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SPRING 2011

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 3 NO. 4

Autism and the Law Throughout the Lifespan

Kids with Asperger's Syndrome, Schools and the Law

By Marcia Eckerd, PhD and
Andrew Feinstein, Esq

Students with Asperger's Syndrome (AS) frequently have behaviors that cause problems in school and lead to extreme consequences. Parents need to know their rights to protect their children.

Florida CBS News affiliate WFOR reported in December 2010 that a boy diagnosed with AS was "kicked out of his kindergarten class after the teacher held a vote among fellow students about his disruptive behavior" (His kindergarten classmates voted 14 - 2 for expulsion). The mother sued, settling for \$350,000 from the school district.

Jason had a diagnosis of AS. His behavior deteriorated significantly in 7th grade. He had meltdowns, was rude and disruptive and walked out of class. Most episodes were triggered by a teacher demanding/asking for work he didn't want to do. He became more threatening over time, knocking over furniture, using ob-



scenities towards his teachers and threatening to kill himself when denied computer time. For eighth grade he was placed in a special behavior management school.

During a class in this new school, Jason audibly burped. The teacher confronted him, telling him to write a letter of apology as a behavioral consequence.

Jason, embarrassed, refused and loudly justified his behavior. As a result, Jason was given the next level of consequence, placement in the time-out corner of the room behind a screen to write the letter. Increasingly upset, Jason again refused. He yelled at the teacher, called her an obscene name and threatened to throw something. He was escorted to the principal's office, where he was told he had to write the letter immediately as well as serve a detention and forfeit earned computer time. Jason climbed on the couch and tried to pull a large framed picture off the wall. The police were called.

Children with Asperger's Syndrome and other PDD spectrum disorders often overreact to situations, as Jason did. They may interpret the actions of others as unfair, deliberately embarrassing or threatening and become emotionally agitated over the triggering situation. At times, as in the case of Jason, their emotional dyscontrol escalates to the point of becoming unsafe to themselves and others,

see Kids on page 30

Beyond Olmstead: Housing for Adults with Autism Spectrum Disorders

By Sheryl Dicker, JD, Professor and
Kristina Majewski, Law Student Fellow
Albert Einstein College of Medicine

The passage of the Americans with Disabilities Act (ADA) of 1990 established that all people with disabilities, including those with ASD, have a legal right against discrimination in most facets of life, such as employment, education, and housing. In 1999, in the landmark case *Olmstead v. L.C.*, the United States Supreme Court held that institutionalization constituted unjustified segregation in violation of the anti-discrimination provisions (Title II) of the ADA. *Olmstead* became the catalyst for deinstitutionalization of individuals with disabilities. The Court noted, pursuant to Title II of the ADA, that states are required to place individuals with mental disabilities in community settings rather than institutions when three conditions are

met: (1) the State's treatment professionals have determined that community placement is appropriate, (2) the community setting is a "less restrictive setting" and the transfer is not opposed by the individual, and (3) in light of the State's available resources, the community placement can be "reasonably accommodated."

Using the *Olmstead* decision, people with disabilities once segregated in institutions have filed lawsuits nationwide to mandate states to provide services and supports in the community. Thus, people with ASD in institutions, including mental hospitals and nursing homes, can use *Olmstead* to create community-housing supports. In Georgia, for example (the *Olmstead* state), the state has been compelled to develop housing in the community for 9,000 individuals, pursuant to the October 19, 2010 settlement agreement. According to this agreement, all individuals currently in hospitals will be transferred to community settings by July

2015. Other examples abound in several states. According to a 2003 study of the states' response to *Olmstead*, conducted by Ohio's Developmental Disabilities Council, more than forty states have created "Olmstead specific task forces." Those task forces have been charged with ensuring that individuals are moved from institutions to community settings by establishing budgets, requesting appropriate funds be made available to provide adequate housing and supportive services, and moving people off waiting lists. Unfortunately, data collected by the University of Minnesota's Residential Information System Program, between the years 2005 and 2009, shows that the number of people living in public and private institutions has not declined in many states including New Jersey and New York. The data further reveals that thousands of people in several states are still waiting to receive residential services (118,122 individuals nationwide as of 2009). Recent

litigation by the Disability Rights of New Jersey, addresses this concern. A complaint was filed against the NJ Department of Human Services, claiming that the rights of 8,000 individuals with developmental disabilities were violated because they remained on residential waiting lists and were not moved from segregated settings to the community. (In 2003, a similar lawsuit was initiated in Oregon on behalf of 5,000 individuals with developmental disabilities). The NJ case argued that lack of money is not a defense for the state because civil liberties are independent of state funds, and indeed, it costs double to care for individuals in an institutional rather than a community setting. It is interesting to note that in *Olmstead*, the plaintiffs reported a cost \$283/day to care for an individual in an institutional hospital as compared to \$112/day for community services.

see Housing on page 28

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Deadline: September 15, 2011

Winter 2012 Issue:

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Deadline: December 15, 2011

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Navigating the Complex Changes Ahead”

Deadline: March 15, 2012

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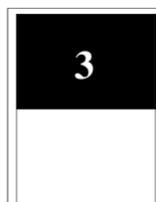
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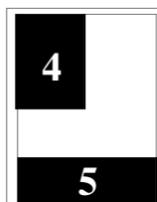
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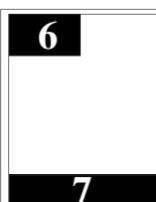
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From the Executive Director

The Importance of Understanding the Legal System and Your Child's Rights

By **Ira H. Minot, LMSW**
Founder and Executive Director
Mental Health News Education, Inc.

From the time an infant is born with autism, their lives are governed by laws. Every family becomes keenly aware that in order to protect and develop their autistic child's abilities, effectively modify their behaviors, and provide them with the best opportunity to integrate into the society, their child must meet the criteria established by the legal system in order to receive the financial, medical, educational, etc. supports they are entitled to receive. Just as early diagnosis and intervention is vital, knowing how to navigate the legal system is equally as important throughout the lifespan of the individual with autism. This issue of *Autism Spectrum News* is devoted to providing vital legal information and education to families with young and adult children on the spectrum and also to the general public to ensure adequate care and access to services, equal rights and fair treatment, and supported community-integration for individuals with autism spectrum disorders.

