building later language skills," said Alice Kau, PhD, of the Intellectual and Developmental Disabilities Branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the NIH institute that



Connie Kasari, PhD

supported the study. "This study confirms that intensive therapy to engage the attention of young children with autism helps

them acquire language faster and build lasting language skills."

First author Connie Kasari, PhD, of the University of California, Los Angeles (UCLA), conducted the research with colleagues Amanda Gulsrud, PhD, Stephanny Freeman, Ph.D, Tanya Paparella, PhD, and Gerhard Hellemann, PhD.

UCLA is one of 11 institutions that receive support from the NIH through the Autism Centers of Excellence Program.

The study findings appear in the Journal of the American Academy of Child and Adolescent Psychiatry.

The 40 children who participated in the study were 8 and 9 years old. Five years earlier, they had been diagnosed with an autism spectrum disorder and received the intensive therapy program or standard intervention, as part of a separate study.

The researchers assessed the children's vocabulary, language, and other cognitive skills. They then compared the results of these assessments to those taken when the children were 3 and 4 years old. The earlier and later assessments also included measures of the child's ability to initiate interactions with adults, the variety of the

child's play, and the quality of interactions with a parent.

The researchers found that children who started the attention-focusing therapy earlier had more advanced linguistic skills at age 8. Those who learned to point or direct an adult's attention to an object of interest at age 3 and 4 also developed more advanced language skills when they were 8. And children who showed greater flexibility in playing with objects at age 3 or 4 demonstrated better memory and other cognitive skills at age 8.

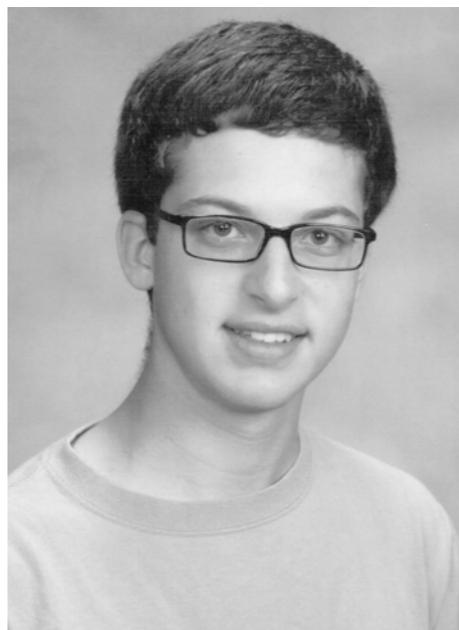
"Our findings show that therapy focused on such basic skills as pointing, sharing, and engaging in play can have considerable long-term effects as children with autism spectrum disorders grow and learn to express themselves with words," said Dr. Kasari.

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) sponsors research on development, before and after birth; maternal, child, and family health; reproductive biology and population issues; and medical rehabilitation. For more information, visit the Institute's website at <http://www.nichd.nih.gov>.

NJ Introduces Innovative Services Act to Address Housing Crisis

By Adam Straus-Goldfarb,
Herbert D. Hinkle, Esq, and
Maria Fischer, Esq
Hinkle, Fingles & Prior, PC

There are roughly 5,000 people with developmental disabilities on the priority waiting list for residential services in New Jersey. That number is growing. Coupled with the more than 2,500 people with developmental disabilities who are currently institutionalized, with many of them eligible for placement into community residential programs, and the need for the development of innovative services, especially residential services, is critical. Many family members and friends of people with developmental disabilities are willing to assist financially with the cost of services, but they have limited options to do so under the current Department of Human Services' system. Further, it is unclear whether the provision of financial support by family and friends could prove detrimental to persons with developmental disabilities with regard to future government funding. People with developmental disabilities deserve the same breadth of choice in housing options as people without developmental disabilities, but they are currently limited primarily to group homes and institutions. The solution to the housing



Adam Straus-Goldfarb

problem is simple: facilitate the growth of innovative service arrangements.

In an effort to spur innovative housing options and change the current Department of Human Services' System, the authors of this article, working with a number of organizations providing services to the developmentally disabled, community and elected officials drafted and introduced the Innovative Services for Persons with Developmental Disabilities Act (the Act).



Herbert D. Hinkle, Esq

Senator Robert M. Gordon, of Bergen County, NJ, sponsored the Act, which was introduced in the Senate on September 19, 2011. This was followed by the Act's introduction in the Assembly on December 8, 2011; sponsored by Assemblywoman, Valerie Vainieri Huttel, of Bergen County and Assemblyman Angel Fuentes, of Camden and Gloucester Counties.

The Act declares it is the public policy of New Jersey to encourage the establish-



Maria Fischer, Esq

ment of innovative service arrangements. It is further noted that private entities are willing to develop innovative approaches to the delivery of services. It is vital that opportunities for these private entities be encouraged and increased. To that end, the Act mandates the Department of Human Services (DHS) to establish innovative service arrangements by providing

see Crisis on page 31

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The Support of Adolescents and Adults with Autism in the Community

How to Establish Community and Life Skills That Will Endure

By Thomas L. Zane, PhD, BCBA-D
Gloria M. Satriale, Esq, BCABA, and
Peter F. Gerhardt, EdD
PAAL

The United States is on the verge of a crisis as more than 800,000 children identified with Autism Spectrum Disorders (ASD) enter adulthood. Consequently, there are vastly larger numbers of adolescents and adults who need interventions and services than ever before. Unfortunately, the need continues to far exceed the available resources, leaving a generation of people with autism and their families in a programmatic, financial and personal limbo, and society-at-large economically diminished. Notwithstanding the recognized impending tsunami of individuals who will shortly enter adult service systems, the bulk of services currently available to support individuals with autism serve ages 0-21 (Gerhardt, 2009). Recently, Autism Speaks announced preliminary results of new research that estimates the costs of autism to society at a staggering \$126 billion per year - a number that has tripled since 2006. The costs of providing care for each person with autism affected by intellectual disability through his or her lifespan is approximately \$2.3 million. In light of the dearth of services and increas-



Thomas L. Zane, PhD, BCBA-D

ing costs, we should establish reliance on natural supports and build community and life skills that will endure so that individuals with ASD can navigate society productively and without complete dependence on service systems.

The community is composed of a diversity of preferences, philosophies, activities, and cultures, all of which operate accord-



Gloria M. Satriale, Esq, BCABA

ing to different expectations or "organizational cultures." For adolescents to learn and maintain requisite skills, education and training must be provided in the community as soon as possible. Specifically, education should take place in community environments where the student is likely to frequent and utilize as an adult (nuclear environment). Early and intense



Peter F. Gerhardt, EdD

community immersion will ensure that the student has opportunities sufficient to develop and refine abilities to navigate and socialize in the community (Wehman & Thomas, 2006). Notwithstanding the research indicating that individuals with autism learn best in an environment in which

see Community on page 29



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Ilene Solomon, PhD, Neuropsychologist
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The Asperger Syndrome Training & Employment Partnership (ASTEP) focuses on employer education and training, and advises employers on how to recruit and manage employees with Asperger Syndrome. www.asperger-employment.org

Asperger Syndrome and High Functioning Autism Association (AHA) provides support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. www.ahany.org

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

www.spectrumservicesnyc.com for clinical services and contact information

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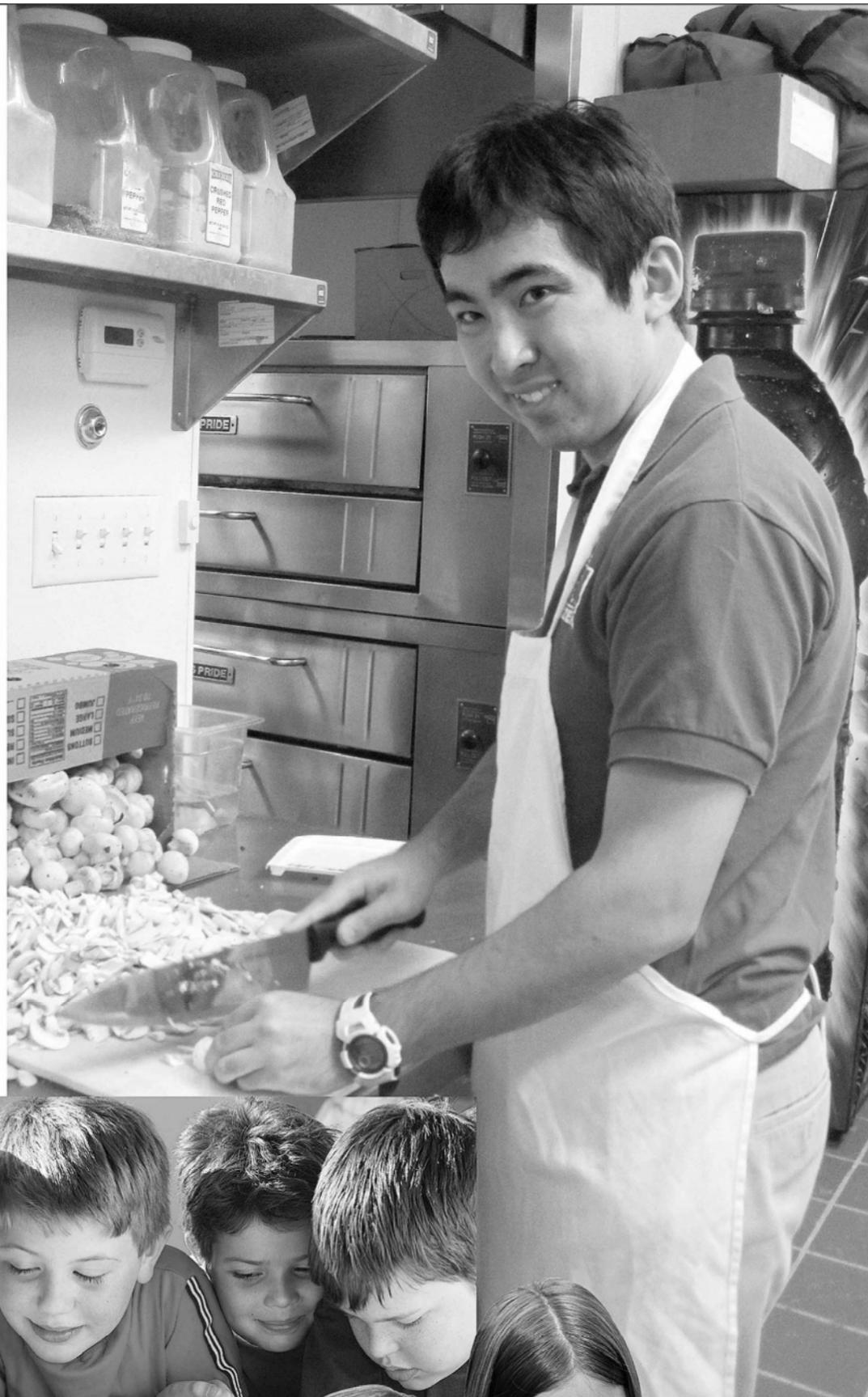
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Or contact our National Referral Office at 800.345.1292.

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Improving Vocational Rehabilitation Services for Adults with ASD

By Yvona Fast, MLS
Support Groups Manager
GRASP

According to recent data, just 15% of autism spectrum adults have full-time jobs, and 7 years after high school, 1/3 of young ASD adults still have no paid work experience. Many of those who are employed have checkered work careers, going from one job to another with long periods of unemployment.

A State's Division of Vocational Rehabilitation (VR) is designed to help all disabled people become gainfully employed. Vocational Rehabilitation counselors are trained to evaluate the individual's vocational strengths and weaknesses, and provide assistance. However, most VR programs aren't equipped to serve individuals with ASDs, and few VR professionals understand the special needs of those with neurological or social handicaps. Because these individuals are intelligent and articulate, their skills and abilities obfuscate their need for supports and services - until they fail. When adults on the autism spectrum seek assistance in obtaining and maintaining employment, they often find that what little help is available doesn't meet their needs. Often, VR agencies want to place people in unskilled, entry-level jobs, rather than jobs commensurate with the person's educational achievement.



Yvona Fast, MLS

Some adults on the spectrum report that the VR counselors they saw felt their employment problems were due to a poor attitude and other personality characteristics rather than to a disability. Others described their lifelong troubles, like difficulty working smoothly with others, and were told everyone has those problems. For Laurie, "Everything VR offered was dependent on speed, required the ability to multi-task and the ability to think on

one's feet" – the very things she has difficulty doing.

Steve describes his experience with the state VR Office: "They would help me look in the classifieds and send resumes to different places. It was kind of bizarre that, for three years, they kept asking me what type of job I was looking for!" He had a few interviews, but with meager results. Finally they said his time was up.

"They didn't have any connections," Steve continued. "It's their job to help people like me, but they can't do it. They had a program that would pay my wages for the first three months on a new job, but even promoting that, we couldn't find anything."

When VR sent him for a vocational assessment, Steve complained the tests weren't vocational and didn't test his computer aptitude or other skills. His complaints were interpreted as a lack of cooperation, and he was removed from the VR program. He felt betrayed. "I met with those counselors every week... not one of them has called me to see how I'm doing. One day they're on your team, helping you, rooting for you. The next day they won't talk to you; they just say they can't help you any more, you've exhausted the funding and you're on your own. They can help a disabled person get a janitorial type job, but they don't have a clue how to help someone who has a college degree, yet has a disability like Asperger's. The business community wants

young people fresh out of college, with no problems or weak areas. Something needs to be done to close the gap between the charitable organizations that help people find work and the business community."

Steve's experiences with VR are not uncommon for individuals with ASD. State VR agencies are used to dealing with mentally retarded individuals who can be placed in low level jobs like dishwashers or janitors. They also are able to help those with physical limitations, who can be employed with the use of accommodations like wheelchair ramps. But they're clueless how to help individuals with neurological dysfunctions like Asperger's, who are intelligent and have college degrees but have difficulty with work environments that cause sensory overload, are fast paced, production oriented, and socially demanding. Their deficient understanding is a function of a numbers-driven system, giving jobs to folks who are more adaptable, easier to accommodate, and provide a less complex challenge.

Intelligent, articulate ASD individuals can experience workplace success with appropriate vocational supports from well informed providers. Without meaningful supports, however, they will continue to struggle and fail.

Often, adults with ASD obtain VR services for other disabilities – like anxiety or depression. Nina's therapist referred her to

see *Vocational* on page 31

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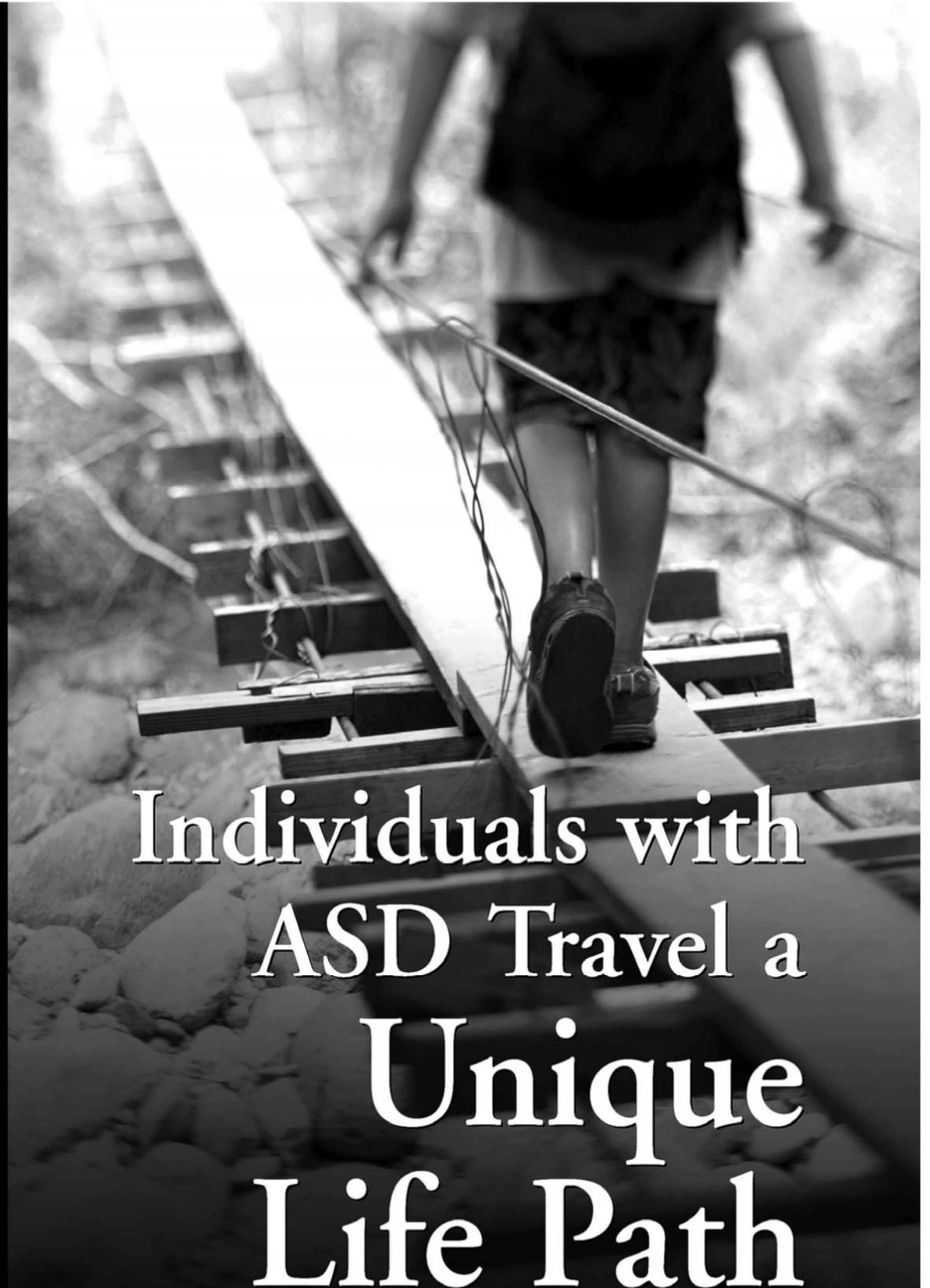


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A Local Parent Support Group Grows to Meet Regional Need

By Carole N. Kalvar
Board Member
Asperger Syndrome and High
Functioning Autism Association (AHA)

In the late 80s, Amy, a very bright fifth grader, newly diagnosed with Autism Spectrum Disorder (ASD) was alternately teased and ignored by her peers. Her mom, Bea, was concerned about how Amy's struggles with social communication and her occasional episodes of diminished emotional control were impacting her school performance. She was also trying to come to grips with this newest diagnosis in a series of possible explanations for her daughter's uneven development. In her search for information she made a call to a newly formed group of parents in her local Long Island, NY community. The group, Advocates for High-Functioning Autistic-Like Children, came together to share information about a little known class of psycho-neurological conditions that were affecting their children's development.

In the late 80s these disorders were barely recognized by medical and mental health professionals. Undaunted, these parents were determined to seek out the information and resources available and use them to advocate for appropriate school placements and effective treatments. Its first support group, held at Stony Brook University Hospital in Suf-



Carole N. Kalvar

folk County, NY was formed with the guidance of Dr. John Pomeroy, one of the few experts in the fledgling field.

The group's name has undergone changes in its 24 years and is now known as *Asperger Syndrome and High Functioning Autism Association* or AHA. It became an influential regional organization with a national reputation and, via the Internet, an international reach. AHA, headquartered in Amityville, NY, with a satellite location in Manhattan (at the offices of Spectrum Services) has a four-fold mission, to increase awareness of Asperger Syndrome (AS) and related conditions among professionals and other

service providers, to make appropriate services, school placements, employment and housing available, to provide an effective network of supports to families coping with these challenges, and to provide individuals, their parents and professionals a useful forum for the exchange of pertinent information.

AHA now offers thirteen support meetings in locations throughout Long Island and New York City. Facilitators are trained volunteer members of AHA. Ten of these meetings serve the needs of parents or other family members. The groups provide an invaluable source of emotional support and a place to get firsthand knowledge from those who've "been in the trenches" about being an effective advocate. At meetings you may hear about CSE (Committee on Special Education) meetings, conferences with teachers, doctors, and therapists, special needs estate planning and guardianship; transition and college issues, social security and disability regulations and the daily challenges of bringing up a child with ASD. Often the group provides a source of strength to participants as each struggles to answer the questions, face the fears and appreciate the joys of having a loved one with ASD.

Paula, whose son with ASD is now 34, has been a member of AHA for over 10 years and regularly attends AHA's support group for parents of older teens and adults. She says, "Only those people who are going through what we live with 'get

it.'" Paula also obtained very practical help from AHA in navigating the NYS vocational training system for adults with disabilities (ACCESS-VR). An educator who is a member of the ASD team for the NYC Dept. of Education's Division of Students with Disabilities, Paula encourages parents to join support groups to dispel the sense of isolation that a child's special needs can cause.

Three of the support groups are exclusively for individuals "on the spectrum." Facilitators may also be "spectrumites." These meetings, one for teens and two for adults, are sponsored by AHA in partnership with GRASP (Global and Regional Asperger Syndrome Partnership) and Spectrum Services of NYC. For many participants this is the first time they've felt understood by peers and able to develop feelings of belonging and camaraderie. While sharing personal stories members build self-worth, confidence, self-advocacy skills and coping strategies.

AHA fields thousands of calls a year to its 24 hour referral and education phone line and responds to email inquiries it gets from as far as Singapore. Bea Gravino who is a long term active member of AHA's Board of Directors, recalls her first contact with AHA. "From my very first call, someone helped me begin to understand what autism would come to mean in my life and how I would have

see *Support Group* on page 34

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Autism Spectrum News Welcomes New Editorial Board Member

Staff Writer
Autism Spectrum News

Autism Spectrum News is pleased to announce the appointment of Dianne Zager, PhD, to the esteemed Editorial Board. According to David H. Minot, BA, Publisher of *Autism Spectrum News*, "I am so pleased to have Dr. Zager join the Editorial Review Board. Dianne exemplifies the outstanding qualities of leadership, commitment, and service to the autism community. She also brings a wealth of editorial experience and expertise that will be a great asset to the publication."

Dianne Zager, PhD, is the Michael Koffler Professor in Autism and Director of the Autism Specialist Graduate Program at Pace University in New York City, where she founded one of the nation's first inclusive college support programs for students with autism. She also founded a campus inclusion program at Pace for New York City public school students with autism and intellectual disabilities. She has worked with students with autism and related learning differences from the early childhood level through postsecondary education as a special education teacher, administrator, teacher trainer, researcher, and advocate.

Dr. Zager has devoted her career to teaching students with significant disabilities, preparation of special educators, and research in disabilities - most especially autism. She is pleased to join the editorial review board of *Autism Spectrum News* and hopes to be an active and involved member of the board. She would like to continue her advocacy work and to serve the readers of *Autism Spectrum News* through active writing and review. As a new member of the editorial review board, she will work to continue the ASN practice of providing evidence-based information that responds to real-life needs of individuals on the spectrum; so that information may be shared among people on the spectrum and their families, educators, clinicians, and related service providers in the field.

"I am committed to continuing and promoting the philosophy and ideals of *Autism Spectrum News*, which foster dissemination of scientific research-based practices that have potential to improve services and quality of life for persons on the autism spectrum. The information included in ASN has helped me to be a better educator and advocate. It is my hope that I will continue the tradition of sharing evidence-based information to improve and increase accessibility to needed services."

Dianne's history of service and leadership at the regional and national levels includes serving as President of the Northeastern Educational Research Association



Dianne Zager, PhD

and President of the New York State Council for Exceptional Children. She is an advocate for students, families, and special educators. She has served on editorial boards of national and international educational journals, and was founding co-editor of *Focus on Autism and Other Developmental Disabilities*, currently one of the most widely read autism journals in the U.S. In addition, she has been editor of *The Educational Researcher*. Awards received include the American Academy of Child and Adolescent Psychiatry Furman Fellowship, Leo Doherty Educational Research Service Award, and the Thomas Donlon Award for Educational Leadership and Mentoring from the Northeastern Educational Research Association.

Dr. Zager received her BS in Special Education/Psychology from Boston University, MS in Education from Boston University, and PhD in Educational Research from Hofstra University. The third edition of her text, *Autism Spectrum Disorders: Identification, Education, and Treatment* was published in 2005. This past year she was senior editor on a text titled, *Educating Students with Autism Spectrum Disorders: Research-Based Principles and Practices* with Michael Wehmeyer and Richard Simpson, published by Routledge/Taylor & Francis. Her most recent text with Carol Alpern and Barbara McKeon, *Educating College Students with Autism*, was written with support from Autism Speaks, and will be released in August 2012.

Dr. Zager has gained national recognition for her work in integrated behavioral experiential teaching, and postsecondary education for students with autism. She has presented over 300 papers, keynote addresses, and workshops across the U.S.; and has authored numerous books, chapters, and research papers on topics related to education of students with autism spectrum disorders.

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The ELIJA School is a 501c (3) nonprofit organization dedicated to supporting children with Autism, their families and the Autism community at large with science-based treatments utilizing the principles of Applied Behavior Analysis (ABA). The school opened its doors in order to improve the quality of education for children with Autism from the Long Island and New York City areas who cannot be served in their available public school settings. The ELIJA School also provides extensive training programs, advocacy and outreach services for professionals, individuals, their families, teachers and caregivers.

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Social Skills Groups Benefit Children and Parents

Susan Miron, OTL, MA, SAS
Director
WJCS Achieving Milestones

Social Skill Groups with toddlers and parents offer many advantages. These small groups provide parents the opportunity to talk with families who share similar concerns and a place to practice new skills to help their children. In the group, there is a sense of community and understanding. It is a safe place for families to learn and support each other. Parent Child Groups provide:

- Parent-to-parent ongoing support
- Professional coaching in a safe environment for parents to practice skills
- A platform where a child's skills can increase in a variety of areas: communication, socialization, play, and behavior
- Opportunities for child and parent to explore new experiences in a safe, supportive environment
- Encouragement to increase consistency in the use of new strategies
- A platform to experience of how techniques work over time
- An atmosphere that encourages posi-



Susan Miron, OTL, MA, SAS

tive and fun play experiences for parent and child together

- Directed observation for parents to notice the positive changes in their child
- Help and emotional support in time of crisis
- Reinforcement for positive coping behaviors
- A base for sharing information, ideas and resources

- Resources and support in dealing with educational, medical and other service agencies
- An opportunity to relieve loneliness and form new friendships

The groups create a platform for parents to practice skills, raise concerns, give suggestions, enjoy their children, explore and play together.

The children who attend the Achieving Milestones of WJCS Parent Child Group programs are ages 18 months to 5 years with different needs but who often have not been in social settings with other children who have challenges interacting with other children. Parents' concerns range from communication limitations such as the child not using words to express him/herself or social/play concerns, such as limited turn taking skills, throwing of toys or inadequate attention to complete a simple puzzle. The group provides a natural social environment for learning to take place.

We would like to introduce you to two of the children who have attended the groups, an overview of the approach used and then a few of the changes seen in these children.

Meet Brandon, a 20-month-old boy with big, engaging eyes who loves to move. His mother was concerned about his lack of speech and had him evaluated through the Westchester County Depart-

ment of Health's Early Intervention Program. He was found eligible for services to help him with communication, play and social skills. It was soon recommended he attend one of the Achieving Milestones Parent Child Groups. When Brandon started attending the group, he moved around the room grabbing any items he could find such as markers, toys, etc. He had difficulty focusing in order to sit and play. He climbed on the table and chairs, did not respond to commands and wandered the room during most activities even snack, his favorite time. His mother reported that everyone at home would immediately say "no" and take things from him that he had grabbed which often resulted in tantrums. Every evening as the family settled down to relax and watch television, Brandon took the remote and played with the buttons and changed the channels. Family members yelled "no" and took the remote from him triggering a tantrum. This was a daily occurrence. Brandon was a challenge at home and in group!

Meet Sarah, a shy two year old. At nine months Sarah had muscle weakness and was not crawling or rolling as expected. When Sarah's mother had her evaluated through the Westchester County Department of Health Early Intervention Program, she was found eligible for services. Sarah started to receive physical and occupational therapy services at

see Social Skills on page 28

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Sibling Perspective on Autism Research

By Ben Rimland
Autism Science Foundation

As the brother of an individual with autism, perhaps the most overbearing feeling is that of tremendous uncertainty. Information on the sources of and treatments for autism spectrum disorders (ASD) run the gamut from reputable to dubious. It can sometimes be a frightening experience to hear stories of ASD children being denied common medical treatment as a result of suspect pseudoscience. While the true causes of autism remain unclear, what is clear is the importance of funding and supporting scientific research. Whether investigating new and emerging methods of ASD detection or analyzing genetic markers for ASD, properly vetted scientific research represents the most viable step forward in providing long term help for our families.

This summer I am working at the Autism Science Foundation. The Autism Science Foundation (ASF) is proud to be at the forefront of the scientific battle against ASD, seeking to foment promising research studies with grants and fellowships. As someone affected personally by ASD, I am drawn to the rational, analytical approach taken by ASF towards disbursing grants to deserving and promising researchers. Studies funded by ASF range from development of Applied Behavioral Analysis therapy for younger and younger children, to analysis of fine motor control development in toddlers with ASD. Dr. Matthew State, chairman of the ASF scientific advisory board, emphasizes that the studies funded by ASF represent a "broad set of perspectives" on scientific work being performed today to combat ASD. Throughout all the studies, the scientific focuses of ASF are clear: effective detection and treatment for individuals of all ages. In particular, a study funded by ASF and conducted by Drs. Klaus Libertus and Rebecca Landa of the Kennedy Krieger institute embodies this philosophy perfectly. The study performed by Landa and Libertus investigates how toddlers both with and without ASD learn to grasp objects. By outfitting the children with special velcro-covered mittens, the children are able to learn grasping at an earlier age as well engage in a common form of "self-initiated"

exploratory treatment. Hopefully, the techniques pioneered by Libertus and Landa will prove integral to developing forms of early treatment and intervention for toddlers who may be on the autism spectrum. In an example of even earlier intervention, an ASF study conducted by Drs. Jessica Bradshaw and Bob Koegel is pioneering an ABA approach for 9 month old babies at risk for autism. This way, no parent will ever have to hear: "Your child is at risk for autism, but there's nothing we can do yet."

Studies funded by ASF do not solely investigate the biological, neurological and genetic effects of autism. Autistic children suffer in ways far removed from the sterility of the genetics lab. I have seen my brother suffer as a result of boilerplate, one-size-fits-all therapies that affect some children differently than others. As ASD children move through the state education system, it is saddening to see that fewer and fewer community resources become accessible to parents of ASD children. By having treatments that are tailor-made to understanding and working with gender disparities and cognitive differences that come with age, we can design therapy that is conducive to, as Dr. Peter Gerhardt puts it, "community inclusion" of children with ASD. In particular, an ASD study conducted by Dr. Ami Klin and Jennifer Moriuchi of the Emory University Marcus Autism Center is committed to designing such therapy. By monitoring the specific differences that emerge between boys and girls with ASD in a classroom setting, the study hopes both to address the needs of a traditionally underrepresented group in ASD research, girls, as well as help in designing future therapies that are more child and gender specific.

The studies funded in part by ASF in the current year represent the culmination in part of a sincere and steadfast scientific mission. By developing efforts at early treatment and intervention, investigating the specific triggers of ASD and designing treatment options aimed at community inclusion of older ASD children, the studies represent the clearest path forward towards winning the scientific battle against autism spectrum disorders. I am enormously proud to be fighting on behalf of my brother with a charity like ASF.



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Health Care Directives: A Safeguard and a Support

By Susan M. Green, Esq
Begley Law Group, PC

It is essential for all adults to execute advance planning documents, especially those adults on the autism spectrum who have the capacity to do so. Chief among these estate planning documents is the health care directive. Often, parents make all health care decisions for their child for the first 18 years of that child's life. When a child turns 18, the parent no longer has the legal capacity to make health care decisions for the child. If your child with autism has the capacity to make health care decisions for herself upon reaching 18, it is necessary for her to execute a health care directive to take effect if she subsequently lacks capacity to make a health care decision.

A health care directive typically contains two elements, the proxy directive and the instruction or advance directive. An individual can choose to utilize only one of these directives, but most individuals execute both (within the same document) in order to establish a comprehensive plan.

Proxy Directive

The proxy directive is essential because if an individual loses decision-making capacity without executing one, it will be



Susan M. Green, Esq

necessary to establish a guardianship in order to have someone named to make medical decisions for the individual. Guardianships are time-consuming, costly, and they do not ensure that the individual's choice of agent will be appointed.

In a proxy directive, an individual names an agent (also called a representative or a proxy) to make health care decisions in his or her stead. Most health care

directives only become effective if the principal is unable to make or communicate treatment decisions due to mental or physical disability. It is extremely important to name multiple successors to this role in the event that the named agent becomes unable or unwilling to act. Attorneys differ with respect to the number of proxies that can be named at one time, but it is good practice to name only one person as a health care proxy because it is easier for a doctor to turn to one point person. People are sometimes shocked to hear that only one proxy should be named to act in a given time period. To allay these concerns, it is possible to include a consultation clause which states that the individual executing the document wishes that if one person is acting as an agent, he or she must consult with the others. For example, when an adult child is appointed as a proxy for a parent, the document can provide that the child consults with his or her siblings before making a final decision about the parent.

Many health care directives include a conflict clause, which states that if there is a conflict, the proxy's decision controls. The purpose of this clause is to avoid situations in which a doctor does not consult with a representative before taking certain actions. It is also essential for the health care directive to specifically refer to and apply to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

The powers explicitly provided to the agent through the health care directive may include supervision of care, ability to employ a care manager or provide a companion, access to medical records, and review and execution of releases required to obtain medical information. An agent should also be empowered to employ or discharge health care personnel, including physicians, psychiatrists, dentists, nurses, and therapists. An agent is typically empowered to arrange for admission of the principal to a hospital or other facility, arrange for home care, summon emergency treatment, and sign admission forms. Other powers often given to a health care proxy include the power to give or withhold consent to psychiatric treatment, power to authorize relief from pain, and power to request, require, or consent to a Do Not Resuscitate order.

Instruction/Advance Directive

The instruction or advance directive is often referred to as a "living will." The most common version of an advance directive states that if two doctors determine that the principal lacks capacity to make an informed health care decision, and there is no reasonable hope of recovery or of regaining a meaningful quality of life, then life-sustaining treatment (LST) should be withheld or withdrawn in each of the following circumstances:

see Directives on page 28

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A Review of a Randomized Control Trial of DIR/Floortime Therapy

By Sara Gershfeld, MA, BCBA, and Tristram Smith, PhD
Board Members
Association for Science in Autism Treatment (ASAT)



Sara Gershfeld, MA, BCBA



Tristram Smith, PhD

Parents and clinicians frequently face the issue of making informed decisions amongst heated debates over the most effective approaches for treating young children with autism (Prizant and Wetherby, 1998). Of the current approaches used to treat autism, there lies a continuum ranging from intensive discrete trial training, to behavior analytic treatment that combines many different instructional methods, to social-pragmatic and developmental approaches. This article provides a basic description of a class of interventions that have recently received increased attention – Developmental Social Pragmatic (DSP) interventions.

Casenhiser, Shanker and Stieben (2011) evaluate DSP as a method of improving social interaction skills of children with autism spectrum disorder (ASD) and state that these different approaches may teach the same types of behavior, but approach them differently than a traditional behavioral approach.

For example, most interventions acknowledge that eye contact is related to increased joint attention and language (Casenhiser, 2011). As such, interventions

aim to teach children with autism to make eye contact. A DSP perspective might suggest that exhibiting eye contact is not what is important, but rather that it is imperative to share the eye contact in a social or play experience. Thus, Casenhiser (2011) reasons that a DSP model focuses on the function of the behavior to engage socially with a peer or adult, whereas a behavioral approach might look at the topography of the behavior as important independent of whether it occurs in a social experience or not (for example, attending to instruction). This basic assumption forms a divide between the DSP

perspective and a behavioral perspective.