Our lead cover story, written by Marcia Eckerd, PhD and Andrew Feinstein, Esq provides two case studies of adolescents with Asperger Syndrome who exhibited troublesome behavior in the classroom and were improperly subjected to the same disciplinary rules as a non-disabled child, resulting in the involvement of the police and the juvenile justice system. "Parents should be aware that misbehavior is a predictable part of being on the autism spectrum. Children should not be punished for having a disability. None of us want children to be explosive, rude, and misinterpret the behavior of others. Yet, we have the right to demand that the school has sufficient understanding to reduce the triggers for misbehavior and to teach the student how to adapt. This is a long-term process and results depend on both the interventions and the child. With education and understanding, the risk can be reduced and positive development enhanced. However, even the best behavior plan will not guarantee good behavior, so it is important that parents know the systems that exist to protect their children."

With the growing adult autism population brings an increased need for appropriate community housing options. States are now required to place adults with autism spectrum disorders (meeting certain conditions) in community housing settings rather than institutions. Meeting the growing demand for housing has proven difficult, given the lack of budgeting, trained staff, and availability of physical locations. In our second cover article, Sheryl Dicker, JD, Professor and Kristina Majewski, Law



Ira H. Minot, LMSW

Student Fellow at the Albert Einstein College of Medicine describe the need for further legislation to support the rights of individuals with autism to have access to community housing options. "In 1999, in the landmark case *Olmstead v. L.C.*, the United States Supreme Court held that institutionalization constituted unjustified segregation in violation of the anti-discrimination provisions (Title II) of the [Americans with Disabilities Act (ADA) of 1990]. *Olmstead* became the catalyst for deinstitutionalization of individuals with disabilities.... As the population of adults with ASD skyrockets, the need for creative housing solutions will soar. Yet, *Olmstead* may only help a minority of these adults. Legislative, not litigative, solutions must be developed that capture the spirit of *Olmstead* and the ADA in state legislation. Only by creative advocacy can we create an array of housing options for all adults with autism spectrum disorders."

Understanding the laws and legal rights surrounding autism is vital for the autism community, but the general population needs to be educated and informed as well. For example, first responders (police, EMT, fire, etc.) need to understand the unique needs of individuals with autism spectrum disorders in emergency situations; otherwise an already dangerous situation could become unnecessarily more complex and treacherous. On page 12, B. Madeleine Goldfarb, MA, Director of Outreach and Education at The Autism Center of NJMS UMDNJ describes how the State of New Jersey has added a required autism awareness training course and curriculum for first responders. "Why is first responders' autism training a critical part of their overall job training? Every year we lose precious children and adults due to adverse incidents which could have been avoided or greatly mitigated if first responder personnel had received the specialized training in autism spectrum

disorders (ASD) that they needed.... [Individuals with ASD] may not recognize their rights under the law, especially in interrogation or the administration of Miranda rights. They may want to end a situation, such as an interrogation, and falsely incriminate themselves by admitting to crimes they did not commit. There are many areas in which the first responder must be aware of regarding the unique profile of individuals on all areas of the autism spectrum. Continuing training which deals with all aspects of emergency response and law enforcement must be provided in an ongoing and comprehensive manner."

A recurring theme found in many of the articles in this issue of *Autism Spectrum News* is the misunderstanding that occurs between figures of authority and individuals with autism spectrum disorders. The Asperger's Association of New England has created a fabulous tool for self-disclosure in the form of a simple Wallet Card for individuals with Asperger's Syndrome to carry with them. On page 26, you can cut out and personalize this Wallet Disclosure Card for your teen or adult to use. "An important time for a person with Asperger Syndrome (AS) to disclose the fact that he or she has AS is when interacting with a 'first responder' such as a police officer, fire fighter, or emergency medical technician. This kind of disclosure may be especially challenging, because the situation may be one in which the person may well feel threatened or unsafe. If you are an adult or teen with AS, we suggest that you carry a copy of the card...in your wallet at all times, to use in such difficult situations. Be sure to write on the card the names and telephone numbers of two people who know you and who explicitly agree to serve as emergency contacts for you if you ever find yourself in a difficult situation with a police officer or other first responder."

Autism Spectrum News serves as a resource providing vital education and information to families and the professional community. We strive to highlight the beauty and extraordinary character of individuals with autism. Carrie Cariello is the mother of five children; one of whom is named Jack and is great at bowling, has a crush on his first grade teacher Mrs. Cushman, and has autism. In her article on page 29, Carrie compares the "paper version" of her son Jack, which parents become familiar with at school IEP meetings revolving around their child's diagnosis, to her real-life son who has talents, unique and special characteristics, and brings spirit and happiness to her family. "I remember attending Jack's very first IEP meeting in Buffalo, New York and listening to the entire group of therapists and teachers refer to him as 'child.' 'Child has lim-

ited verbal skills.' 'Child needs visual cues to communicate' 'Child is self-directed.' It went on and on until I wanted to light each one of my eyelashes on fire and dart from the room. But what I wanted to do even more was shriek things like, 'His name is Jack! He is two years old! He's really cute! And he loves Cool Whip!' From that point forward I resolved to never reduce Jack to a paper boy, but instead to spring him to life in all of his autistic glory."

In addition to our featured cover articles, there are many more that address other vital areas of interest including the latest advances in autism science, evidence-based treatment practices, transitioning into adulthood, and helpful information for parents of a newly diagnosed child by experts in the field of autism that we hope will inform and inspire you.

Let me conclude by telling you about our exciting roundup of themes in the upcoming quarterly calendar of *Autism Spectrum News*. Our summer issue's theme will be "The Need for Science-Based Treatment and Services for Individuals with ASD." The deadline for articles and advertising for this important issue is June 15th, 2011.

Our calendar continues with our fall issue which will focus on "Understanding and Addressing the Unique Needs of Individuals with Asperger's Syndrome and High Functioning Autism." Next winter we will take an in-depth look at "Science Matters - The Latest Advances in Autism Research," and next spring our theme will be "Transitioning into Adulthood: Navigating the Complex Changes Ahead."