Over the course of development of DSP approaches, treatment options such as the Hanen Method (Manolson, 1992), Relationship Development Intervention (RDI; Gutstein, 2001), and Developmental Individualized Relationship-based (DIR) Intervention (Greenspan & Wieder, 2006) have received attention from parents of individuals with autism despite a lack of research that uses the “gold standard” of research methodology – a randomized controlled trial.

In this study, Casenhiser and colleagues (2011) examine a DSP approach

known as a developmental, individual-difference, relationship-based (DIR®) model, which is often interchangeably referred to as Floortime Therapy. The DIR®/Floortime approach focuses on helping individuals with ASD master skills related to communication, thinking through understanding of developmental milestones and challenges, and asserting the importance of building relationships with primary caregivers to encourage development (Greenspan & Wieder, 2006). Although the theory behind this type of approach is well explored using anecdotal evidence in Greenspan and Wieder’s book “Engaging Autism,” there is a lack of robust evidence to validate its effectiveness experimentally (2006). As such, Casenhiser and colleagues evaluate the DIR®/Floortime approach as an intervention aimed at improving the socio-communication skills of individuals with autism using a randomized control trial.

Method

This study enlisted 51 children ranging from 2 to 5 years old. Though this highlights the relatively large sample size, it is unclear how many children did not qualify for this study, did not enroll, or dropped out. Casenhiser also mentioned that recruitment occurred with parents

see *DIR/Floortime* on page 26

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Evaluating from page 1

Rarely will they indicate that the treatment or intervention is 100% effective with 100% of the population.

Popular press publications also accept money from sponsors who pay for advertisements. This can lead to a bias regarding what types of research are published or not. A research finding that might upset a major sponsor can result in the manuscript not seeing the light of day. Peer reviewed journals do not accept advertisements. The manuscript must be rigorous and survive on its own merit. The research findings are subject to debate and public scrutiny under this approach. Other researchers in the field will attempt to replicate the findings which lends further support that a particular intervention technique is truly effective and worthy of trying with an individual on the spectrum.

Once a parent or a treatment professional locates a peer reviewed journal to determine if an intervention technique is effective, then he or she should attempt to locate as many research studies on the technique as possible. By reading the abstracts of each article, the reader can glean a sense of how well the technique is withstanding repeated empirical testing. Re-



Ernst O. VanBergeijk, PhD, MSW

searchers will generally come to a consensus as to how effective a technique is with a specific population.

The testing of interventions or drug regimens generally utilizes quantitative research techniques. Quantitative tech-



Paul K. Cavanagh, PhD, MSW

niques test hypotheses by collecting data that are transformed into numbers. Researchers use statistical methods to analyze the data and look for relationships between variables. Quantitative research designs are on a continuum of rigor. The

least rigorous design is the case study where only one subject is observed and the results are based upon the single patient. Next along the continuum are the Single Systems Designs also known as the Single Subject Designs (SSDs). These designs are considered more rigorous than a case study because more data points are collected. The subject is observed until a steady baseline of the target behavior is achieved. Next an intervention is introduced for a period of time and the effect upon the target behavior is recorded. The next phase in this research design is the withdrawal of the intervention. The target behavior is observed and data are collected. The data are plotted upon a graph to visually see the impact of the introduction and withdrawal of the intervention. This technique offers little control for extraneous factors causing the change in the target behavior so it is difficult to tell if the intervention technique really worked. It is also difficult to generalize results, i.e., say with any certainty that this technique works with other people.

Toward the right side of the continuum of increasingly more rigorous research designs are a group of research designs

see Evaluating on page 23

Do you have a child with an Autism Spectrum Disorder and noncompliant behavior or hyperactivity?

Yale Child Study Center is conducting a research study comparing parent training and parent education for young children with ASD.

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CONTACT: 203-785-5805. Yale IRB # 0411027217.



Yale Child Study Center is also conducting a research study to test the effectiveness of a **non-stimulant medication**, extended-release guanfacine (Intuniv®), for children with PDD and hyperactivity. Eligible children are **at least 5 but younger than 14 years old, with autism, Asperger's, or PDD-NOS**, and clinically significant **hyperactivity**, currently medication-free or on ineffective medication. **CONTACT: 203-737-5317. Yale IRB # 1001006172.**

Comprehensive from page 1

disabilities. Psychiatric services include consultation, evaluation and treatment for individuals with autism spectrum disorders, including identification of comorbid neurological and neuropsychiatric disorders and participation in the development of a comprehensive integrated interdisciplinary treatment plan.

Psychological and Psychosocial Services - Each individual's treatment plan is tailored to address his or her unique social, behavioral, language, and academic difficulties. Since other disorders commonly co-occur with ASDs, which include depression, obsessive-compulsive disorder, anxiety disorders and ADHD, the specialty team treats each individual according to his/her needs. Treatment includes: cognitive behavioral psychotherapy (CBT), social skills intervention (both group and individual), parent training, family training, parent support groups and transitional life planning.

Speech and Language Services - The speech pathologists at the Lindner Center are keenly aware of the specific language deficits that accompany an ASD diagnosis. The therapists are specially trained in evaluating and providing treatment to individuals with various speech and language deficits, including those with pragmatic and semantic disorders across the age span. Therapy is provided both individually and within small social language groups. Groups are often used to target real time social communication and perspective taking deficits amongst peers.



Nancy Weiss, MS, CCC/SLP

School Consultation Services - The Lindner Center works with children, adolescents and families and their schools to promote each child's opportunity to meet his or her maximum potential by working closely with school-based personnel. The Lindner Center is able to build multidisciplinary teams that can develop and implement effective learning programs tailored to meet the needs of each child with a concentration in the areas of social skills, academics and behavioral planning.

Social Skills Groups - The Lindner Center

provides ongoing weekly, social skills groups for tweens, teens and adults. These groups are run by a specially trained psychologist or speech pathologist in the area of social skills. Each session targets a specific social language skill and activities selected to best facilitate carry-over of the new skill.

Social and Recreational Programming Services - The Lindner Center holds socials for tweens, teens, young adults and adults in order to provide an opportunity for individuals with ASDs to meet, socialize and network. Previous socials have included but limited to: holiday parties, cooking, art projects and game activities. Most socials consist of a theme and all participants are encouraged to actively participate in all activities.

Furthermore the Lindner Center provides holiday and school break programs when school is closed. These programs integrate specific social skills training and friendship skills while participating in fun, age appropriate recreational programming and life skills training.

Peer Mentorship Program - Peer mentors are an integral component of all of the social skills groups, as well as the social and recreational programming services, in order to model appropriate peer interactions. Each peer mentor has been trained in autism spectrum disorders and effective techniques to facilitate conversation and social interactions.

Life Skills Services - The Lindner Center offers a weekly life skills program which focuses on ADLs while further

fostering friendships and appropriate social skills.

The Fay J. Lindner Center for Autism and Development Disabilities offers an extensive range of vital services for individuals of all ages with ASDs. What makes the Lindner Center truly a center of excellence is the comprehensive and collaborative approach that is used within all the programs and services by highly trained and respected professionals in the field of autism.

In order to address the complex needs of individuals with ASDs, when identifying and selecting services, it is essential to look for a program that is both current in the latest research and understands the individual needs of persons with autism. Moreover, when choosing programs that provide a collaborative approach to the various services provided, there is a more holistic, integrative style to assessment and intervention, which maximizes communicative, cognitive and behavioral success.

The Fay J. Lindner Center for Autism, an affiliate of the North Shore-LIJ Health System, was formed to meet the needs of children and adults with autism and related developmental disabilities and their families. The Center is located in a state-of-the-art facility on AHRC Nassau's Brookville campus. The Center offers a wide range of programs, clinical services, professional training, community education, specialized program consultation and research, to individuals, families and schools. Visit us online at www.FayJLindnerCenter.org.

Tips to Promote Caregiver Emotional and Physical Health

B. Madeleine Goldfarb, MA
Executive Director
Noah's Ark Institute

Autism is oftentimes confusing, unpredictable and hard to manage. As parents and caregivers you are required to traverse the highs and lows of the autism diagnosis.

From the outset of parental/caregiver concern to the day your loved one receives the diagnoses on the autism spectrum and everyday of your life thereafter, you must make difficult decisions and understand a daunting array of processes which will impact you, your loved one and your family... forever.

The information required to absorb, while caring for your loved one, is relentless. The obligation to make life altering decisions on an almost daily basis can take its toll. The endless questioning of oneself as to your proficiency at determining the proper course of action may become overwhelming: "Have I learned enough about X, Y, or the new Z therapy? Should I consider this or that treatment? If I try that treatment, how much or how often should I try it? Have I seen progress with this or should I change to that? Which specialist are we seeing today? Is the school district participating with us or do I have to fight for services? What do I need for due process? Who will take care when I am gone? Do I need



B. Madeleine Goldfarb, MA

to get guardianship for my loved one? How are my assets protected? Who has the answers I can trust?"

With so much going on, it is vital that you are in optimal health and emotional well being. If you do not take very good care of yourself you cannot be on top of the situations you will be faced with.

Here are some tips about caring for yourself. This is very important. Do not feel guilty about keeping yourself healthy. If you are not healthy, both physically and emotionally, you cannot provide the optimal care, direction and discussion making you will need to provide for your loved one.

Madeleine's Top 15 Tips For Self-Care

- 1. Get Enough Sleep.** Sleep enables your body to replenish, grow, and heal. If you are having difficulty sleeping, listening to peaceful, slow music and/or doing relaxation techniques just before you go to sleep may be very useful. Sleep is how your body strengthens your immune system. Sleep issues are not uncommon with a diagnosis of autism. Work with your loved one's therapist and medical team to help find solutions. If your loved one is not sleeping, chances are no one in the household is getting a good night's rest.
- 2. Eat Healthy foods** such as fruits and vegetables. Try to avoid skipping meals. A good metabolism relies on frequent replacement of energy (food). That said, make healthy choices in your diet a priority. As a rule of thumb, the less processed and more organically grown a food, the better. Avoid simple processed sugars like sugary sodas. **Avoid overuse of**
- 3. Drink an Ample Amount of Water.** This will help hydrate your skin and your body. Water also flushes toxins out of your body and keeps your internal engine working properly. Hydrate...Hydrate...Hydrate. Try and drink enough water so that your urine is clear. Water is not coffee. Water is not tea. Water is not soda. Nothing but water is water, preferably filtered.
- 4. Organize Your Spaces.** With everything that is going on it is easy to get overwhelmed. An organized place where you can find what you need is going to be extremely helpful. Start small, if you have a very disorganized home. Start with one room or even one drawer at a time. Having a dedicated filing system for all of the reports, medical team evaluations and school documents will be very helpful. Create a file with business

see Health on page 33

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Using Relationships to Support Children with ASD

By Lisa Tazartes,
Mike Kunin, MA,
Jennifer Buri da Cunha, MA, and
Kyle Avery
Ramapo for Children

Working with children, whether as a parent, teacher, or caregiver, is an inherently social process. This is no different when we are talking about children on the autism spectrum. In order to impact children with ASD, the adults in their lives need to employ a set of activities, strategies, and skills that form a strong adult-child bond as the basis of any intervention. This requires that we see autism not through the lens of social skills deficits, but rather with the understanding that children with autism seek comfort from and desire interaction with adults. In fact, the stress and anxiety that social situations trigger for the child with ASD actually heightens his or her need for meaningful relationships with caring adults.

Personal relationships are frequently the catalyst for motivating behavioral change and, therefore, are a key component of good teaching. Once rapport is developed, a budding relationship between an adult and child becomes as reinforcing as any tangible reward used to manage behaviors and teach new skills. When this relationship is mutually enjoyable for the child and the adult, the child wants to ex-



Children with ASD want to learn social skills in a fun and relaxed way

hibit behaviors that receive positive recognition from the adult and the adult is able to intervene effectively when maladaptive behaviors are exhibited.

All children with ASD want to learn social skills in a fun and relaxed way, but they need a facilitator to help navigate social situations. Unlike many typically developing children who learn to socialize through imitation or trial and error, children with ASD lack a road map for navi-

gating social situations and need clear and deliberate models. Models are comforting and offer support, helping to dissipate stress and anxiety associated with such interactions and allowing the process of true social learning to begin. Regular caregivers can be very effective instructors for modeling behavior because they are uniquely positioned to promote social learning and generalizing skills in a natural environment.

The value of building relationships with children on the autism spectrum goes beyond instruction. It also forms the basis for better communication and significantly impacts how effectively adults manage difficult behaviors. Though relationship building may seem like an imprecise art, there are specific, concrete, and actionable steps that caregivers can take immediately to improve relationships. Here are a few tools that Ramapo for Children uses and teaches to facilitate relationship building, and examples of those tools in action:

Take the Time to Understand a Child's Uniqueness and Special Interests. Recognizing what interests the child and integrating engaging topics in other activities is critical to nurturing a relationship and, ultimately, to building valuable skills.

At Camp Ramapo, Ramapo's summer camp for over 550 children with social, emotional, or learning challenges, including children with ASD, counselors become experts at helping campers transition from an isolated interest to integrated play. When Camille, a 12-year-old girl with a special interest in fairies, first came to camp, she isolated herself with her fairy dolls and would refuse to engage in social activities. She had difficulty taking a break from stressful or escalating situations, and she would resist reviewing her daily schedule by covering her ears and screaming.

see Relationships on page 27

Autism Parent Support Groups

A Successful Model Providing Information and Support

By Kate Macaluso, LMSW
Supervisor
YAI LINK

Families often lack information about the autism diagnosis such as what to expect, treatment options, and how to access services. Support groups serve two main functions. They provide families and caregivers with much needed information on a variety of topics related to autism spectrum disorders (ASD). And, just as important, they provide interpersonal support so that parents and caregivers do not feel isolated and alone. Group support offers parents the knowledge, understanding and acceptance they seek (Banch, et al, 2009). YAI has been running an Autism Family Support Series since 2006. Over the years we have adapted our model based on lessons learned and feedback from parents.

Impact on Families

Families caring for a child on the autism spectrum confront a variety of issues and concerns, including managing aggressive and self-injurious behaviors, selecting an appropriate educational placement, wondering what happens after graduation and managing caregiver stress.

The emotions of having a child with

autism vary and are very personal for each family member. There may be grief over the diagnosis and mourning for not having a typical child. Families might feel anger and wonder, "Why did this happen to me?" Parents report feelings of shame and embarrassment over the child's behaviors and uncertainty about how to respond. These emotions can cause families to feel different and distanced from others. Research indicates that caregivers who participate in support groups feel increased competence, knowledge and empowerment in regards to meeting the needs of their family member with autism (Banch, et al, 2009). Support groups provide an environment where parents can talk openly and honestly about their concerns.

A Model of Information and Support

The format of YAI's support groups has evolved over the years into a model that combines information and support. The structure entails a 60-to-90-minute presentation on a topic of interest, followed by an hour of peer support. The peer support helps families to process the information they have received, share personal experiences and discuss how they can integrate new strategies in caring for their family member.

The support group runs year-round, with about one group a week. Consistency

is important, as parents come to rely on the groups as an outlet to express their feelings and receive support. Some only attend a group that is relevant to them, while others participate in as many sessions as they can, regardless of the age of their family member, because they benefit from the information and support.

Developing Relevant Topics

Support group topics are based on feedback attendees provide either during sessions or on evaluation forms. Sometimes, presentations are selected in response to current and timely issues, such as the upcoming DSM changes and New York state's People First Waiver. Other "hot topics," ranging from genetic research to toilet training, are selected by surveying staff and families to determine needs.

Some frequently requested topics that attract the largest parent turnout are: Special education issues, guardianship/future planning, use of psychotropic medication, sensory integration strategies, social skills, behavior management, stress management, and sexuality. It's also helpful to schedule an "open topic" to allow families to discuss any pressing issues, thoughts or concerns in place of a formal presentation.

Be creative and resourceful in finding speakers to present on issues which will be useful to families. In addition to having

YAI staff present, we also turn to individuals from other organizations who are experts in certain areas. Any time there is a parent of a child with autism who has an area of expertise that is relevant, use her or him as a resource for the support group.

Tips for Successful Groups

Outreach can be widespread or targeted. Mailings, email blasts and websites are good ways to spread the word about the group. Clinicians and other providers should consider support groups as part of the system of care available to families and provide referrals (Mandell and Salzer, 2007). Schools, service coordinators, provider agencies, libraries and other community resources are good vehicles for flyer distribution. Keep an updated database of family members who attend.

Participation in the YAI support group has been bolstered by the fact that it is open to families from all boroughs, and there is no charge. Pre-registration helps to ensure adequate space and materials for all who attend. The attendance ranges from five to 40 families, but the average is around 10 families. Parents represent a diverse mix of families from all over the metro New York area. Caregivers come from different cultures, ethnicities and

see Successful Model on page 24

How is Autism Different for Girls on the Spectrum?

By Eileen Riley-Hall, BA, MA
Author, Teacher, and Mother



Eileen Riley-Hall, BA, MA

As I look back on my life, I suppose in many ways I was prepared to be the parent of children on the autism spectrum. I have always been interested in helping people with special needs. While in high school, I baby sat several children with varying challenges, and during college summers I worked as a camp counselor for children with special needs. I learned a lot about autism, and one sweet blond-haired little boy, who was non-verbal but fluent at signing, was my charge at camp for an entire summer. After college, I became an English teacher, and my first job was in a middle school where I taught a few students on the spectrum. Still, college summer jobs and the teaching the occasional student on the spectrum are very different than having autism become a permanent part of your life. And I certainly never expected that it would be my two daughters who would be diagnosed on the autism spectrum.

My life changed ten years ago when my older daughter Lizzie, a contemplative five-year old with big brown eyes, was having trouble socializing at nursery school. Lizzie was extremely anxious at school and was avoiding her peers, which worried her teacher. At her teacher's urgent suggestion, I made an

appointment with a developmental pediatrician. As a stay-at-home mom at the time, I always had both my girls with me, so Caroline, my almost three year-old, was in tow on the day of the appointment. While the pediatrician evaluated Lizzie, Caroline sat on the brightly colored carpet methodically lining up blocks. As fate would have it, bringing Caroline along turned out to be profound because the doctor ended up diagnosing her as well.