We would like to invite everyone to participate in these exciting upcoming issues. Our goal is to continue our format of providing evidence-based news, information, education, advocacy, and resources on a variety of topics of importance to the autism community.

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We look forward to hearing from you. Please e-mail us at dminot@mhnews.org and tell us what topics are important to you, so that we can address them in future issues of *Autism Spectrum News*.

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AUTISM SPECTRUM NEWS DESK

Updated 2011 IACC Strategic Plan for ASD Research

Focuses on Interventions for Nonverbal Individuals, Health Promotion Efforts, and Safety

The Interagency Autism Coordinating Committee

The Interagency Autism Coordinating Committee (IACC) has released its 2011 Strategic Plan for Autism Spectrum Disorder (ASD) Research (<http://iacc.hhs.gov/strategic-plan>), which is intended to provide a blueprint for future ASD research efforts. The Plan provides a set of research recommendations to guide federal autism research efforts and serves as a basis for partnerships with other agencies and private organizations involved in ASD research and services.

"Federal and private investment in autism research has increased markedly in the past two years," said IACC Chairman and NIMH Director Dr. Thomas Insel. "At the same time, the IACC has heard from the community about the growing need for research and the importance of new areas for rigorous scientific study. This updated research Strategic Plan builds on recent discoveries and emerging opportunities to identify new areas where science can make a difference for individuals and families with ASD."



Thomas R. Insel, MD

Several new areas of focus have been identified in the 2011 Plan, including studies on the use and accessibility of Alternative and Augmentative Communication (AAC) tools for nonverbal individuals on the spectrum and studies of health promotion and the prevention of

related health concerns such as obesity and mental health issues. In addition, in response to public concerns about the health and safety of children and adults with autism, the committee added new objectives related to understanding safety issues that may contribute to the increased risk of injury and premature death that has been reported in the literature.

In total, the IACC added 16 new objectives to the Plan during the update and added an addendum section to each chapter describing what has been learned over the past year, what gap areas have emerged, and what progress has been made in fulfilling the existing objectives. During the annual update of the Plan, which is required under the Combating Autism Act of 2006, the IACC considered input from ASD community, advocacy groups, research funding organizations, and the scientific community. Also incorporated was information from the IACC Portfolio Analysis of ASD Research Funding in 2009 (the most recent year for which there was complete funding data), the 2010 IACC Summary of Advances in ASD Research, the Request for Information (RFI) on the 2010 Plan, and the proceedings of the IACC Services Workshop held in November 2010.

In developing the 2011 Plan, the committee highlighted many successful collaborations that have been recently formed among member agencies and organizations. These collaborations included a joint conference held by the National Institute of Environmental Health Sciences (NIEHS) and Autism Speaks on autism and the environment; an information portal called AutismNOW supported by the Administration for Children and Families (ACF), in partnership with the Autistic Self-Advocacy Network (ASAN) and the Autism Society; and the Autism Informatics Consortium, which is designed to improve the utility and usability of informatics tools for ASD researchers and represents a collaboration between NIH, Autism Speaks, and the Simons Foundation. These public-private partnerships embody the spirit of collaboration described in the Plan's Mission Statement and are critical to making progress toward understanding ASD and improving the lives of people on the spectrum, as well as those of their families.

The Interagency Autism Coordinating Committee (IACC) is a federal advisory

see IACC on page 42

Fay J. Lindner Center for Autism Welcomes New Clinical Director

The Fay J. Lindner Center for Autism

The Fay J. Lindner Center for Autism & Developmental Disabilities recently welcomed Dr. Natalia Appenzeller as its new Clinical Director. As the Clinical Director, she oversees the clinical services offered by the center, is the lead clinician on the multidisciplinary evaluation team, and is director of the psychology graduate training program. She also serves as the liaison between the center and the community regarding issues related to awareness, education and advocacy.

Dr. Appenzeller, PhD is a licensed psychologist and has vast experience and knowledge in the field of autism and developmental disabilities, allowing her to successfully oversee the programs offered at the Fay J. Lindner Center.



Natalia Appenzeller, PhD

Dr. Appenzeller joined AHRC Nassau in 1994 as a School Psychologist

for the Education Center. In that position, she developed, trained and supervised the ABA program, conducted parent/staff workshops, administered psychological evaluations and chaired multidisciplinary team meetings. In 1999, she became the Supervisor for the Home/Community-Based Program under the Brookville Center for Children's Services and continues in this capacity to date. As the Supervisor, she is responsible for the hiring and supervising of therapists and teachers who provided services in the homes and communities with an emphasis on compliance and quality of service. She coordinates with the Department of Health and School Districts to ensure the acquisition of services for Early Intervention, CPSE and School-Age students.

Prior to joining AHRC Nassau, Dr. Appenzeller worked as a psychologist in both in and outpatient settings and

special education schools. She received her doctorate from the University of North Carolina at Chapel Hill. She is a Licensed Psychologist and holds New York State certification as a School Psychologist and School District Administrator.

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.

Advertise Your Upcoming Event in Autism Spectrum News! - See Page 5 for Details

AUTISM SPECTRUM NEWS DESK

Spectrum Services Opens its Doors to the Community *Group of Professionals to Provide a Variety of Clinical and Support Services*

Staff Writer
Autism Spectrum News

On March 13, 2011, Spectrum Services hosted an Open House to introduce themselves to the local and broader community. Founded by Lynda Geller, Ph.D., Spectrum Services is a cooperative of independent practices and organizations specializing in Asperger Syndrome and related conditions. The goal of this cooperative is to offer the highest caliber clinical and support services in an interdisciplinary format so that clients benefit from a coordinated approach. By involving an array of professionals operating from various perspectives, clients have access to many different approaches that target the multiple skill sets that individuals on the spectrum need to develop an independent and fulfilling life. Finding such a variety of needed supports has always been difficult for families of children and nearly impossible for adults with Asperger Syndrome. Spectrum Services is not a medical model in that so many additional educational and support services are available, from a social skills seminar to coaching to family support to executive function instruc-



Lynda Geller, PhD, Founder of Spectrum Services

tion to courses for families and professionals. In addition, clinical services are based on a positive skills development approach rather than more typical models of disease. Clients are understood as people, not

diagnoses, and help is designed with an individual's very specific needs in mind.

Spectrum Services is a group of professionals who have all worked for many years with individuals on the autism spec-

trum and other related developmental, social, psychological, and psychiatric conditions including nonverbal learning disability, social anxiety disorder, executive functioning problems, ADHD, and a variety of other related conditions. The services include diagnosis and evaluation, specialized psychotherapy, social skills and pragmatic language groups, neuropsychological assessment, psychiatric services, speech and language, college coaching, executive function services, educational consultation, couples counseling, vocational assessment and support, social skills seminar, neuropsychological evaluation, free adult and family support groups, courses on college and transition coaching, and a seminar series on autism spectrum issues.

This group of practices includes many who have worked in various settings supporting individuals with Asperger Syndrome including public and private schools, colleges and universities, medical schools and centers, and specialized clinics and practices. Together at Spectrum Services can be found Lynda Geller, Ph.D., Mary Riggs Cohen, Ph.D., David A. Cooperman, M.D., Enid Gort, Ph.D., Rhea L. Hooper, M.A.,

see Spectrum Services on page 34

Autism Science Foundation 2011 Doctoral Training Awards Announced *New Projects Funded to Study Animal Models, Biomarkers, Treatment and More*

The Autism Science Foundation

The Autism Science Foundation, a not-for-profit organization dedicated to funding autism research, recently announced the recipients of its annual pre and post-doctoral fellowships. In all, \$220,000 in grants will be awarded to student/mentor teams conducting research in autism interventions, early diagnosis, biomarkers, and animal models. This funding level represents a 22% increase over last year's training fellowship grants.

"We are thrilled to be increasing our funding in only our second year of operations, and to be supporting such high quality grants", said Autism Science Foundation co-founder Karen London. "Outstanding research is the greatest gift we can offer our families. We are so grateful to all our donors and volunteers who have come together to support autism research."

The following new projects have been selected for funding:



Dr. Jill Locke and Dr. David Mandell
University of Pennsylvania
Implementing Evidence-Based Social Skills Interventions in Public School Setting

Several successful social skills interventions for children with autism have

been developed for use in school settings. Children who receive these interventions from a research team show marked improvements in friendships and playground behavior, but these gains usually fail to maintain because the school staff do not continue the interven-

tion after the research study ends. In this study, we will modify one of these social skills interventions that was designed for skilled clinicians to use so that it can be used by school aides to improve the social involvement of children with ASD in schools. We then will test the intervention to see whether the intervention is as successful when aides deliver it. Training aides will increase children's opportunities to practice social skills with their peers at school and increase opportunities for generalization and maintenance of skills, since aides are so frequently present during social periods such as recess and lunch. If successful, this project will provide school districts with a cost-effective, easily implemented, and sustainable program that improves socialization in children with ASD within school settings. Once aides are trained, schools will have a built-in mechanism for continued success that will help many children with ASD and their families address the social challenges associated with ASD.

see Awards on page 38

Using Video Modeling as an Evidence-Based Intervention for ASDs

By Jill Krata, PhD
YAI Network

New research indicates that video modeling is effective in enhancing social communication and functional skills in children and adolescents with autism spectrum disorders (ASD).

Video modeling entails watching a video of a desired behavior and then imitating that behavior. Video models can be used with peers, siblings or adults (Bellini & Akullian, 2007). A similar intervention, video self-modeling, allows the individual to imitate targeted behaviors by observing him or herself successfully performing a behavior on video.

Research suggests that children are more likely to respond to a model that they perceive as skillful, and who are similar to themselves, either by physical characteristics, age, group, affiliation or ethnicity.

Promoting and Maintaining New Skills

These interventions not only help individuals with autism learn new skills and maintain them over time, but also have met evidenced-based practice standards. To meet these standards, the intervention must be studied by at least three different researchers in three separate geographical locations, and the combined studies must include at least 20 total participants (Horner, Carr, Halle, McGee, Odom et al., 2005). Video modeling and video self-modeling have met these criteria and are considered to be evidence-based interventions by the Council for Exceptional Children.

Video modeling and video self-modeling are especially helpful interventions for children and adolescents with ASD because they help individuals see that they can accomplish tasks being modeled. Individuals on the spectrum attend more closely to a video model, as compared to a live model in which external distractions such as noise, lighting, or other activities might inhibit



Jill Krata, PhD

learning. Video models eliminate social distractions and anxiety, which may significantly improve one's ability to focus on a new learning task.

Easing Anxiety While Learning

Children with ASD typically focus on details, rather than the bigger picture, so watching these videos also helps increase their attention to the desired behavior reflected in the video.

For many individuals, watching a video creates less anxiety than interacting with a person and is more likely to promote learning. The positive gains—new skills or desired behaviors—from this intervention are maintained for months after the intervention is over. This is particularly important for children and adolescents with autism who have difficulty transferring skills from one setting to another.

Visual Learners

The reason these interventions are successful may be because they integrate a visually-cued instruction. Research shows that using video models is particularly effective for children who enjoy watching videos and prefer visual learning. These interventions can be implemented with minimal human interaction which, again, reduces much of the distress and anxiety related to social interactions for children with autism (Bellini & Akullian, 2007).

Enhanced Social-Communication Skills

Video modeling and self-modeling lead to substantial increases in verbal requests and responses in children with autism. Social interactions and reciprocal play behaviors increase social initiation skills, play behaviors and spontaneous verbal requests in the school setting. An impressive finding was that these skills were maintained at the one- and three-month follow-up sessions with these children.

The success of video modeling and video self-modeling in promoting conversation skills for children and adolescents with autism has also been well documented. Video modeling is effective in teaching conversational skills to children and they transfer these same skills to other settings, such as school and at home.

Promoting Functional Skills

Research also supports the effectiveness of these interventions in promoting skill acquisition and learning activities of daily living among children and adolescents on the spectrum. They are a highly effective method for teaching functional skills to children, and they were able to maintain the skills one month later.

One study demonstrated how video models were used to promote the functional skills of shopping in the community. Individuals were videotaped making purchases in grocery stores. One individ-

ual is heard giving instructions, such as “find the bread,” “put it in the cart,” “bring it to the counter,” and “pay the cashier.” Breaking tasks into small steps and showing them on a video makes learning these tasks far more manageable.