The appointment was lengthy and overwhelming, resulting in the unexpected verdict that Caroline had two feet firmly planted in autism and Lizzie was surfing the spectrum somewhere between Pervasive Developmental Disorder and Asperger's. I was stunned at first. Having two daughters on the spectrum seemed so impossible to believe; it ran contrary to all I had known about autism. Autism, or so I thought, was something that occurred in boys. After I recovered from the initial shock of the news, I decided to learn all I could about autism and how it affects girls. I knew my girls didn't fit the definition of autism as I knew it, so I wanted to find out what makes girls with autism unique and how I could best help my daughters.

As it turns out, girls with autism are not as rare as experts once thought. Although the CDC still estimates girls to be only twenty percent of the overall autism population (CDC 2011), this may not be an accurate figure for a variety of reasons, not the least of which is that girls often present differently and therefore their symptoms are too often missed by physicians, parents, and educators (Giarelli *et al.* 2010). In addition, girls are often misdiagnosed, usually with mental health issues, and consequently may suffer years without appropriate interventions. We need to begin to consider the "girl" factor when evaluating children and designing programs for our daughters. Only then can

we offer our daughters the most appropriate and effective interventions possible. The bottom line is, girls with autism are still girls, and that changes everything.

So, how exactly do girls on the spectrum differ from their male counterparts? Researchers and therapists are beginning to identify traits and needs specific to girls on the spectrum. While obviously all children vary on an individual basis, researchers have identified three general trends of difference. Girls with autism are often quieter and more compliant than boys. Girls with autism may possess a greater capacity for imaginative play. Girls on the spectrum appear to have a deeper longing for friendships than boys, making them more susceptible to depression when they feel lonely and socially isolated.

While not universally true, girls in general tend to be more compliant than boys, especially in their younger years. Whether by nature or nurture, girls on the spectrum are more likely to be quiet, follow directions, and fade into the background when confused or overwhelmed. Therefore, girls on the spectrum can often seem to behave more typically than boys on the spectrum, but that quiet compliance can mask a girl who is not engaging in her environment, or is not able to communicate her struggles or needs (Giarelli *et al.* 2010). When my oldest daughter Lizzie was in the early years of school,

see *Girls on page 32*

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

By Carrie Cariello

Jack's Birthday

Every year I write each of my children a letter on their birthday and keep it in a small journal. These letters describe the person they are at that particular age; their likes and dislikes, favorite activities, and overall temperament. This letter is to my autistic son, Jack, as he celebrates his birthday today.

Dear Jack,

Happy Birthday! Today you are eight, and I can hardly believe how much you've changed in one year (or, as you would say, 365 days).

Your school year has gone smoothly, and you adapted well to the demands of second grade. You've become an excellent reader, but you struggle to grasp math. In class they asked you to divide two cookies among four kids, and you became visibly agitated. They asked again, and on the third try you blurted, "You need to make more cookies! Two are *not enough!*"

You were tickled to learn your teacher was pregnant, and loved watching her stomach as the baby grew larger. You were even more tickled when she named her new son Jack.



Charlie, Joey, and Jack

You have a crush on a girl in your class, and you asked us to buy the house next door so the two of you can get married and live there when you "turn eighteen and are grown-ups."

Always literal, for a while you insisted on carrots for breakfast and bok choy every night for dinner after we explained that vegetables keep your body healthy. You still won't touch yogurt or canned

peaches, but this year you made a giant leap in communication and explained one night how "slimy foods make my tongue feel weird." You love marshmallows.

You seem to be happiest around your siblings; the five of you run in a tight pack. Seeing you play and dance with your brothers and sister is perhaps one of my greatest rewards. Hearing you talk, laugh, and even argue with them makes every dirty dish, every wet towel, and every spilled glass of milk worthwhile.

Your latest obsession is the calendar; a big change from last year's preoccupation with cars. You can remember the dates for events small and large, going back as far as three years. As I was preparing dinner one evening, you asked me, "Mom, what color is Monday?" When I answered that I don't see the days of the week like that, you explained how you see days and colors together - Friday is orange.

Throughout last spring and early summer you wrestled with the slippery grip of anxiety. Within weeks it transformed you from a happy little boy into a child we barely recognized. You were frantic about everything from the wind chill factor to riding the bus, and simple daily activities like using the bathroom were overwhelming. You barely slept. Terrified, we

see *Birthday* on page 25

Vital Services to Promote Child and Family Resilience

Judy Grossman, DrPH, OTR
Director, Special Needs Project
Ackerman Institute for the Family

It is common knowledge that having a child with ASD has an impact on the family, and the family has a profound impact on the developing child. Why then are there so few services to support families as they deal with the cumulative challenges they face managing child behavior, family relationships, family routines and interactions with medical, early intervention and special education providers and policymakers?

Raising a child today is very stressful because of the pressures to help our children succeed – demanding homework, afterschool activities, and the pull of technology. Family life often suffers as parents have work and other roles that leave little time for self and family. Raising a child with special needs adds additional stress beginning with the first suspicion or complaint that something might be wrong with your child. This begins the discovery process and relentless appointments and decisions about treatment, educational placement and services.

Professionals recognize that best practices involve family-centered services, but this philosophy is not always translated into practices that include parents as active members of the team, nor do they bolster the parents' confidence and ability to cope.



Judy Grossman, DrPH, OTR

When the focus remains narrowly child-centered, parents may feel anxious, unprepared and unsupported as they attempt to make meaning of the diagnosis, manage the tension between reality and hope, and develop effective parenting strategies.

Below are some thoughts to help professionals, families and the general public appreciate that we cannot afford to be exclusively child-centered, the entire fam-

ily is affected when there is a child with ASD and all family members need understanding and support.

Family Relationships and Family Life

Parent-Child Relationship - Even before a child is diagnosed with ASD, the parent-child relationship may be affected by the child's developmental and behavioral challenges and the parents' struggle to form a secure attachment and be responsive to their child's needs. When therapy begins, the parent role is often expanded to include *teacher, therapist and advocate*, or restricted because the parent must give up a satisfying job due to 24/7 demands and responsibilities. Other children in the family may react – they may take the role of good child so they do not burden their parent, or the role of bad child to get attention. Comments about unfair treatment are based on the reality that parents often spend more time managing the child with special needs. Parents need to have realistic expectations for the typically developing child and give them age-appropriate information about their sibling's disability. Most importantly, parents must find time to attune and connect emotionally to each child.

Marital or Co-Parenting Relationship - Parents may vary in a number of ways as they raise their child with ASD: different beliefs about etiology and effective treatment, as well as different parenting prac-

tics and coping strategies. Self-blame and blaming the other may affect the marital relationship when fear, anger, anxiety and sadness are not acknowledged or expressed. It is helpful for parents to clearly define their roles and tasks so they function cooperatively, supporting one another as they deal with constant reminders that their child is different from the one they imagined at birth. A working partnership includes time to nurture the marital relationship and form a strong alliance which promotes the parents' physical and mental health.

Other Relationships - One of the unique features of ASD is that the child may look typical so that other family members or friends expect age-appropriate behavior and judge the parents when the child demonstrates unusual or defiant behavior. They do not understand the parents' struggles to get through the day. These individuals need to be informed to help them understand the child's disability and provide the support and affirmation that parents need to function optimally.

Family Routines and Rituals - Family life is composed of daily routines and rituals that celebrate family traditions and special occasions. Children with sensory issues may become overwhelmed at birthday parties, holiday celebrations or during morning and bedtime routines. The more

see *Resilience* on page 24

Everyone Can Play - Using Theatre to Promote Developmental Gains

By Jenna Gabriel, BFA
Executive Director
Daytime Moon Creations

When curtain call begins for my students, the look of pride on their faces is magical. The beaming faces of their parents, though, tell a fuller story. I teach theatre to children and young adults on the autism spectrum, and many times the concept of a full theatrical production seems like an unattainable goal to families. Although they see potential and excitement in their children, often they voice concerns about children who are rigid thinkers, who have limited verbal ability, or who have trouble playing with others.

Yet with every program, my students teach me about the joys and challenges of theatre, but most importantly its vital role in helping individuals on the autism spectrum feel comfortable engaging with others. In each program I teach, my staff and I work with the children to develop a play entirely of their own making, including characters they love, stories they respond to, and music they want to sing. There are times when it's lyrical chaos, but the finished product is, without fail, always a testament to the unbelievable creativity and potential of our students.

As therapies have grown and developed with our increased understanding of the autism spectrum, we've seen a move-



Jenna with a Daytime Moon student working on lighting for their play

ment toward the incorporation of play. DIR/Floortime, Social Skills groups, and play-based ABA all target the social deficits and communication challenges unique to individuals on the spectrum.

Research literature, too, reflects this shift. In a 2003 literature review in the UK, 40% of the studies analyzed cited the relationship of play to developmental skills like theory of mind, language and joint attention (Williams, 2003). Specifically, they suggest correlations between

play (defined in different studies individually as exploratory behaviors, turn-taking games, back-and-forth games and joint object engagement) and development of problem-solving abilities, early communication skills, comprehension, and understanding of social rules, including relating to others and regulation of affect. Further, in a 1995 study, McCune found that the start of symbolic (pretend) play directly preceded language development in a specific way, with singular play instances

preceding single word utterances, sequenced play instances preceding word combinations, and planned play preceding short sentences and phrases.

The beauty of *pure play* is that it comes without expectations. In theatre, there is no right answer. So, by inviting young people struggling with the benchmark-oriented nature of structured interventions into a place where there is no measure of "success," we invite them into a place where "failure" becomes an impossibility. Thus we are creating a safe space to explore the often scary terrain of play.

Many of the challenges that come to individuals on the autism spectrum (e.g. a rigid adherence to routines, perseverating on one particular interest, and a misunderstanding of social cues and how one's behaviors and communications can affect relationships) are addressed by play. Further, beyond the gains that play encourages when left to its own devices, we can *harness* play and effectively use it to target these areas of deficit in an engaging, enjoyable, and lasting way.

Think about your child's routine. It can be an overwhelming and anxiety-inducing task to alter it; the ability to "roll with the punches" isn't something that can be taught overnight. In theatre, we counter this with the principle of "Yes, and." In a scene, when your partner makes a statement or presents an idea, your only rule is

see *Theatre on page 30*

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known as the "Quasi-Experimental Designs." The Quasi-Experimental Designs are more rigorous than SSDs and involve enough subjects and data to allow statistical analyses. The difference between Quasi-Experimental Designs and Experimental Designs has to do with how subjects are assigned to the treatment groups. In a true experimental design subjects are assigned to the treatment or control groups randomly or by chance (e.g. via a toss of a coin). Control or comparison groups do not receive the treatment or intervention that is being tested. In a quasi-experimental design subjects are not assigned to a treatment group and a comparison group by chance. There is a reason why people are assigned to the various groups which can lead to bias. This bias may obscure whether or not an intervention is effective. The gold standard for quantitative research studies is the "double blind research study." Both the subjects and the researchers are "blind" as to whether the individual is assigned to the intervention/treatment group or the control group. This type of design is thought to be the best at reducing bias in the results.

Being conscious of the fact that some research studies are more rigorous and better designed than others can help parents of children with autism decide whether they should attempt an intervention with a problematic behavior. The larger the number of subjects in the study, the more rigorous the design, and the more times other studies have found similar results regarding the effectiveness of an intervention technique, the more comfortable a parent or treatment provider can feel about trying a new intervention. Once you do find a study that appears to be conducted in a rigorously scientific manner, also search for discussion or critiques of that article that may have been published in the same journal in subsequent issues. Beware of the publication that touts a cure based on case studies or small sample sizes. Be skeptical of the article that cites a great deal of theory, but does not provide sufficient data to demonstrate the effectiveness of a technique. Likewise, be wary of the article that offers testimonials. Individuals offering testimonials may be invested (sometimes quite literally) in insuring that the intervention technique is effective or may be emotionally invested in seeing their loved one improve.

Another category of research studies that a scrupulous consumer of research findings will come across are qualitative research studies. Generally these research designs are not used to test whether an intervention technique is effective. Qualitative techniques are used to gain a deeper understanding of a phenomenon. These techniques use small sample sizes and attempt to provide richer understandings of complex social phenomenon (e.g. How parents cope with raising a child on the autism spectrum). They are not used to generalize findings to large groups of people. Parents should not use qualitative research study findings to determine effectiveness of an intervention technique.

A final source of information regarding the effectiveness of intervention techniques for individuals on the autism spectrum is the National Autism Center's 2009 National Standards Report. This report divides interventions into three broad categories: Established; Emerging; and Unestablished Treatments. Of the eleven established treatments, the overwhelming majority are behaviorally-based (i.e. based upon Applied Behavior Analysis). Another 22

interventions show some promise of effectiveness. However, there were a number of more recent interventions (e.g. dietary changes) that were deemed as Unestablished. Parents and treatment providers need to be critical consumers of research findings before embarking upon an intervention targeting a problem behavior involving an individual on the autism spectrum.

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ROBIN'S VOICE ~ A Resilient Mom's Commentary on Autism

By Robin H. Morris, Freelance Writer

Getting the Word Out

It is no surprise that vital services and supports in the community are part and parcel to Advancing Services for Adults with Autism. There is no argument here. It is easy to be magnanimous on paper. The general population does not necessarily reflect on how they can make this happen. Perhaps it is the hustle bustle of life. Perhaps, in fairness, people become so involved with their own daily pressures that there is hardly room to think "out of the box."

However it is imperative to get the message out. My mother used to remind me that sometimes, "You have to spoon feed people." Not a bad idea to propose. Choose your vehicle. We walk with Autism Speaks; our letter to friends and family speaks volumes. What better way to feed the message, without forcing a response. Contributions come in all sizes, shapes and colors. Yes, financial donations are essential, yet not a singular cause. When the word "autism" becomes a household word, it perpetuates the no-



Robin's son Paul (right) as featured in a recent donation campaign for Autism Speaks

tion that paying it forward will change the world. Today's children are tomorrow's employers, real estate developers and educators that will make a difference.

This year, we encouraged our son Paul, who has autism, to give his ideas for our walk letter. It simply says it all:

Dear Friends and Family,

It's me. Paul. There I am, on the right.

I'm pretty handsome, don't you think?
I look a little like my Dad and I have his

sense of humor.

I worry a lot, just like my Mom.

I worry about my autism.

I worry about my life.

I used to be little, just like the other kids in this picture. Autism grows right along with us.

We get bigger and taller and maybe even smarter, but autism just hangs on

us, like a chain.

I want to break this chain. I want a cure. But until then, what about now?

We are here now.

We need tolerance.

We need community.

We need jobs.

We need housing.

We need understanding.

We need patience.

We need awareness.

We need you.

My team is called "Paulie's Promise," because ten years ago Mom and Dad made a promise to make a difference for me and all of us living with autism.

Love, Paul

Robin Hausman Morris is a freelance writer and can be reached at RobinHausmanMorris@gmail.com. Robin is a parent examiner for Examiner.com - www.examiner.com/autism-and-parenting-in-national/robin-hausman-morris.

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socio-economic backgrounds. Although the majority of attendees tend to be mothers, there are several fathers who attend regularly. The common denominator of autism brings everyone together and creates a space for people to support one another regardless of background.

New York is a melting pot of different cultures and languages. Groups should be available in English, Spanish, Chinese dialects and other languages whenever possible. It is so valuable for families to get information and support in their own language to increase their knowledge and create peer networks.

Maintaining a Supportive Environment

Family members who have "been there" and who share similar experiences can

provide support and critical information about how and where to obtain services and, in some cases, can come together to advocate for needed resources and services (Mandell, and Salzer, 2007). Family members with more experience navigating the system benefit from sharing their experiences with parents who are new to the autism diagnosis. Parents still adjusting to the diagnosis are relieved to know that they are not alone.

Each support group is facilitated by two social workers or mental health clinicians. Their roles are multi faceted. They make families feel welcome, comfortable and supported. They keep the speaker on track and answer any questions about resources available in the community. The facilitators ensure that each parent who wants to speak gets a chance to be heard. Support groups are a safe place for parents and caregivers to discuss challenging issues, feelings or emotions related to

caring for a child or adult with autism.

It is imperative to keep the support groups closed to outside professionals and strictly open to parents and caregivers. Parents need a place to express their fears and feelings in a safe, supportive environment with their peers. The dynamics change when professionals are in the room.

Feedback Critical to Group's Future

Feedback from attendees is crucial to evolving the program and ensuring that it is meeting everyone's needs. Feedback is best when it is timely, so collecting it at the end of each session is ideal. Assessment of the group should be an ongoing process. Feedback often conveys what topics parents want to hear, what changes should be implemented and what the challenges might be for some attendees. Evaluation data can also be used to access funding sources for your group.

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parents understand the unique needs of their child, the more they can provide the appropriate environmental and parenting supports to keep their child regulated. This may result in parental decisions to forgo, adapt or create new and meaningful routines and rituals that create family identity.

Despite the increasing prevalence of children with ASD, there remains a scarcity of high quality family-centered treatment. Families can benefit from a range of vital services depending on need: couples and family therapy, multiple family discussion groups, fam-

ily education and support programs, consultation and coaching services. In addition, special education, medical and related service personnel need training opportunities to address the full range of family needs and promote child and family resilience.

At the Ackerman Institute for the Family, an experienced team of family therapists are working together to develop best practices in family-centered treatment for children with ASD and other developmental disabilities. Families have complex needs and therapists need to augment their systemic and relational treatment approaches with current knowledge regarding brain research, special education policies

and practices, and evidence-based treatment. In addition to individual referrals to the Ackerman Treatment Center, the team will be facilitating multiple family discussion groups in the fall. Because of our clinical work, we are able to share training tapes and anecdotal stories that highlight the families' voice in our professional workshops which are offered each year.

There is much we can learn from parents, the experts on their child's struggles and strategies to help him or her succeed. They need more than our support; they need knowledgeable, competent and responsive professionals who use family-centered, strengths-based practices. High

quality family services are vital to promote good outcomes for children with ASD.

Judy Grossman, DrPH, OTR is the Associate Director of the Center for the Developing Child and Family at the Ackerman Institute for the Child, Director of their Special Needs Project, and adjunct faculty at New York University. Prior experience includes Associate Research Scientist at Yale School of Medicine and policy research for the New York State Department of Education. She lectures widely on family resilience, early intervention, mental health consultation and program development and evaluation.