One of Many Evidence-Based Interventions

Families should look for interventions that have been replicated over time which demonstrate effectiveness, reliability and validation. An important step forward is to apply evidence-based practice interventions more frequently in an effort to appropriately and effectively care for individuals with autism.

Video modeling is a viable strategy that is easily available to parents and professionals. However, it is just one of many evidence-based practices. Having a repertoire of different evidence-based strategies and interventions that focus on the child's individual needs will lead to the most beneficial outcomes and positive results for children with ASD and their families.

Jill Krata, PhD, is Associate Chief of the Premier HealthCare Autism Research and Treatment Institute and Manager of Clinical Services at the YAI Autism Center. Premier HealthCare is a member of the YAI Network. For more information or for services, call 1-888-YAI-Autism or visit yai.org.

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YAI Network's 32nd Annual International Conference to Focus on Autism

By The YAI Network

Autism spectrum disorders (ASD) will be a major focus throughout the YAI Network's 32nd Annual International Conference (www.yai.org/resources/conferences/yai-conference) “Bridges to Success in Developmental and Learning Disabilities.”

The conference will take place May 2-5, 2011, at the Hilton New York and feature some of the most prominent experts from throughout the U.S. and abroad to address critical issues in the field of ASD.

In addition to numerous panel discussions and seminars, extended sessions will provide attendees with even more in-depth training. Highlighted extended sessions on ASD include:



- “No More Meltdowns: Handling Challenging Behaviors and Teaching Social Skills presenter,” by Dr. Charles Cartwright, Director of the YAI Autism Center at the YAI Network, and Dr. Jed Baker, Director of The Social Skills Training Project
- “Understanding the Hidden Curriculum for People with High Functioning Autism and Asperger Syndrome,” presented by Dr. Stephen Shore
- “The Roots of Literacy: Play and Language,” presented by Dr. Carol Westby, the developer of the Westby Play Scale

The autism track at the YAI Network's International Conference is supported in part by a grant from the New York City Council's Autism Awareness Initiative.

This year, in conjunction with our International Conference, the YAI Network is proud to host the International Society on Early Intervention's conference (depts.washington.edu/isei/ISEI_3rd_conf.html) on early intervention and early childhood. Many of the sessions in this conference will address autism spectrum disorders.

For more information on the YAI Network's International Conference, visit www.yai.org/conference, or contact conference organizer Abbe J. Wittenberg at abbe.wittenberg@yai.org or 212-273-6472.



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Autism Training for First Responders: A Lesson in Safety

By **B. Madeleine Goldfarb, MA**
Founder and Director
The Noah's Ark Children's Association

The public asks a tremendous amount from our first responders. As we run away from danger, they are the ones who run in. Without hesitation they put themselves in the line of danger every day, and we as a society are forever grateful for their dedication to our welfare and to their potential sacrifice on our behalf.

We also require training for all first responders in every possible emergency scenario that they may face. Although first responders receive training on an ongoing basis, many have not received training to recognize and work appropriately with individuals on the autism spectrum. Given that there are many specialized techniques which may be necessary to utilize in a call to service which involves a person with an autism spectrum disorder (ASD), specialized training is essential.

Why is first responders' autism training a critical part of their overall job training? Every year we lose precious children and adults due to adverse incidents which could have been avoided or greatly mitigated if first responder personnel had received the specialized training in autism spectrum disorders (ASD) that they needed.

When working in the field of autism it is easy to become sensitized to all things



B. Madeleine Goldfarb, MA

autism. However, the reality for the general population not personally involved with autism is that they may not even know someone identified with autism. Most of us, who even casually follow current events, have seen a news report or program about autism, but may not truly know details or specifics of the disorder or how they will be impacted by it.

One area the autism training course should cover deals with the individual on the spectrum's attraction to water¹. Like Alzheimer's patients, some individuals with autism will wander away from their homes and caregivers. A first responder who may be called to help locate a missing child or adult must be made aware that the first line of defense should be to search for the missing person near water. This may be near a pond or stream, a neighbor's pool or local drainage system. Every year we lose individuals on the spectrum to drowning who have wandered away. This is one of the greatest hazards faced by this population every day.

Another area where the proper training is essential is in restraint. Physical restraint is defined as one or more human beings applying their hands and/or other parts of their bodies to an individual's body to prevent that individual's freedom of movement. Mechanical restraint is defined as affixing any form of device to any part of another person's body, again, to prevent that individual's freedom of movement. This is another area where outcomes are directly related to training. Many individuals with autism have underdeveloped or poorly developed upper trunk areas. The trunk is the area around the upper torso, which includes the muscles responsible for the support of the lungs and diaphragm. Though the individual with autism may exhibit a level of strength which is outwardly powerful in response to an attempt

to restrain, this may conceal the fact that this individual may still have a weak upper trunk. Here again, we lose individuals every year do to positional asphyxiation.

"Positional Asphyxia" is defined as death that occurs because the position of a person's body disrupts the individual's process of respiration (breathing). This may occur due to excessive or improper restraint, and it is very difficult to differentiate between the person who is resisting to escape from their restraint and the person who is frantically struggling to breathe.

A first responder may be in a situation where restraint is necessary for a safe resolution to a call to service. If a first responder must go "hands on" there are modifications that first responder should keep in mind. These include:

- Clearly stating what you are doing to the individual using simple sentences in easily understood language which is non-idiomatic
- Approach from the side
- Frequent change of position
- Frequent check of the individual's vital signs for possible dangerous escalation, as this individual may continue to resist restraint even after being immobilized

see Training on page 36

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When Behaviors Result in Real Trouble: Legal Challenges in Individuals with ASD

By Peter F. Gerhardt, EdD,
Mary Jane Weiss, PhD,
Nicole Pearson, MA, and
Cece McCarton, MD
The McCarton Foundation

When we think about legal matters and individuals with ASD, we often think of the relationship between the law and advocacy. Legal entitlements apply to individuals with disabilities, a free and appropriate education is guaranteed, and certain accommodations must be made to make settings and experiences accessible to all. In these contexts, the law is a major help to individuals on the spectrum and to their families, informing them of rights and assisting them in accessing services.