Motivational Interviewing

A Useful Approach for Families and Counselors Planning for Post Secondary Transition

By Christine Alter, LCSW
Social Counselor/Instructor
New York Institute of Technology
Vocational Independence Program

Motivational interviewing is a counseling approach which was originally developed to work with substance abusers to assess and facilitate readiness for treatment. Its principles and techniques have been proven effective when dealing with people who are ambivalent about change. Motivational interviewing engages an individual in discussion about the process of change and the resolution of ambivalence. Individuals with autism spectrum disorder are well documented to prefer the routine, and experience increased anxiety regarding change. Students with Autism Spectrum Disorders, like substance abusers need to develop intrinsic motivation to overcome anxiety and take the risks associated with post-secondary programs. Significant resources and efforts are required to successfully complete post-secondary programs. Consequently, it behooves individuals with high functioning autism, their families and their counselors alike to assess readiness to commit to such programs prior to entering them. The principals of motivational interviewing might prove helpful in assessing readiness and developing a plan for individuals with high functioning autism who are



Christine Alter, LCSW

transitioning from adolescence to adulthood.

Researchers have identified change as a fluid process which moves between several phases. The motivational interviewing approach respects and supports this concept of change. Prochaska, Norcross, and DiClemente have identified five key phases of change: pre-contemplation, contemplation, preparation, action and maintenance

(Changing for Good, 1994). The first stage of change, pre-contemplation, occurs when an individual is either unaware or minimally aware of a problem. During the second stage of change, contemplation, an individual begins to develop some awareness of issues but have little or no interest in change. These first two phases are easy to overlook but crucial to begin the process of change.

Families of children with an autism spectrum disorder tend to be solution focused and may not consider the preliminary stages of change important. Such parents are often less likely to explore issues around transition and more likely to move right along to the planning stages. Unfortunately, this well intentioned focus can be in direct conflict with their child's possible lack of awareness or readiness to confront problems. The principles of motivational interviewing address the first two phases of change by emphasizing listening skills and the expression of empathy.

The general strategies of motivational interviewing include: reflective listening, asking open ended questions, using statements of affirmation, summarizing how an individual feels and eliciting self-motivational statements. Those who utilize the general principles of motivational interviewing build a positive relationship with the individual and use that relationship as a springboard to promote change.

Reflective listening is a central component of the motivational interviewing approach. Miller and Rollnick, pioneers in the development of motivational interviewing techniques believed listening was the answer whenever you were in doubt about what to do. Reflective listening can be as simple as repeating back to someone what you heard, or paraphrasing what was said and offering some feedback. The tricky part of listening reflectively is avoiding warning, judging or directing someone. If you are too pushy you can put the individual on the defensive and cause a breakdown in communication.

The use of open-ended questions is a great tool to discover an individual's motivation for change. Open ended questions are an essential tool of motivational interviewing. Questions such as, "Would you tell me about...", "How would you like things to be different...", "How can I help you...", "What do you want to do next...", or "What have you tried before..." sends the message that you value someone's opinion while also helping you to understand the individual's perspective and interpretation of a situation.

Another important communication tool used in motivational interviewing is summarizing. By summarizing what you have learned you can highlight "change talk" by reviewing and clarifying potential ideas

see *Interviewing on page 32*

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brain development, and the genetic bases of autism spectrum disorders.

Following the basic science discussion, a Clinical Panel focused on topics such as parent-mediated interventions for children with ASDs, teaching children with autism to imitate peers, refining the ASD diagnostic criteria, and meeting the needs of adults with ASDs. Clinical panelists included Dr. Michael Siller and Dr. John Brown, co-directors at the Hunter College Autism Center; Dr. Linda Meyer, Executive Director of the advocacy organization Autism New Jersey; Dr. Catherine Lord, world-renowned autism expert

and director of the Center for Autism and the Developing Brain; and Dr. Martha Herbert, Professor of Neurology at Harvard Medical School. At the end of each panel, speakers fielded questions from the audience in an interactive round-table discussion.

Attendees continued networking throughout the afternoon, as local advocacy groups offered information on their support services during a lunchtime tabling session, and service providers generated discussions during three age-specific breakout group presentations. The event concluded with an evening reception that brought together attendees and the day's presenters to exchange in-

formation and answer any last minute questions.

The Autism Symposium was the second of its kind but the first hosted at Weill Cornell Medical College, with the previous symposium held at Hunter College in collaboration with the Hunter College Autism Play Lab. The symposiums are a supplement to the Weill Cornell Autism Research Program, a multi-disciplinary research study that combines clinical assessments of individuals on the spectrum with focused genetic studies in both affected individuals and their families. The program seeks to link the DNA and protein studies to the behavioral assessments of ASD participants, as a basis for under-

standing symptomology and improving therapies. As the Weill Cornell Autism Research Program works toward an improved understanding of ASDs through basic science and clinical research projects, investigators will continue to share research findings and unite families and professionals through annual symposiums.

Visit the CTSC and WCARP Facebook pages to view videos from the event: www.facebook.com/WeillCornellCTSC and www.facebook.com/weillcornellautismresearch. For additional information about the Weill Cornell Autism Research Program, please visit <http://nyp.org/komansky/wcarp>.

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watched as you started to disappear down a deep, dark hole, and we were powerless to lift you up and out. For two months you never laughed.

Little by little, we found solutions to release anxiety's hold over your mind and spirit, and slowly you returned to your sunny self. I will never take your smile for granted again.

I realized something special this morning as I was writing this letter: for the first time in eight years, I am not panicking on your birthday. I don't have a small pit in my stomach and a tiny voice in my head saying, "He's not where he should be, he'll never catch up." At your first birthday I worried you might never speak. When you blew out three candles I was preoccupied with your tantrums, and by the time you

turned six I longed for a crystal ball to predict your future.

But today? Today, I'm thrilled to celebrate you, and I think I finally understand that you will always be in exactly the right place, no matter where you are.

This year, Jack, I want to share you with the world. I want people to understand the extraordinary gifts you offer as a result of your autism, and the colorful

way in which you see life. You have a lot to teach us all.

Love,
Mom

Carrie Cariello lives in New Hampshire with her husband and five children. You can read her weekly blog and learn more about her online at www.WhatColorIsMonday.com

DIR/Floortime from page 17

who were interested in receiving a DIR-based intervention. It is not articulated whether parents who were eligible but did not have a specific interest in DIR therapy were not included in this sample.

Numerous exclusionary criteria were applied that are not atypical for these types of comparison studies (Dawson, et al., 2009). Twenty-five participants were assigned to a target group that received 2 hours of DIR®-based therapy and parent coaching at the Milton & Ethel Harris Research Initiative (MEHRIT). Twenty-six participants were assigned to a community group that received an average of 3.9 hours/week of a variety of different services ranging from an unspecified combination of speech therapy, applied behavior analysis (ABA), occupational therapy, social skills, day care, and/or other alternative treatments including diets and hyperbaric oxygen therapy.

Although the community group represents a diverse spectrum of treatments that a typical individual with autism might receive, neither treatment groups received intervention at the suggested intensity documented through experimental literature to show progress in a number of developmental domains. Additionally, the intervention received by the community group was well below the hourly level of researched low-intensity interventions (Eldevik, Eikeseth, Jahr & Smith, 2006), despite numerous past research studies indicating that intensive behavioral intervention is more effective than eclectic therapy (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005). Lastly, the authors did not indicate whether the community group participants received this eclectic combination of services from the same providers or if there were any standard methods documenting whether staff had the proper training necessary to administer the therapy used in the community group. For example, for an individual receiving ABA, training and supervision should assure competencies in a number of areas including having experience designing and implementing comprehensive ABA programming for individuals with autism, which should involve areas ranging from "learning to learn" (e.g. listening, imitating, following directions), social interaction, self-care, school-readiness, communication, to play and leisure (Celiberti, Buchanan, Bleecker, Kreiss & Rosenfeld, 2004). If these and other competency-based measures are not met, it is expected that an individual with autism receiving this type of service at any intensity or duration will likely make minimal (or at least less than optimal) progress. Thus, concerns can be raised regarding the control group chosen in this trial.

Treatment implementation for the target group occurred by licensed speech-language pathologists or occupational therapists. These staff members were trained for 3 weeks on a number of DIR® techniques. The authors do not address a basic question regarding external validity: Is the training received by these staff members aligned with the training level of typically trained DIR/Floortime therapists? The authors mention that there is a certification offered through Serena Weider, but many DIR/Floortime therapists provide therapy without this certification. Even with a certification, there lacks a manual or guide used to standardize the intervention techniques. There is no meas-

ure of whether the providers implemented the intervention as intended by the developers of the intervention. Thus, it is difficult to say what occurred in the intervention session or how it could be replicated. As such, results of the study may not reflect those that would be observed if an individual with autism received this treatment in a natural setting.

Results and Data Analysis

Results indicated that there were no significant differences observed on all scales prior to treatment. Ratings were coded by trained staff blind to the treatment condition. After treatment, the researchers examined the relationship between participant group placement and 5 scale items (attention to activity, involvement, compliance, initiation of joint attention and enjoyment in interaction). Improvement was significantly greater on these items than those made by the community group, except in the domain of compliance. In all measures, the community treatment group did worse at the end of 12 months except in the category of independent thinking.

Speech-language pathologist staff, blind to the participant condition, conducted pre- and post-assessments and found no significant difference on two standardized language scales (PLS-4, Zimmerman et al., 2006; CASL, Carrow-Woolfolk, 1999). A modified standardized measure had predictors of language change (mCBRS, Kim & Mahoney, 2004), but the authors noted that it was difficult to ensure validity since this scale had been modified following scale standardization. Caregiver behavior was also investigated and statistical differences showed that the MEHRIT group showed improvement on all items except a Sensory-Motor Support item. No significant associations for compliance were indicated in this scale either.

Though these results indicate some improvement based on the intervention, statistical significance only indicates that the differences between groups (however small) are not likely due to chance factors, but does not indicate that these differences are meaningful. It is also unclear how the group averages apply to individual children within the groups (for example, how many children within each group made significant gains or to what extent outcomes varied from child to child). In addition, because the intervention contained multiple components, it is uncertain how each component influenced the behavior of the parent and child.

Discussion

By standards of experimental autism literature, this experiment has notable strengths. Casenhiser enrolled a relatively large sample size. The randomized control trial used a randomized design consisting of two groups – a treatment ("target") group and a control group. Participants were randomly assigned to either group. Participants were paired based on age and baseline language level. This sampling procedure ensured that both treatment groups were similar before intervention. Well-established outcome measures were used to identify participant progress, and included an assessment of whether parents acquired new skills. The experiment also monitored the treatments obtained outside of the study.

Aside from these strengths, this study leaves considerable question regarding the

validity of the treatment group improvement when compared with a poorly conceptualized control condition. This control condition was not a "no-treatment" control group, but instead was an undefined blend of procedures with no evidence of procedural integrity, at a level considered less than adequate in the research literature. A better comparison might have contrasted the MEHRIT treatment group with a no-treatment group; an eclectic group at the correct duration or dosage; or a group receiving a behavior-based treatment with high procedural integrity. In addition, results were significant on a modified scale, potentially lacking validity.

A significant area of treatment administration that did not show significant results was in the domain of compliance. Compliance is an important skill for individuals with autism, and many demonstrate opposition when required to complete basic tasks (Ducharme & Drain, 2004). The necessity of learning-to-learn skills such as compliance, attending, orienting, choice-making and simple imitation must be taught early in the intervention process before more complex skills, such as social communication and play, can be addressed (Luiselli, Russo, Christian, Wilczynski, 2008). It is standard to ensure that a foundation for these skills is present before addressing some of the variables that were explored in this study.

Treating an individual with autism often encompasses biological, developmental and/or behavioral approaches to autism treatment. These approaches all aim to remediate the most pertinent symptoms of an individual with autism. Among behavioral and developmental approaches, there are misconceptions about the difference between these two approaches and the utility of both. Casenhiser (2011) attempts to validate Developmental Social Pragmatic (DSP) Interventions, specifically DIR®/Floortime (Prizant & Wetherby, 1998). Although this study provides an indication of the effectiveness of this approach, it should be independently replicated before it is considered empirically valid. DIR® is an emerging treatment, however families are urged to continue with treatments that are currently empirically supported.

If you would like to sign up for this free newsletter, please visit www.asatonline.org/signup.

This article was originally published in the 2012 Spring Issue of the Newsletter of the Association for Science in Autism Treatment. You can view this issue for free online at www.asatonline.org/pdf/Spring2012.pdf.

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Finding The Right Guardian For When We Are No Longer Here

By Sandy Rochelle Schachter
Parent/Advocate

No matter how well our adult children seem to be doing in their various day programs, a constant ache that keeps parents awake at night is: "When we are gone, who will ever love them the way we do?" and, "Who will do the little things for them that mean so much?" It is a painful truth that *no one will*.

We need to stack the deck in favor of our adult children as much as possible, for as much as they may improve, they remain very much the same. It is this stark reality that keeps me up at night. My son David (now in his 30s) is my last thought at night and my first thought upon waking – and I am sure he will be my last thought as I take my final breath.

In the past (when David was much younger) we had several well-meaning, but young, guardians. As life would have it they eventually moved on with their lives – along with their commitment to David. We investigated various agencies that would provide guardianship, albeit in a very impersonal way. Those families fortunate to have a family member (e.g., a sibling willing to stay the course) are very fortunate. We are unfortunately not in that situation.

When looking for a future guardian, several factors are crucial. The person(s)



Sandy Rochelle Schachter

needs to be a professional committed to the field of autism. They need to be mature enough to "know who they are" and must have a sincere commitment to the person that will be in their care for life; a person who is married to someone who shares their same values and lifestyle; A person that you know intimately and have shared many life experiences with. The future guardian should become familiar with the quality of life that you have established



David Schachter

over the years, one that you wish to continue for your loved one when you are no longer here. Time spent together is a perfect opportunity to introduce a potential guardian to the activities that you have established over the years.

Although we are not fortunate enough to have an extended family, we have been gifted with an exceptional relationship with a reliable and loving young man named Ronnie Caccavale that

we met as a result of our involvement with On Your Mark of Staten Island, New York, the agency that provides our son David's Day Program and Group Home. Ronnie is family. We have traveled together extensively and Ronnie knows and understands David and the activities that bring him pleasure. He is also aware of David's health needs, which is crucial.

On weekends when David is not able to come home he spends time with Ronnie and his family. It is also a tremendous asset that Ronnie's wife Tammi shares his same values and commitment.

We are also extremely fortunate to have met Gene Spatz, Executive Director of On Your Mark and David's standby guardian. Both Ronnie and Gene appeared at court in order to assume the role of legal guardians.

I have accepted the reality that no one will ever love David as I do, nor will anyone do the little things for him that I enjoy doing. However, I have faith in the integrity of his guardians that he will continue to participate in and enjoy the quality of life that we established and that he will be loved, cared for, and respected, and that is the best "sleeping pill" on the market.

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Relationships from page 20

To address these issues, the team of staff that worked with Camille reframed activities to include a splash of magic, such as giving Camille her daily schedule by "fairy mail" or asking her to go on a "fairy hunt" when she clearly needed a break from the current activity. Additionally, they gave her short, pre-arranged times to play with her dolls during the day and provided the opportunity for her to earn more time by meeting behavioral expectations, as long as she included another person in her play.

Once Camille had gained some success with the plan, the staff began to gradually fade out the fairy references and increase the expectations for earning playtime with the dolls. By the end of the session, Camille significantly decreased the amount of time she spent playing alone with her dolls, participated more often in her group's activities, reviewed her schedule without resistance, and made a friend who motivated her to behave more appropriately.

Build a Positive Self-Image. Recognize the unique skills of a child and connect these to tasks. This will allow them to use their strengths and talents to add value to the community. As a result, they're more likely to feel confident and take initiative.

Ramapo's Staff Assistant Experience (SAE), a residential transition-to-independence program for young adults with social, emotional, or learning challenges, including ASD, is designed to take into account the skills and struggles of each individual participant. By blending social, work, and home life with the typically developing peers who serve as room-

mates, mentors, and job coaches, SAE not only enables participants to see positive behaviors in action, but also allows Ramapo staff to get to know the abilities and passions of these young adults and therefore increase opportunities for them to do what they love.

When a young man named Seth came to Ramapo, he had experience working with animals, but working with people proved to be challenging. He had been unable to hold down a steady job because of his difficulty interacting positively with others, and his issues with depression sometimes made it a challenge to go to work at all.

To help him build his interpersonal skills, SAE first placed Seth in Ramapo's on-campus corral, where he began by keeping the horses healthy and then slowly learned to help young campers pet and groom the horses. Because he felt secure in his ability to work with horses, he was more open to receiving the constructive feedback on his social and emotional development that both recognized his strengths and provided steps to improve his weaknesses.

Soon, his mentor saw Seth gain an increased ability to communicate with colleagues and greater confidence in his work with campers. He even took the initiative to enroll in nearby college courses on equine studies, a prospect that previously would have been daunting for the young man. With Seth's new skills in evidence, his mentor was able to find a position for him at a nearby horse farm, where he could utilize his natural affinities while gaining job skills that he could transfer to future work in any environment.

Create an Atmosphere of Belonging.

Develop routines and traditions that acknowledge children and help them feel like an important and unique part of your world. Help children feel that they are in a safe, nonjudgmental space.

Ramapo Retreats welcomes over 8,000 participants every year to share new adventures, discover new strengths, form new bonds, and be inspired to grow as individuals and as a team through short-term stays on campus. When a new group steps off the bus, facilitators make them feel welcome from the start by greeting them and showing enthusiasm for their arrival. During meals in the dining hall, facilitators always announce and recognize every group to make them feel like a part of the community.

For a returning group consisting of children with ASD and their families, however, feeling a sense of belonging is a greater challenge that requires more than just being recognized. These parents are all too familiar with feeling outside their community, used to receiving stares when their children throw tantrums or act out in public. To them, a trip to a new place can be especially intimidating.