We do not often think of the ways in which the legal system may be an adversary or an impediment to an individual with ASD. Yet, these challenges are a reality for many. At times, the behavior of individuals with ASDs violates social norms and mores, and the end result can potentially carry with it significant legal ramifications for the individual. In this article, we will review some of the behaviors that occasionally create these legal challenges, and address ways to prevent negative outcomes for individuals with ASDs in these contexts.



Peter F. Gerhardt, EdD

Social Deficits as a Risk Factor

Individuals with ASDs have major social deficits that put them at risk for a variety of social misunderstandings. The tolerance for socially odd/unacceptable behavior diminishes with age. While a young child may run up to someone at a mall without much negative consequence or awkwardness, a large teenager who hugs a stranger is often considered a threat.

Furthermore, the period of adolescence is marked by many physical and emotional changes and sexual feelings in this population, just as it is in other populations (e.g., Henault & Attwood, 2002; Nichols & Blakely-Smith, 2010). Sexuality education, however, is often sorely lacking. This puts individuals with ASDs at high risk for a number of problems (Gerhardt, 2006). Most importantly, it makes them vulnerable to exploitation and abuse. Without adequate instruction in appropriate and safe behavior, individuals with ASDs may be victimized. Inherent difficulties in self-expression and communication with others can further contribute to an individual with ASD being unable to let someone know such abuse is happening to them. The lack of educational effort in this area combined with core social deficits of ASD increases the likelihood the individual will be misunderstood, misinterpreted, or perceived as threatening by others.

In addition, some of the unique features associated with an ASD such as sensory issues, can exacerbate what is already considered unusual behavior. This can result in serious legal consequences for the individual who is unable to either regulate such behavior or is unaware that it is inappropriate. For example, there may be a sensory-seeking aspect of an unusual behavior, such as touching a female's legs or sniffing an individual's feet (e.g., Nichols & Blakely-Smith, 2010). When these more deviant behaviors occur

in an adolescent or adult, they are generally seen as highly offensive and as willful. This is the context in which legal ramifications may result.

In reality, many of these behaviors are instances of what Dave Hingsburger termed "counterfeit deviance" (Hingsburger, Griffiths, & Quinsey, 1991). They are not deviant behaviors per se; rather, they result from a lack of social skills, a core naïveté, or a lack of accurate knowledge (Hingsburger, Griffiths, & Quinsey, 1991) [what about poor judgment/discrimination abilities too?]. Individuals with ASDs who have good academic skills and normal intelligence are at highest risk for having such behaviors erroneously labeled as deviant and deliberate. When strengths obscure deficits, the attributions made by others are often that the behaviors were purposeful.

Many of the skills that we might identify as crucial sexuality skills are essentially social skills (e.g., Henault, 2004; 2006; Stokes & Kaur, 2005). For example, while we may teach and reinforce privacy, we may not explicitly teach the importance of not being naked in public. But for many individuals with ASDs, this explicit level of instruction may be necessary to ensure clear understanding and compliance. Sexuality education must include a focus on issues such as privacy, modesty, boundaries, and rules. When developing this educational content, it also

see Behaviors on page 36



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How to Combine Cooperation and Advocacy at Your IEP Meeting

By Maria C. McGinley, Esq
Mayerson and Associates

The IEP season is now in “full swing” and parents often wonder how they should conduct themselves at their child’s IEP meeting. It truly is a balancing act to be “cooperative” with your child’s IEP team while also advocating for the educational supports that are appropriate for your child. Striking the right balance between cooperation and advocacy can be difficult for some parents. The following tips may be useful.

Identify and Prioritize Your Objectives Before the IEP Meeting

Before you attend your child’s IEP meeting, you should identify clearly what results you would like to achieve from the IEP meeting, and what issues are most important to you. For example, you might be satisfied with the placement your school district is recommending for your child, but you feel that your child requires higher related service mandates or other IEP modifications. On the other hand, you might be wholly dissatisfied with the placement and program recommendations that your school district is offering and thus, you might be considering a different (more appropriate) school placement and program for your child.



Maria C. McGinley, Esq

The objectives you identify, of course, will be based upon the unique and individual needs of your child. For example, let’s assume that your daughter, Sara, is diagnosed with Asperger’s Syndrome. In order for Sara to make “meaningful progress” in her “least restrictive environment,” Sara may need to be placed in a mainstream classroom with typically developing peers, but she also requires a significant amount of “social skills” sup-

port. If your school district recommends an appropriate mainstream setting for Sara, the “objectives” for your IEP meeting might be geared toward securing appropriate social skills supports for Sara.

Create a list of factors that are important and arrange your list in order of importance. If you identify your educational imperatives *prior* to the IEP meeting, you will walk into the meeting prepared to advocate for your child’s needs, and you will be able to better navigate the meeting knowing where you can and cannot compromise.

Use Your Child’s Evaluations to Identify Your Objectives and Support Your Requests for Services and Programming

It is strongly recommended that you secure evaluations with specific recommendations from the professionals working with or evaluating your child. The recommendations of your child’s providers will help you identify the core components that should be a part of your child’s educational program and placement.

You should provide your school district with all reports and evaluations prior to attending your child’s IEP meeting. At the IEP meeting, make sure that everyone on the IEP team has a copy of the reports and ask all members of the IEP team to meaningfully consider the recommendations.

For example, recent education evaluations for Jim, a student with autism, recommend 40 hours per week of 1:1 Ap-

plied Behavior Analysis (ABA) therapy, five 60-minute sessions of speech and language per week, five 45-minute sessions of occupational therapy (OT) per week in a sensory gym, and two 30-minute sessions of physical therapy, all as part of a 12-month school year program. You can rely on this evaluation during Jim’s IEP meeting to ask the IEP team to consider all of Jim’s needs and encourage the IEP team to implement these services as a part of Jim’s IEP. It is always preferable to make the discussion, “this is what the professionals are recommending,” as opposed to, “this is what parents want.”

To determine whether the school district’s proposed placement and program would be appropriate, you might ask the IEP team: Does your program provide services during the entire 12-month school year? Where, if at all, is the “summer” program located? If my child attends your program, how many hours of 1:1 ABA can you provide? Who will be assigned to teach? What related services do you offer? Do you have a sensory gym? Will the school district therapists actually be able to fulfill the IEP’s related service mandates?

Use the recommendations on the reports and evaluations to guide not only your objectives, but also your questions at the IEP meeting.

see IEP on page 32

**Hear Our Senior Counsel, Tracey Spencer Walsh,
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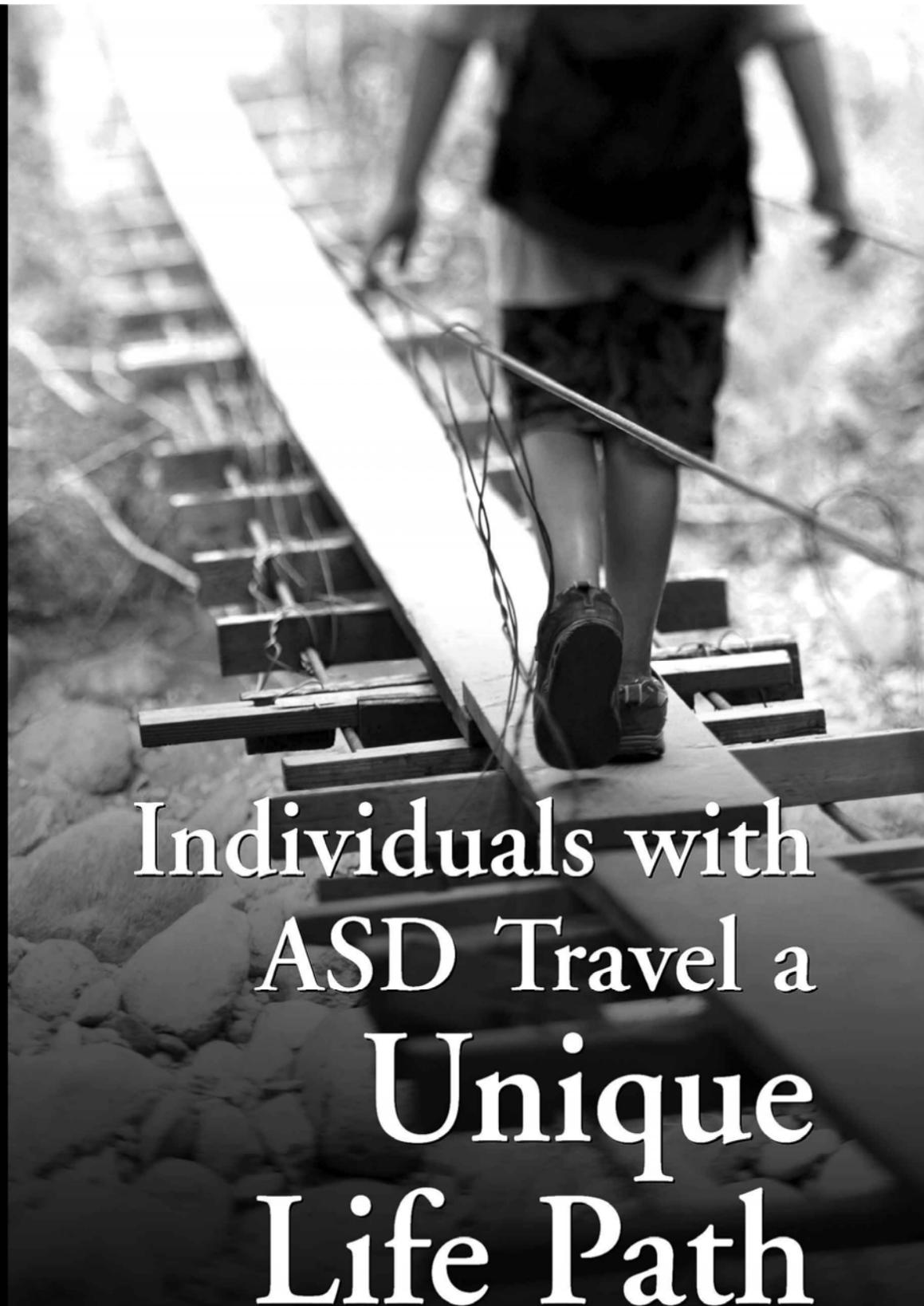
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ASD and Internet Crime

By Mary Riggs Cohen, PhD
Spectrum Services
Asperger Center for Education & Training

In the past few years a disturbing trend has emerged. Increasing numbers of ASD individuals being arrested and incarcerated for internet crimes involving child pornography and inappropriate contact with minors. As a clinician who specializes in autism spectrum disorders, I have been asked by defense attorneys to evaluate these individuals and recommend appropriate treatment to the court. In the majority of cases there are issues particular to the diagnosis of Aspergers or Pervasive Developmental Disorder that contributed to these illegal behaviors.

Emotional Immaturity

Some ASD adults have lifelong struggles with a lack of social awareness and understanding which has resulted in isolation and at times inappropriate behavior. In my court evaluations it is often apparent that the adults have little sex education and do not understand how to have a normal sexual or intimate relationship with another person. In individuals with autism spectrum disorders, their social naiveté and ineffective communication can lead to inappropriate behaviors that may be interpreted as stalking or unwelcome sexual advances (Debbaudt, 2004). In his article



Mary Riggs Cohen, PhD

Generic Treatment - Sex Offenders are not all Created Equal, Dr. Richard Dowell states that many ASD males are “unable to engage peers in social (or sexual) relationships and as a result tend to drop down” to younger individuals. As a result of the isolated way in which many ASD individuals explore their sexuality (and their lack of sexual education), they may begin communicating with younger kids online, and began looking at sexually

explicit pictures of young girls or boys. Dr. Henault (2005) has said that many adult ASD individuals are drawn to younger people because they feel that age emotionally. It is also the case that some ASD individuals, due to their lack of social understanding and sexual instruction, are unaware of what constitutes child pornography and deviant sexual material.