To help these families feel like a part of the Ramapo community, facilitators address children's negative behaviors without judgment and with the competence they've gained from experience. They provide a structure for the day so parents and children alike know what to expect, and they include family favorites like call-and-response songs and boating on the lake to help the retreat feel like a tradition. At night, they round out the day with a campfire, where families can share their experiences with each other in a safe space.

Spending a weekend in an environ-

ment that supported and included the whole family was a fun time for the kids and a relief for the parents. Their trip became a respite instead of a strain, and the families returned home more relaxed than when they had left.

Over the past 90 years, Ramapo for Children has developed a unique ability to create environments that help children of all abilities align their behaviors with their aspirations, and in recent years has exported that approach to over 300 schools and youth agencies throughout the New York metropolitan area via training programs. Those experiences on- and off-campus have made evident the fact that relationships are the cornerstone of behavioral change; without that connection, children have no motivation to increase their social and emotional skills. Though building a positive, mutual relationship with a child with ASD may seem daunting, the process consists of a set of skills and activities that can be taught. When the adults in a child's life stop acting as passive or reluctant receptors of autistic behaviors, and instead feel comfortable intervening and shaping interactions, the adult-child bond becomes richer for both parties.

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Social Skills from page 14

home. Later speech services were added. When Sara was 2.3 years old it was recommended that she enroll in the Parent Child Group to help with social skills and play in a group setting. Sarah had not been with other children for a play group because her mother was concerned that she could not tell someone what she wanted, that she did not play much with toys and often grabbed or threw toys. When Sarah first attended the group, her mother was very concerned that she would hurt another child. Sarah had many sensory fears and was not able to touch any mushy, soft materials such as play dough, bath foam or fingerpaints. Food intake also was limited due to similar sensory discomforts with food.

To help the children and parents we use an effective, proven approach developed by Dr. Alan Kazdin from Yale University called Positive Behavior Management (PMT). In order to implement the practice, we determine the best PMT strategy for each child and create an individualized program using the ABC's planning approach: antecedent, what happens before the behavior; behavior and consequence, what happens right after the behavior occurs. All behaviors serve a purpose, whether to self-soothe, avoid, seek attention, etc. Parents and therapists work together to understand the child's behaviors and make an effective plan tailored to each child's skills and needs.

Two of the techniques used in PMT are "positive framing" and "active ignoring." An example of positive framing is stating the desired behavior such as "feet on the floor" instead of yelling "No. Get

down." The child learns what the expected behavior is as the message is clear, and receives support and attention for accomplishing the desired behavior.

When Brandon would climb on a chair he was given the direction "feet on floor" with gentle physical assistance to guide him off the table or chair. After one month in the program, he responded to the verbal prompt without the physical cue to sit on the chair. Within two months, he rarely climbed onto the chair and no longer onto the table.

The technique of "active ignoring" means that although an adult is nearby, always making sure the child is safe, direct attention to the child is withdrawn. So we may sit near the child but we would not look at the child or speak to the child except to state a positive expectation such as, "When you are calm, we can go to the playground."

During our group we set aside time for parents to meet separately with the social worker. At this time the children are in a play group with another professional (special education teacher or speech or occupational therapist) in a connecting room. The doors are often open and the children can "check in" with their moms as needed during the initial adjustment period, usually a few sessions. If the child goes back to the adult area after the child appears comfortable to play and stay in the play area, this behavior may be considered attention seeking rather than the need to check in with the parent. Coaching support for "active ignoring" is provided for the parent to avoid responding to the child through conversation or eye contact. Parents are encouraged to continue with

their conversation among the adults. Within a few minutes we observe the child starts to look around the room for something else to do and then returns to the play area. The frequency of the child's visit to the mom's group decreases over time as there is no attentional reinforcement or reward for this behavior.

When parents tell us that the suggestions are working at home, then we know we have been successful! Brandon's mom told us that at home they provided a substitute toy for Brandon and although he got upset, it did not last long. He now had something else to play with other than the TV remote. Family members stopped yelling "no" so stress was markedly decreased at home!

When we ask parents what they like about the Achieving Milestones Parent Child Groups they say, "Meeting friends for us!" We hear that even after the group has ended parents continue to get together, which is one of the many goals of parent connections!

As for the progress of the children, changes often occur within one to three months. After three months we noticed Brandon sitting through the entire snack time (10 minutes). He would request "more cracker" and he was singing some of the words to the circle time songs. Brandon no longer climbs onto the table or chair. And Sarah has stopped throwing toys and enjoys pretend play with dolls and a stuffed dog! Sarah has made handprints with finger paints and plays with our home-made play-doh! These are positive sensory, play and social experiences!

Note: Names are changed to protect the confidential nature of the program.

For information, please contact Susan Miron, Director by phone at (914) 922-9333, fax at (914) 922-9336, or by email at smiron@wjcs.com.

WJCS is an approved provider of EI Services and is under contract with Westchester County to deliver EIP services which are funded and regulated by the NYS Department of Health and Education and in Westchester by the County Department of Health (DOH). Milestones is a New York state program funded by Westchester County. In order to access the EI Program children must be referred to the Westchester County at 813-5094.

Children's eligibility is established by state-approved agencies that have an active contract with the DOH. Once eligibility is established, the County will arrange for a service provider to deliver approved services. All such services are identified in collaboration with the parent and DOH. Services are provided at no out-of-pocket costs but health insurance will be accessed for reimbursement. If services are delivered in a day care, nursery school or other community setting, the parent is responsible for paying any costs associated with such settings.

Achieving Milestones, a program of WJCS provides therapy services through the contract with the Westchester County Department of Health for children birth to five. For children who do not meet the eligibility criteria or who may be seeking services outside of the WCDOH EI, or School District's Preschool Special Education program, private pay options are available. Social skills groups are located in New Rochelle, Yorktown and Yonkers. Other services are provided at similar locations and within the home and community.

Directives from page 16

Permanently Unconscious - There is no reasonable possibility that the principal will return to cognitive life. This includes, but is not limited to, a persistent vegetative state.

Terminal Condition - The condition is reasonably expected to result in death within 12 months regardless of treatment.

Experimental Treatment - LST is unproven or experimental, is unlikely to prolong life, and would merely prolong the imminent dying process.

LST is defined in each of the above three circumstances as the following:

- Procedure, drugs, surgery, or therapy that uses mechanical or artificial means to sustain, restore, or supplant vital body function
- Cardiac resuscitation, defibrillation, cardioversion
- ACLS drugs, cardi-selective drugs/infusions
- Mechanical respiration, balloon pump (IABP)
- Blood /blood products transfusion
- Surgery or invasive diagnostic tests
- Kidney dialysis

- Antibiotics
- Chemotherapy

Instruction directives usually request that all medical treatment be given to provide comfort and to relieve pain. In this most common directive, the individual requests that artificially-provided fluids and nutrition (feeding tube) shall not be given if LST is withdrawn in the three previously-noted circumstances.

One alternative to this common version is a directive in which the principal requests that if any of those three circumstances occurs, they would be treated aggressively, rather than LST being withheld or withdrawn.

The second alternative is like the most common option described previously, except that the individual requests that artificially provided fluids and nutrition always be given, even if LST has been withdrawn. This choice is reminiscent of the Terri Schiavo case in which Ms. Schiavo was kept alive with a feeding tube despite being classified as being in a persistent vegetative state.

Finally, an advance directive can be used to denote whether individuals wish to donate their organs and whether they wish to donate their bodies to science.

Advance Directives for
Mental Health Care

Some states have statutory provisions for a psychiatric advance directive (PAD). The New Jersey Advance Directives for

Mental Health Care Act became effective in 2006. Like a typical health care advance directive, the mental health care advance directive can include a proxy directive, an instruction directive, or both. The PAD is most suitable for adults who are already diagnosed with mental illness and those who are current or likely consumers of mental health treatment. As with a typical proxy directive, an individual can name a specific mental health care agent to make mental health care decisions in her stead if at least two doctors determine that she is unable to do so. In the instruction directive, an individual can provide his or her general mental health care philosophy and can state preferred treatments and institutions or mental hospitals, preferred medications, preferred means of crisis intervention, specific wishes regarding provision, withholding, or withdrawal of mental health care, and/or consent to admission to a psychiatric facility for a specified number of days.

An advance directive for mental health care is valid for an indefinite period of time if it does not list an expiration date. If the directive expires during a period of incapacity with respect to a particular mental health care decision, it remains in effect until the principal has regained capacity. A principal may modify or revoke a directive, even if the document does not explicitly indicate that he or she may do so. A principal may revoke a directive by oral or written notification to the mental health care representative, a professional, or a reliable witness, or through the execution of a subsequent directive.

A mental health care professional is permitted to depart from the decision of a mental health care representative only if compliance with that decision would:

- Violate the accepted standard of mental health care or treatment under the circumstances of the patient's mental health condition;
- Require the use of a form of care or treatment that is not available to the mental health care professional responsible for the provision of mental health services to the patient;
- Violate a court order or provision of statutory law; or
- Endanger the life or health of the patient or another person.

Supports must be put in place for adults on the autism spectrum. One essential safeguard is an executed health care directive to provide an individual's loved ones with the ability to make health care decisions in the event of incapacity.

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the behavior is most likely to be displayed (Natural Environment Training; Koegel & Frea, 1993), or the seemingly common sense nature of the positive impacts of community immersion, full community integration is not yet a reality for many adolescents and young adults with ASD. This is especially true given that most individuals with ASD have not achieved effective social integration (Howlin, 2000; Orsmond, Krauss, & Seltzer, 2004).

Although attempts are made to develop sustainable and generalizable skills that will be useful for successful community life prior to leaving public school systems, positive outcomes have not been noted. In the fields of education and training, the term “generalization” refers to displaying the knowledge or skill - learned in a teaching or training situation - in contexts where that knowledge or skill was not initially taught (Stokes & Baer, 1977). In other words, generalization occurs when a learned skill “transfers” to novel environments or contexts. Some examples of generalized skills include paying for a meal at a restaurant (after learning money skills in school), dressing to go to work (after learning how to put on and take off clothes at school), and responding to greetings at the mall (after learning to greet and respond to greetings at school). When learned knowledge or skill does not generalize, performance of a previously acquired skill fails in a novel environment. For example, an individual fails to cross a neighborhood street safely after practicing it correctly in school, fails to use a telephone at home when learning to do so at school, and cannot use a credit card in a store after practicing it successfully in a vocational training center.

In education and training, the generalization of behavior is not only important, but is actually the fundamental goal to which all educators strive to achieve with every student (Cooper, Heron, & Heward, 2007). Stokes and Baer (1977) in their seminal paper on this topic, defined “generalization” as: “the occurrence of relevant behavior under different, non-training conditions (i.e., across subjects, settings, people, behaviors, and/or time) without the scheduling of the same events in those conditions. Thus, generalization may be claimed when no extra-training manipulations are needed for extra-training changes; or may be claimed when some extra manipulations are necessary, but their cost is clearly less than that of the direct intervention. Generalization will not be claimed when similar events are necessary for similar effects across conditions” (p. 350).

Generalization can be particularly challenging for individuals with ASD, and, therefore, becomes an important issue. Research shows that persons with developmental disabilities fail to automatically transfer skills learned in training contexts to untrained contexts more so than learners with typical intelligence and no disabilities. And without this generalization, skills learned before entering community environments are not likely to be used in those environments. We need to train community skills in a way that will naturally be used by these individuals.

The most effective supports that can be offered for adolescents and adults with ASD who need to survive in a variety of community settings is to train community skills in a way that will lead to natural and

automatic generalization of these skills. The model explained here describes an efficient facilitation of generalization and focuses on four fundamental points: (1) training is done in the community settings where the individual will be living and working (nuclear environments), (2) the targeting of skills that will be naturally maintained in community contexts (NET), (3) the use of teaching strategies that best “fit” community environments (organizational cultures), and (4) the intervention on behavioral issues while in community activities (establishing priorities).

1) Training is Done in the Community Settings, Not in a Separate School-Like Context

All training is done in the natural environment, where the individuals live, work, and play. The school building can be likened to an airline hub, students and teachers coming in and out as necessary for fluency based instruction or instruction in functional academics, but mainly is used at the beginning and end of the day simply for bus pickup and drop-off, and a place for staff meetings. Otherwise, all substantive training occurs out in the “real world,” at office buildings, hospitals, hotels, fitness centers, grocery stores, movie theaters, and any other community place. Understanding the importance of generalization of skill development, the philosophy of this model is to train where the skill will be used, so that the issue of generalization is less challenging and ultimately moot and irrelevant.

2) Skills Targeted for Training Must Be Naturally Reinforced and Supported By The Environment

The staff, students, and their parents/guardians work together to select meaningful goals and objectives for training. These encompass work, leisure, and community areas. Since all training occurs in the natural environments where the students live, the skills targeted will more likely to be naturally reinforced and maintained. For example, work objectives are selected based upon the importance of those objectives in accomplishing “real world” job requirements. These objectives will be naturally maintained by either reinforcement (for mastering the work objectives) or through correction (by fellow employees or supervisors). Either way, the student’s work performance, once learned through the training protocols, will be maintained due to its relevance to real-world work for that particular work context.

Another example is the acquisition of leisure skills. A favorite activity of society-at-large today is developing healthy lifestyles including physical activities at a local fitness center. Consequently, most students learn workout routines at a local public fitness center. The students target the acquisition of the use of specific workout equipment (e.g., treadmill), smooth transitions among workout activities, and locker room routines. The public who attend the fitness center naturally maintains both sets of skills. Appropriate use of the equipment is reinforced through social acceptance, and inappropriate use is consequted through staff and member critical feedback. Appropriate locker-room routines (e.g., showering, shaving, dressing) are naturally maintained by those

environments through the same mechanisms. Thus, all of the goals and objectives, when taught in the environments in which they will be used, inherently possess this quality of maintenance by the natural community of consequences.

3) The Development of Training Protocols That Are “Environment-Friendly”

The teaching programs used to establish these community skills are fundamentally behavior analytic in nature. We commit to the technology of education and training as derived from the science of applied behavior analysis. Community based training protocols are no different in that respect from other good quality instructional programs. However, the development of the teaching protocols is different in the sense that they must conform to, be sensitive to, and respect the environments in which the training will take place. Training cannot always be done in the same manner as a school environment. For example:

Training Materials: The training materials brought into the community environments are physically smaller. Instead of massive ‘program books,’ crammed with data, we use much smaller materials, and fewer of them. Data books are approximately 5 x 7 inches making them easy to carry and, most importantly, less conspicuous to the public. With increased technological capabilities, training programs and data collection can all take place on a mobile device, such as a tablet computer.

Reinforcement: The use of naturally occurring reinforcing consequences is used more than in a non-trained environment such as a school. For example, when completing a work routine of preparing food in a kitchen, the naturally occurring result could be the consumption of soda or small food item, which naturally follows many of the work routines in a kitchen.

Prompting Hierarchies: Verbal prompts are generally discouraged unless the action verbally prompted is a verbal response, however, in community based instruction it is noted that society-at-large operates on verbal prompts. Physical prompting, recognized as easier to fade than verbal prompts, is not socially accepted. For skill acquisition programs (e.g., job tasks, shopping, etc.), nonverbal prompts, such as gestures, models, and physical guidance, are used only

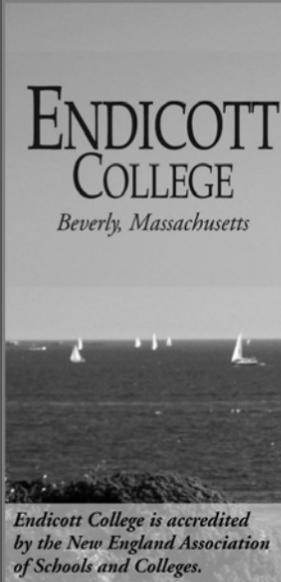
where not stigmatizing. In the community, the use of physical prompts may create more of a negative stigma than verbal support. Here, the use of technology can assist in prompt and prompt fading through the use of Bluetooth (to deliver and fade verbal prompting) and iPads and iPods (e.g., video modeling for physical demonstrations).

4) The Intervention on Behavior Problems In Community Settings

Students begin going into the community immediately upon entering the program. There are no criteria for an absence of maladaptive behaviors before entering job and other community sites. The philosophy that influences our program remains consistent – the best places to learn are in the natural communities where the behaviors will be expected to occur once acquired. In the traditional training environment, behaviors are targeted for improvement in the school or center context, and once improved, the individual then enters community locations, with the hope that the improved behavior generalizes. However, as noted earlier, generalization is not likely to happen. So, students who engage in various problem behaviors – such as stereotypy, obsessive-compulsive behaviors, shouting, and others – continue to do their training programs and go where they are scheduled to go. By the time of the age of adolescents or adulthood, behavior patterns are entrenched with long histories. Therefore, behavior reduction programs should be prioritized and implemented only where behavior impedes skill acquisition, job performance (fluency) or results in ostracizing stigma.

Machalick, O’Reilly, Beretvas, Sigafoos, & Lancioni (2007) reviewed interventions for use in reducing challenging behaviors and found that most treatments involve the imposition of strategies external to the curriculum or activities in which the individual is engaged. Examples of such strategies include social stories, video modeling, and token reinforcement. When working in community settings, overreliance on these types of interventions are cumbersome to implement and could likely increase stigma towards the individual with ASD. In contrast, our approach to behavior management primarily emphasizes overall motivational variables inherent in the individuals’ daily activities. One general strategy is to match, as

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much as possible, student interests with student activities. Incorporating student interest into the activities has been shown to reduce behavior problems and increase participation and compliance (e.g., Hinton & Kern, 1999; Koegel, Singh, & Koegel, 2010). Consider exercising at a workout facility as an example. First, preferences from the student are solicited regarding the type of exercise equipment and routines in which to engage. Using an exercise machine that the student has chosen increases the student's control over his own environment and a sense of confidence, thereby increasing a positive experience and decreasing likelihood of problematic behavior. Another strategy is to ensure that the activities result in naturally occurring reinforcement. Research has indicated that activities that result in reinforcement that naturally occur for that activity can result in decreased behavior problems and improved performance (e.g., Kern, Childs, Dunlap, Clarke, & Falk, 1994). An example of how this is implemented in our program relates to a community job at a country club, at which the student works in the dining room. His job routine consists of filling drink stations with crushed ice. After the entire task is completed, the student has the opportunity to get a drink of soda, a natural consequence for this particular activity.

Differential Reinforcement of Other Behaviors (DRO) reinforcement programs that are external to curriculum and student activities are also implemented, however, the schedule of reinforcement is thinned rapidly so that most students are scheduled to receive reinforcement once every hour or longer. This thin schedule reduces the necessity of frequent implementation of potentially stigmatizing external reinforcement procedures, and overreliance on artificial plans. As with any good behavior analytic program, data are taken daily on occurrences of targeted behaviors.

For those students who engage in behaviors that could be physically dangerous to themselves or others, access to community environments takes a slower and more gradual schedule and is shaped to increasingly longer periods of exposure. Frequency

and duration data drives rates of increased immersion into community settings. Working on behavior issues in the community is beneficial in at least two ways. First, these students are integrated into their communities faster than in traditional educational settings in which there may be a criterion (for sustained days of appropriate behavior) before returning to the natural community. Second, natural consequences for engaging in inappropriate behavior often occur, helping to reduce or eliminate the behavior. For example, one student with a very strong interest in women's shoes often talked about them to female staff in the office building where he worked. These female workers quickly learned to reprimand him for such questions and comments, and the student engaged less often in that behavioral pattern around those women.

Conclusion

An entire generation of our nation's most vulnerable citizens is about to leave the entitlement-based world of special education and enter the already overwhelmed and under-funded world of non-entitlement adult services. While exceptional adult programs and services exist in every state, they tend to be more the exception than the rule, leaving many individuals and their families to fend for themselves. This is completely unacceptable (Gerhardt, 2009).

Adults with ASD deserve the same opportunities and options that those of us not on the spectrum, more often than not, take for granted. This would include the opportunity for a real job, a home in the community, people in their life for whom they care and who, in turn, care for them, to be free from abuse and neglect, to have access to healthcare, leisure and, if desired, a community of faith, and to be treated with dignity and respect. Our greatest possibility of achieving these goals is to encourage a shift in the current traditional educational paradigm away from the four corners of the classroom and protections of school buildings and toward total immediate and intensive immersion into nuclear real world environments. Properly cultivated, community members become invested partners in the educational process and develop into

natural supports, replacing 1:1 assistance of paraprofessionals. Reinforcement becomes intrinsic and tied to naturally occurring consequences. Direct training of vocational tasks, leisure activities, and life skills in the contexts where those skills will be used will obviate the concern for generalization of skills from training to non-training environments, which the training literature has regularly shown to be of a concern. The learning of new skills will take place more quickly when the training is done in the natural settings, leading to naturally occurring reinforcers. Maladaptive behaviors are likely to be reduced more quickly when intervention takes place in the community environments where the behavior is likely to be displayed.

The community is the future to a quality of life for individuals with autism and an untapped educational resource for maximizing access to personal reinforcement and satisfaction, enhancing the quality of life and personal well-being. We would be wise to take advantage of these vast resources just outside of our schools' doors.

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Theatre from page 23

that you say, "Yes, and." You accept their idea as good and true, and you add your own idea to it. During a recent character exercise, Steven chose to be a stubborn werewolf king looking for a treasure on his own and was intent on sending whoever wouldn't cooperate to the dungeon. On the other side of the room, Michael had chosen to be a leprechaun. I approached Steven and asked if he thought there was anyone in the room who might be able to work with him to find the treasure. With gentle guiding and working within the principles of "yes, and," Steven was able to see that a leprechaun could be a great ally in a search for gold. He began accepting that his ideas can adapt with the input of the people around him; the improvised scenes between Steven and Michael became a part of the final script. A werewolf's search for treasure isn't your child's bedtime routine, but by stretching the muscles of pretend during play, we create a ripple effect that generalizes into daily life.

When I first met Alex a few years ago, it was difficult to have a conversation

with him about anything not related to his great passion: music. Alex knows every single word to every single Johnny Cash song that has ever been written. A rehearsal hall is a collaborative environment, though, so our goal was to build on his love for Johnny Cash while accounting for the many different views in our group. By gradually targeting small changes, we were able to make significant adjustments. In our first play together, Alex portrayed a superhero whose power was his ability to play the mandolin. He sang a song to the tune of a Johnny Cash song but with different words. This is ENORMOUS growth for a kid who views those lyrics as sacrosanct. In our second play, he played an old country singer who sang an original song. And in our current play, Alex picked a magnifying glass from our costume chest and cast himself as a detective named Jackie Chan who is helping a king search for his lost treasure.

A year and a half ago, Alex was a child whose intense focus on one specific man and his music made it very difficult for him to find any sort of conversational common ground with our other participants.

Through small, playful, and enjoyable steps, we have been able to break enough of that focus to help him find other things that give him the same sense of pleasure and allow him to interact with others.

Perhaps the most important effect of participation in theatre, though, is in the realm of communication. Theatre is a universal form of expression and there is something here for everyone, regardless of comfort with verbal language. First, theatre plays with emotion. By examining a scene, actors are able to understand the feelings and behaviors of their characters without the immediate stress of being directly involved with the situation (much like using a Social Story at school or home). Then, actors begin to embody those feelings: What does it look like when you're sad? When you're happy? When you're angry? When you're scared? Kids learn to identify those emotions in themselves and in others while protected by the fact that it's all pretend. And together the ensemble deals with those imagined feelings while scripting the scene - What can we say to a character who's feeling anxious? What kinds of

things help you when you feel that way? - so that kids can better handle those moments when they're happening for real.

In plays, like any story, events happen because of the behaviors of the characters. So in the development of a play, participants learn that behaviors have consequences and that an adjustment in behavior can often change what happens next. When interacting this way, words often cease to matter. Emotion is conveyed through facial expression, gestures can help communicate relationships, and a movement towards or away from another character can speak volumes about feeling. In many of our programs, I see participants grow in their language skills and, equally important, I see students who struggled with nonverbal communication grow in their ability to alter their vocal and facial expression to convey their character's journey.

Take Justin and Kevin: Though in our program last year, Justin's verbal skills were limited to repeating phrases and answering short questions, through physical

see Theatre on page 33

Crisis from page 6

technical assistance, soliciting proposals from potential providers, removing obstacles, encouraging development and creating incentives for innovative service arrangements funded by public and private sources, as well as providing grants and other aid to foster additional innovative service arrangements. The Act specifically allows for the facilitation of donations from the person with a developmental disability or this person's family, friends or guardian. Further, the Act explains that innovative service arrangements include residential or day services funded in whole or in part by private or governmental sources and includes a provision for DHS to undertake funding once state funding is available or when a reasonable amount of private funds are legitimately exhausted.

The Act includes preferred characteristics for innovative service arrangements, which include encouraging persons with developmental disabilities to engage in social interactions with persons of their own choosing, including non-disabled peers and allow persons with developmental disabilities to be active and integrated members of the community. Further, inno-

vative service arrangements must be designed in a manner consistent with federal and State law so that persons with developmental disabilities and their families participate in the design of and have access to community services, individual supports, and transportation. The goal is that innovative service arrangements will promote self-determination, independence, productivity, and integration and inclusion in all facets of community life; thereby allowing persons with developmental disabilities to successfully move from developmental centers or the home of a parent to an independent community setting.

The Act mandates oversight procedures, including requiring the Commissioner of DHS to report to the Governor and the Legislature. Additionally, the Legislature must establish a mechanism to learn about the development and implementation of efforts as well as obstacles which may arise in the development and implementation of innovative services, particularly if the Legislature may be able to eliminate these obstacles. The Act also allows for an expeditious resolution of any dispute, which may arise between a person proposing to establish an innovation service arrangement or a person seek-

ing to use such an arrangement and DHS.

It is interesting to note that other states have already begun to implement innovative housing solutions and their results have been overwhelmingly positive. The Arizona-based Plaza Companies have worked in conjunction with Hyatt to develop a Continuum of Care Retirement Community that caters to persons with developmental disabilities. In California, Hallmark Community Solutions was able to get the state-funded mortgages for its Bay Area Housing project classified as service dollars, making the mortgage payments eligible for a 50 percent match with federal funds. This model was so cost effective that the developer was able to secure all the financing needed for acquisition and construction of the property from Bank of America, a traditionally private lender. These are just two of the many innovations sweeping America. These types of innovations will revolutionize the way we approach housing for the developmentally disabled and afford a higher quality of life for persons with developmental disabilities.

Support for the Innovative Services for Persons with Developmental Disabilities Act from within the developmentally disabled community has been tremendous.

Organizations that have voiced their support include The Healthcare Association of New Jersey, the ARC, Autism Speaks and Autism New Jersey. In the State Legislature, Senator Robert Gordon, Assemblyman Angel Fuentes, and Chair of the Assembly's Human Services Committee Valeria Huttle are sponsoring the bill.

Adam Straus-Goldfarb is a high school student at the Princeton Day School who interned with Hinkle, Fingles and Prior, P.C. He is the brother of a person with Autism. As a result, Straus-Goldfarb is active with the Special Olympics, Princeton Special Sports and is committed to advocating for people with developmental disabilities.

Herbert D. Hinkle is the founding partner of Hinkle, Fingles & Prior, P.C. with offices throughout New Jersey and Eastern Pennsylvania. He has practiced disability law since 1974 and teaches Trusts & Estates at Rutgers School of Law Camden.

Maria E. Fischer is an associate with Hinkle, Fingles & Prior, P.C., a multi-state firm representing individuals with disabilities and their families. The mother of a daughter with multiple disabilities, Fischer is personally committed to her work in the area for disability law.

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Vocational from page 10

VR based on problems caused by PTSD. She recalls: "My ASD sensory overload problems aggravated my tendencies to have PTSD flashbacks. VR sent me to a course, associated with a local community college. At first, the teachers didn't understand why I kept pestering them with so many questions. They almost kicked me out of the program and told me I needed a job coach to learn how to function in class. So VR provided me with a job coach. With the combination of great counselors and an excellent training program, I had a very positive experience. I was able to pass the program, learned computer programming and eventually found a job. I got fired from this job about 4 1/2 years later. VR helped me find my current job with a federal agency. They offered job coaching when I needed it. I have now worked for the same agency for over 10 years and am completely financially independent. I do wish that my ASD issues had been recognized earlier. Not screening for ASD was one of the failings of my VR program, but it's understandable because most counselors don't know a lot about ASD. I couldn't understand my own behavior, my tendencies to burst out, asking questions, and having 'mini-meltdowns.' However, because of my PTSD diagnosis, I did end up getting decent services which helped me attain and keep a job."

At 38, Sheldon has worked before but has trouble in team environments and doesn't always move as quickly as others want him to. Frustrated with the length of time it's taking to get skills that make him employable, he struggles a bit with his college classes. He has a strong need to do useful work and his VR counselor has picked up on that.

She is available, friendly, patient, kind, yet firm with Sheldon, attempting to get him to be more proactive. She explains things to him, and always stays cool, calm, and collected. She is arranging for him to shadow some people who do CNA (nursing) work. There's a local restaurant chain with a paid two week shadow/work program; that's another avenue to try. He's also interested in handyman work, so may do some work for Habitat for Humanity. Hopefully, by the end of summer or early fall, he'll find something that he can do for a long time.

It is important to acknowledge that autism spectrum disorders are serious conditions which require accommodations in the work setting, and provide those accommodations that allow the individual a measure of accomplishment and success. People with ASD need help finding a work environment where they can succeed, and obtaining leads to jobs in the hidden job market, which aren't advertised. In order to comply with VR programs, they need very specific, detailed, clearly spelled out expectations.

There is a desperate need for systems-wide training for VR personnel. Vocational counselors, job coaches, and others working with or helping this population must understand this disability and how it affects the VR client. They need to know that a person can go to college, achieve a degree (or two) and still have difficulty with specific tasks required for work. They need to understand that all people with ASD are different. Many are visual learners who, like Sheldon, can benefit from shadowing programs. Others don't learn by observation and need specific, detailed instructions to carry out a task.

Barbara Bissonnette, Principal of *Forward Motion Coaching* and author of the *Asperger's Syndrome Workplace Survival Guide*, has some suggestions for VR counselors working with folks on the autism spectrum. "The most important thing to realize is that these individuals process information differently. They can be easily overwhelmed by too much information, and find many things about job hunting and the workplace confusing. These are concrete, literal thinkers who focus on details and require explicit instruction and examples. You cannot presume that they understand what a job really entails just from reviewing a post, or that they can apply information they read to their particular situation. If tasks aren't completed, it may be that the steps are too big, or that the individual doesn't know how to begin. The person might be too anxious to make telephone calls or visit a company to fill

out a job application."

Barbara feels that educating the VR counselor and the employer is critical for better employment outcomes. She explains: "Right now, we're asking the person with ASD to do all of the adjusting. While nearly everyone can learn and improve skills, someone with ASD is not going to become neurotypical. It's my experience that when employers understand the ASD profile – especially not to take communication gaffes personally – they are very willing to make modifications."

Information, education, and training about the strengths and challenges of people with ASD is imperative in order to effectively help individuals on the spectrum to succeed in the workplace. Only then will VR be able to place these valuable, skilled employees in a suitable work setting. If they don't understand the challenges faced by these people, they won't be able to explain the individual's strengths and weaknesses to the employer, ensuring acceptance, understanding, and a good fit.

Yvona Fast is the author of a career guide for individuals with ASD. Employment for Individuals with Asperger Syndrome or Nonverbal Learning Disability was published by Jessica Kingsley Publishers in 2004. Her website, www.wordsaremyworld.com, has more information. She also works as Support Groups Manager for GRASP (the Global Regional Asperger Syndrome Partnership).

Interviewing from page 25

for change. You are also able to ensure that you clearly understand an individual's perspective. For example you might say, "Let me see if I understand thus far."

Giving affirmations is another strategy used in motivational interviewing to promote a positive relationship. Making statements that are genuine, and identify an individual's strengths, help build the individual's confidence in future success and ability to change. It establishes that you both are on the same team and working together towards change.

Motivational interviewing principals are also useful during the preparation, action

and maintenance phases of change. Although it might appear counter-intuitive, it is imperative to respect and accept ambivalence and resistance to change. After discussing the pros and cons of making changes, an individual must next translate identified potential changes into specific reachable goals to develop a plan of action. During this time, resistance to change can be strong. Motivational interviewing addresses ambivalence about change and manages resistance by using known strategies such as reflection, clarification, shifting focus, and emphasizing personal change. Again, the key is to keep communication open and avoid the perception of being in conflict or judgmental.

Readiness for change should be generated from the individual, not the counselor or family. Studies show that when you argue for change resistance increases and increased resistance is usually associated with poor outcomes (Journal of Social and Clinical Psychology 24 (6), Markland, Ryan, Tobin and Rollnick, 2005). Hence it is important that individuals who decide to enter a post-secondary or vocationally-based program understand, and are in agreement with, any proposed transitional plan. The ability to "roll with the resistance" is a core principal of motivational interviewing. By managing resistance, counselors and parents can assist young adults who are ready and determined to

successfully facilitate change.

Motivational interviewing is an engaging and encouraging approach to promote change. The principals of motivational interviewing emphasize patience and empathy while promoting insight and self-determination. The relationship building communication tools of motivational interviewing, can be used to assist an individual in identifying personal values and life goals. Motivational interviewing techniques can help an individual with high functioning autism and his family decide whether they are ready to commit the time, resources and effort required for success in a post-secondary or vocationally based transition program.

Diagnosed from page 4

- Those identified as having ASD at younger than 5 years were diagnosed most often by generalists (such as pediatricians, family physicians, and nurse practitioners) and psychologists. Those identified later than 5 years were diagnosed primarily by psychologists and psychiatrists.
- Nine out of ten school-aged children with special health care needs and ASD used at least one health care service, such as behavioral intervention or modification services, sensory integration therapy, cognitive based therapy, occupational therapy, physical therapy, social skills training, or speech or language therapy.

- Social skills training and speech or language therapy were the most commonly used service, each used by almost 60 percent, or three out of five, of these children.
- More than half of school-aged children with special health care needs and ASD used at least one psychotropic medication. "Psychotropic medication" refers to any medication used to treat a mental disorder.
 - Almost 33 percent of these children used stimulant medications
 - 25 percent used anti-anxiety or mood-stabilizing medications

◦ 20 percent used antidepressants.

Further findings are available in the NCHS Data Brief at www.cdc.gov/nchs/data/databriefs/db97.htm and Frequently Asked Questions at www.cdc.gov/nchs/data/slraits/PathwaysFAQ.pdf.

Significance

The new data detail the experiences of young children with ASD, describing when they are first identified as having ASD, who is making those identifications, and the services and medications the children use to meet their developmental needs.

What's Next

NIMH encourages researchers to

access and analyze the new dataset to produce more studies on the early life experiences and the diagnostic, service, and treatment issues relevant to children with ASD and special health care needs. The Pathways to Diagnosis and Services Study dataset can be accessed at www.cdc.gov/nchs/slraits/spds.htm.

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Girls from page 21

her primary coping skill when confused or anxious was to withdraw and avoid social interaction. She was never a behavior problem; however, she was not really participating in nursery school. She would come home and tell me who played with dolls and who jumped rope, but it was not until months later that I realized she was watching her classmates like a television show, instead of interacting with them. That is why it is so important for teachers to assess your daughter's level of participation and her ability to interact with adults and peers. A quiet, passive little girl may actually be quite lost in school.

One hopeful distinction that many girls on the spectrum seem to possess is the desire and ability to play imaginatively. Styles of play are often a key indicator when a child is evaluated for autism. Typically a child on the spectrum will choose to play in a rigid fashion: lining up blocks, building with Legos, etc. They tend to avoid playing with dolls and stuffed animals because those toys require open-ended play and replication of social scenarios. In many ways, imaginative play is therapeutic and allows children to rehearse and internalize key social relationships in life. Research has found that some girls on the spectrum do have the capacity for imaginative play (Nichols, Moravcik, & Tetenbaum 2009), and this is a wonderful strength. I know my older daughter Lizzie always loved playing dolls, and it allowed me to teach her in a fun way how people should and do interact, express feelings, and display affection. While Caroline, my younger daughter, has been slower to come around to imaginative

play, her love for her dolls has provided an avenue to draw her out and talk to her about her feelings. Imaginative play builds on a lovely part of childhood and offers a multitude of opportunities to teach our girls social skills. This appears to be a strength that girls on the spectrum possess.

Another difference researchers have discovered is that while boys on the spectrum often enjoy math and logic based endeavors, many girls gravitate towards visual art and writing (Bazelon 2007). I know both of my girls enjoy drawing, and Lizzie seems to have born with the ability to put feelings into words and appropriately use semi-colons. Girls on the spectrum seem to enjoy creating their own worlds, whether pictures or written stories, which may be an extension of their greater capacity for imaginative play. And many of the girls' drawing and narratives are magnificent windows into their thoughts and feelings. Windows that could reflect on what autism truly is, how it feels, and how best to help all of our children.

Finally, the last difference seems to be in the way boys and girls on the spectrum feel about friendships. Friendships are a challenge for all of our kids, and boys struggle with this as well. Yet many boys appear content to be with their close family relationships. Girls, however, often express great loneliness and longing when it comes to friends. I am not sure if it is part of our social expectations or has a deeper biological basis, but as girls we place a high priority on our friendships; we love and need our girlfriends. For our girls who struggle socially, it is mighty undertaking to make friends with typical girls who are critically aware of social

nuances and norms. Our girls are often delightfully quirky, genuine, and earnest, but unfortunately, these virtues can lead to rejection by their status-conscious typical peers. Research shows that a lack of friends can create profound sadness in our girls and puts our girls at greater risk for depression (Kim *et al.* 2000). The desire for friends is hopeful, but the process of making friends can be difficult.

We need to be proactive in helping our girls find friends to avoid the loneliness that too often leads to depression. Early diagnosis is again essential as it offers our girls appropriate support throughout school to make and keep friends. The deep need all children have for friendship and acceptance is also why schools must be more proactive with programs like peer networking, where typical peers are educated about autism and act as liaisons for their classmates on the spectrum. In addition, preventing bullying must be a priority for teachers, administrators and parents. Many of our girls are able to articulate their feelings and schools need to hear them. Our girls' voices can inspire schools to educate typical peers, fostering empathy and understanding. Finally as parents, we need to help educate our daughters about the importance of appropriate grooming and clothing, and it is crucial for us to model good social skills through our own behavior. We must welcome and foster the friendships our daughters do make. Although at times a struggle, the desire for friends is healthy and positive, and can provide motivation for our girls to make strides in all areas.

The study of autism has historically been a study of boys, which is under-

standable given the common conceptions of what autism is and how it presents. However, now that we have a deeper understanding of how autism affects girls as well, and in significant numbers, it is time to reframe the conversation and broaden both the research studies and therapies to address the needs and strengths of girls. Are all of these observations about girls true in every case? Absolutely not. Every girl and every boy with autism is a unique human being with his or her own likes, struggles, and talents. But in identifying differences, we can also identify strengths and specific ways to help our girls. In many ways, the strengths girls tend to possess can potentially provide avenues of therapies and growth for both boys and girls on the spectrum. In addition, the ability many girls have to give words to their feelings can increase the world's understanding of what it means to be on the spectrum. It is time for the multi-colored spectrum of autism to include the color pink; because girls on the spectrum are still girls, and that changes everything.

Eileen Riley-Hall is the mother of two teenage girls, one with Asperger Syndrome and the other with Autism. She is a high school English teacher at an inclusive public school in New York State and has worked with special needs students from preschool through to high school, in various settings, for over 25 years. Eileen is also the author of Parenting Girls on the Autism Spectrum: Overcoming the Challenges and Celebrating the Gifts, which is available on Amazon.com as well as a variety of bookstores. For more information, please contact Eileen at punkysmom@nycap.rr.com.

Health from page 19

- cards of all those involved in the care of your loved one.
- 5. Create a Sanctuary.** Any room in your home can potentially be a sanctuary. Your sanctuary may be a "Mom cave" or "Man cave." If you do not have the space, a good place to start is simply in the bath. Wash yourself with great smelling soaps in one of your favorite scents like strawberry or calming lavender. There are bath salts or bath bubbles if you prefer. Treat your hair with a great smelling shampoo/conditioner. You can be a little indulgent and take this time to unwind and decompress. Literally wash the cares of the day away. There are great manly scented soaps and lotions out there as well. Real men do take baths!
 - 6. Stop, Breathe, and Tell Yourself, "I will get through each situation one step at a time."** Autism is the reality through which you see the world and it takes time to incorporate the breadth of what this diagnosis entails in your life. Identify the steps you need to take first, and focus on each step one at a time. It may be helpful to write down what you need to accomplish in a daily or weekly planner. Give yourself time and be kind and patient with yourself and what you are able to do.
 - 7. Acknowledge Your Feelings.** Once you identify, name, and accept your feelings, you will feel less out of control. After that, find a comfortable place to express your feelings. Anger, tears, sadness and frustration are normal, so do not feel guilty about expressing yourself in this manner. It is important during those times of powerful feelings to acknowledge your feelings as your own and do not lash out at others.

Theatre from page 30

explorations and "interview" style games about things he loved, we were able to come up with a simple character—a museum painting of the greatest baseball player ever. He loved practicing his swing, and, since he was absent for the final performance, we used film as a medium for him to appear onstage so he could have many takes in which to practice his short lines. In his next program, Justin returned with a greater sense of confidence. He created a character himself, a cranky old sea captain with a phenomenal grumpy face. His lines are longer, and his verbal abilities have grown immensely.

Alternatively, Kevin possesses stronger verbal skills, but struggles with understanding the viewpoints of others and why he sometimes needs to adjust his behavior to account for their feelings. His group had written a script about a prankster and her principal, with Kevin as the principal. While working on script analysis, character emotions and objectives, Kevin initiated a conversation about his wife, suggesting that perhaps they'd gotten into a fight that morning. A short conversation illuminated Kevin's understanding that a fight would make him feel frustrated, thus impacting

- 8. Embrace Supportive Relationships.** It is important to find others who are going through the same thing that you are. Though you may feel very isolated, there are others going through the same things as you. The company of others is important for your emotional well being. Make spending time with people you enjoy a priority. Choose friends, neighbors, colleagues, and family members who are optimistic, encouraging, and interested in you and your family. It is going to be challenging to find people who will truly understand what it is like to care for a loved one with autism or any other disability who is not a caregiver themselves. Be patient and be practical. Seek out those who will be supportive of you and what you are going through. Look for area support groups which meet regularly.
- 9. Know Your Limits and When You Need to Let Go.** For situations within your control, remember change takes time. You may be able to control more than what you think you can. One of the hardest things to do is to acknowledge that some situations are beyond your control. If something cannot be changed, work at accepting it for what it is. It may help to repeat something like, "It is what it is, I am going to accept it." If you feel like you need help letting something go, you may find that creating a journal and writing down your experiences can be a helpful outlet.
- 10. Art is Healing.** Studies show that simply walking through an art gallery can lower blood pressure and reduce stress. The same goes for strolling through a park, admiring architecture, or watching a sunset. Expressing your feeling through the artistic process can be very healing. Try poetry, painting, dance or theatre to express what may be going on inside you. The arts and artistic processes are also superb activities for your loved one with autism. People with autism have a lot to tell us and utilizing the arts is an excellent bridge to that communication.
- 11. Be a Lifelong Learner.** It is very easy to eat, sleep and breathe autism twenty-four hours a day. As compelling as that may be, try to take time to expand your interests. Take an adult education class, join a book club, visit a museum, and/or learn a new language. Get away for a while through meditation, a book, a movie, or taking a short trip. Return to nature. Take a long walk. Breathe the fresh air and smell the flowers. Garden, plant and enjoy the growing natural process.
- 12. Engage in Physical Activity.** Engage in activities that naturally release endorphins such as walking, bicycling, dancing, and playing team sports. Include your loved one when you can and take time by yourself when you need. Get out from behind your TV or computer screen. Screens will never have the same effect as a look of concern, a comforting hug or a stroll through the park, arm in arm.
- 13. Volunteer.** Doing something that helps others has a positive effect on your self esteem. The meaning and purpose you find in helping others will enhance and develop your life beyond your everyday focus on autism. There is no limit to the individual and group volunteer opportunities you can explore. Schools, places of worship, nonprofits, and charitable organization of all sorts depend on volunteers.
- 14. Join in.** You are asked to be an observer and report so much of the time as a caregiver. You may poten-

his anger level with the students' pranks, while a positive morning would perhaps make him less inclined to punish the student. The conversation ended with Kevin exclaiming, "So I guess we had a fight this morning, because it makes more sense with the script." The gains here can be looked at through an academic lens: he's learned writing and reading comprehension. Through a theatrical lens, he's just completed conservatory-level script analysis. But on a much more important level, Kevin's expressed an understanding of how things going on in a person's life can affect their interactions. He's gained empathy.

It has been said that great education is special education; it is the role of any good educator to adapt their methods to reach the child in whatever way he/she needs. Every single person, regardless of age, language, or (dis)ability, has within them something that they want heard and every therapy has the goal of helping unlock that potential in our students. Theatre adapts naturally, reaches students right where they are, and gives them the tools to help them share without the pressures of a traditional educational environment.

Perhaps the most harrowing discovery in play research can also be the most powerful in inciting change in how we think

about and use play. In a 1990 study, Dawson, et al. found that, "In free play situation infants and young children with autism were significantly less likely than developmentally matched children to combine smiles with eye contact in a way that conveyed communicative intent and to smile in response to their mother's smile. Mothers in response were less likely to smile at their children and showed fewer smiles overall." The best part about play is that it's reciprocal, but it's also the catch-22: If we believe that our students will have difficulty with play, then that will be the case. But if we look at them and only see their unlimited creative potential, however differently they may communicate it to us, then we set them up for nothing but success. It may be more one-sided or require more compromise at the beginning, but your child will grow in his reciprocity. Everyone can play.

Note: To protect the anonymity of Daytime Moon's participants, all names have been changed.

Jenna Gabriel holds her BFA in Drama from New York University's Tisch School of the Arts, with concentrations in Applied Theatre and Child and Adolescent Mental Health Studies and is currently pursuing her

tially be asked to observe the effect of a new medication, activity or therapy. You are then asked to report on those observations to the therapeutic, clinical or school team. That is quite enough observing...Join in. Join networking, social action, conservation, and special interest groups that meet on a regular basis. These groups offer wonderful opportunities for finding people with interests that match your own.

- 15. Understand When You Need Help. Manage Your Stress Levels.** Stress takes a heavy toll on physical as well as emotional health, so it's important to keep stress under control. While not all stressors can be avoided, stress management strategies can help bring things back into balance. Try to avoid becoming absorbed by negative thoughts about yourself and your loved ones. These thoughts may drain your energy and trigger feelings of anxiety, fear, and/or depression. **Know when you need to seek help yourself.** If you are feeling overwhelmed with your situation, seeking professional help is nothing to be ashamed of and is to be encouraged. Your insurance provider is a good place to start to find mental health providers in your area. Finding the help you need will not only help you, but will also give you the ability to best care for your loved one.

B. Madeleine Goldfarb is the Executive Director of Noah's Ark Institute, which provides program support and training about autism for the community. "We must give every individual the opportunity to build skills and thrive within the fabric of a caring community. If we can do that, than we have fulfilled our promise to our families," Goldfarb said.

Noah's Ark Institute is a nonprofit organization. Find out more about Noah's Ark Institute at www.noahsarkinstitute.org.

Master's Degree is Intellectual Disability/Autism at Teachers College, Columbia University. Jenna is the co-founder and Executive Director of Daytime Moon Creations, a nonprofit organization that offers recreational theatre programs to children and young adults with a wide spectrum of special needs. For more information, please visit www.daytimemooncreations.org or email Jenna at jenna.gabriel@daytimemooncreations.org.

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Support Group from page 12

help along the way." Callers receive practical guidance and referrals to trusted service providers who have been helpful to AHA members.

This past fall, AHA presented the 22nd Issues in Education conference for school personnel. Invited speakers are the most highly regarded innovators of programs for students with ASD and have included Paula Kluth, Brenda Myles, Lynda Geller and Michelle Garcia Winner. A talk on the science of autism is also featured. Past speakers have been such notables as John Pomeroy of Stony Brook University, Ami Klin, Director of the Marcus Autism Center and former co-director of Yale Child Study Center, and Allison Singer, founder and President of the Autism Science Foundation.

AHA invites teen-aged students with ASD to participate as panelists at this conference and present their personal accounts. Their experiences convey a complex array of strengths, courage, and abilities that contrast with the obstacles that impede their success in the usual school setting. These personal stories do so much to raise the consciousness of the educators in attendance.

In the spring of 2000 the organization held its first Issues in Independence for Teens and Adults on the Autism Spectrum conference. This conference, which just celebrated its twelfth consecutive year, is presented in collaboration with Adelphi University, ASPIRE Center for Learning and Development, GRASP, Compass Project, and Spectrum Services. The university hosts this popular daylong event which has welcomed noted keynote speakers and workshop leaders. Prominent among them are Temple Grandin, Valerie Paradiz, Stephen Shore, Zosia Zaks, Jerry Newport, Dennis Debbaudt, and John Elder Robison. Topics have included housing, employment, sexuality, post-secondary education, sensory issues, empathy, au-

tism and substance abuse, autism and the criminal justice system. A favorite highlight of the conference is the panel discussion featuring individuals with ASD. Amy, that isolated 5th grader, now a Master of Applied Behavior Analysis/ABA, has made presentations at both AHA conferences. The conference also provides attendees an opportunity to interact with a group of trusted service providers who are invited to exhibit at the conference.

Nina, a member of AHA and the mother of a child with ASD is a regular conference attendee. As a mother and psychologist, she deplors the lack of specialized services in the Northern Westchester area where she and her family live but through her AHA contacts she has connected with professionals in NYC who provided effective treatment and guidance for her son and she credits AHA with helping her become a more effective advocate and professional.

AHA is a non-profit 501(C)(3), member organization with over 500 active members. One of the perks of membership is the bi-annual publication, *On the Spectrum*, filled with current useful information, book and film reviews, research summaries and practical guidance. Bernice Polinsky, Deputy Director of AHA and *On the Spectrum* editor adds, "Our publication puts the most current thinking about autism into the hands of our members. Our contributors have included prominent experts but many of the most useful articles are written by parents and individuals with ASD who share their practical knowledge. Our members are able to pass these ideas on to family, friends and, most importantly, the teachers and other professionals working with their children."

AHA has an Internet presence with a website, www.ahany.org and an eNewsletter, updated weekly with current news about autism and it is sent to over 3,500 national and international subscribers. Members are also able to participate in monthly family bowling, the Abby Irwin

Annual Picnic, additional talks by local service providers, and an annual "Rock N Bowl" fundraiser. The funds raised through membership dues, conference fees, individual donations, and "Rock N Bowl" enable AHA to sustain its headquarters, its satellite office in Manhattan, and its array of meetings and activities.

AHA employs 2 part time staff, both of whom have a child with AS. A dedicated cadre of volunteers and its 14 member Board of Directors provide the better part of the labor it takes to run the organization. This team is led by AHA's executive and deputy directors, Pat Schissel and Bernice Polinsky. While some directors have specific administrative duties, all participate in community outreach and participate in autism and special needs events throughout the community. Patti Fitzgerald, Director, a speech and language therapist and AHA's education liaison, commends AHA for being a "grassroots, down to brass tacks group. [Providing] the support for all the puzzle pieces representing the mosaic of the autism spectrum." Kenia Nunez, AHA board member, has been invited to speak at university and corporate events and is called upon to assist Spanish speaking families of children with special needs. Susan Deedy, Esq, AHA's recording secretary, a special needs attorney, points out that many of her clients benefit from AHA's resources and its "fun activities where individuals on the spectrum have the opportunity to just 'be themselves'."

The evolution of AHA is largely the vision of its leaders, Pat and Bernice. Both have championed the cause of ASD, working in various capacities, to educating the public about autism's many faces. Pat offers this comment about AHA's mission, "AHA's focus is in educating families, individuals and the public on the strengths and potential of people on the autism spectrum. This has created a broader knowledge base for all. So many more of our children are able to rise to higher education and become successfully

employed in their area of interest and expertise. We have more to do but we are on the right path."

AHA's leaders represent the organization at numerous community activities, reflecting the spirit of collaboration crucial to finding solutions for the challenges of ASD. A few of the standouts bear mentioning. Pat serves on the editorial board of this publication, *Autism Spectrum News*, and on the advisory board of ASTEP, an organization working with employers and developing job opportunities. She is also a founding member of The Westbrook Preparatory School, a residential program for youth with ASD. She was invited to represent AHA at the signing of the NYS Insurance legislation, expanding health care coverage for treatment of ASD, a cause AHA worked hard to promote. This year she read grants as a community investigator for the NIH Autism Centers of Excellence. Bernice works very closely with YAI, a New York based full service agency and regularly attends the LI Task Force on Aging Out. Bernice and AHA VP Mike Buffa are attendees at the annual NYS Legislative breakfast where they have the ear of elected officials.

As AHA approaches its 25th year in the service of the autism community there are plans for continued growth to meet its needs. Though it is a time of concern as incidence rates of ASD rise, it is also one of opportunity and promise. You may contact AHA by email at info.ahany.org or phone at (888) 918-9198.

*Carole Kalvar has been on the Board of Directors of AHA for 10 years and is largely responsible for managing their database. She has two adult children. Her son with ASD lives independently and works full-time as an office assistant. Her daughter is a graduate of SUNY New Paltz and now studies nursing. Carole has authored several articles for *On The Spectrum*, one of which was republished by *Autism Spectrum News*.*

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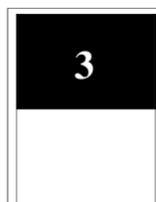
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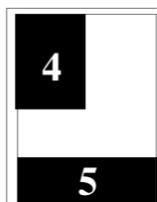
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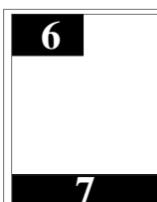
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