Compulsive Surfing/ File Collecting

Individuals on the autism spectrum are particularly vulnerable to pornography addiction due to their obsessive compulsive tendencies, perseverative behavior and social isolation (Henault, 2005). They compulsively surf the internet and are often drawn into hard core pornography sites due to their sexual curiosity and lack of real life experience. Some individuals report that they collect pornographic images because of their novelty and a desire to understand sexual behavior. Many collectors amass large numbers of images, which can affect them negatively if prosecuted.

Some adults with ASD lack the capacity to regulate their emotions (Bolton et al., 2006). This difficulty is also evidenced in poor management of sexual arousal which, combined with poor social skills, creates sexually problematic behavior (such as fetishes). These involve the need for objects, such as underwear, for sexual arousal. Others may develop a de-

pendency on pornography for sexual arousal and as a result become conditioned to be aroused only by atypical images such as pornographic cartoons, hentai (Japanese animated pornography), child pornography or sado-masochistic material. While this behavior does not necessarily make ASD individuals at risk for sexual offenses, it will cause more isolation and prevent development of healthy engagement with others. The only known treatment for pornography addiction is abstinence from viewing pornography for a minimum of one to three months (Carnes, 2007). This treatment also requires a reduction of homebound time and internet access, development of new interests and activities as well as support from family and friends.

Need for Education/Monitoring

It is imperative that ASD individuals understand the consequences of viewing or distributing child pornography as well as inappropriate internet chat with minors. Our current legal climate has no tolerance for such behaviors and demonstrates little leniency in sentencing. In the eyes of the law, a picture, video, photograph, film, or computer-generated image of anyone less than sixteen years constitutes child pornography and is a felony. Requesting a sexually explicit picture or video of any

see *Internet Crime* on page 39

Advice from a Neurotypical on Being Successful at Work

Barbara Bissonnette, Principal
Forward Motion Coaching

An often quoted statistic is that 85% of adults with Asperger's Syndrome (AS) are either un- or under-employed. Whether that number is accurate or not, clearly there are too many intelligent, college-educated individuals who are not utilizing their talents in the workplace.

Kevin summed up a big part of the problem. He was crushed after losing his first post-college job in just six weeks. “At school it was about getting good grades,” he said. “At work it’s about figuring out what people want.”

The clients that I see in my coaching practice are smart and skilled. Most have college degrees. They are young people who are just entering the workforce, and people in their 30’s, 40’s, 50’s and even 60’s who have spent years working in all kinds of careers. They all struggle to adapt to workplaces that are dominated by neurotypical individuals.

Allan, for example, is a brilliant programmer who forgets to make eye contact and to smile. He irritates co-workers with painfully blunt, but usually accurate, assessments of their ideas (“That’s dumb and won’t work!”). Doreen has lost over a dozen technical writing jobs for asking too many questions and being “rude.” Notoriously, she tried to empathize with a



Barbara Bissonnette

colleague by observing, “I can tell that your diet isn’t working because you’re still fat.” Mark’s supervisor laments, “He can be an incredibly creative, out-of-the-box thinker, but gets so caught up in the details that he loses sight of what we’re trying to accomplish.”

I wrote the Asperger’s Syndrome Workplace Survival Guide: A Neurotypical’s Secrets for Success to help individu-

als like these learn how to meet employer expectations. It features realistic strategies that will work for those in entry-level jobs, mid-range manager positions, and who are earning six figure salaries.

Since interpersonal communication plays such an important role in career success, emphasis is placed on how to be perceived as professional and personable. Rather than relying on scripts, which are of limited use in the workplace, readers learn specific techniques for clarifying expectations, accepting feedback, dealing with authority, and working in groups. There is even a chapter on office politics.

The Asperger’s Syndrome Workplace Survival Guide features many examples from client cases to illustrate how concepts are applied in actual situations. It offers insight into how neurotypicals work, and why it is so important to fit in.

Workplace disclosure and accommodations are also addressed. For some, disclosure can make the difference between keeping a job and losing it. Todd, for example, contacted me at a crisis point. Employed in a director-level job for two years, his literal interpretation of instructions and difficulty seeing the big picture frustrated colleagues. His supervisor expected him to assume “a leadership role,” something Todd had no idea how to do. When we met, he had been given two weeks to improve his performance or be fired.

Todd disclosed his Asperger’s Syndrome and over the next few weeks, he

and his manager worked out accommodations. Then, an opportunity arose for Todd (at his own request) to give up the director role and become a senior manager instead. The new position allows Todd to use his considerable technical ability and off-load the troublesome “leadership” duties.

The pragmatic recommendations benefit those who are entering the workforce, struggling to maintain employment, or wanting to improve their performance and advance their careers: People like Adam, who ignored instructions that he thought were stupid; or Lynn, who thought that people should listen to her because of her superior intellect; or Tina, who panicked over making minor mistakes. Professionals, and business people who supervise Asperger’s employees, will also find a wealth of ideas for creating job success.

Until the day when companies are “Aspie-friendly,” the burden is on Asperger’s individuals to find ways to fit in. The Asperger’s Syndrome Workplace Survival Guide is designed to be a handy reference that they can consult again and again to enhance performance and solve problems.

Barbara Bissonnette is the Principal of Forward Motion Coaching. She specializes in career development coaching and advocacy for adults with Asperger’s Syndrome. She also consults with employers and professionals. The Asperger’s Syndrome Workplace Survival Guide is available through www.ForwardMotion.info.

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Lynda Geller, Ph.D. Founder of Spectrum Services and Psychologist

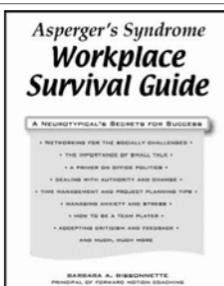
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The Americans with Disabilities Act Amendments of 2008

US Department of Justice Issues Long-Awaited Major Revisions

By Lawrence W. Berliner, Esq
Klebanoff and Alfano, PC

On March 15, 2011 revised federal regulations to implement the *Americans with Disability Act (ADA)* became effective. This change occurred because on September 25, 2008, former President George W. Bush signed the *Americans with Disabilities Act Amendments of 2008*, a federal statute with an effective date of January 1, 2009. Since that date, various federal agencies including the U.S. Department of Justice have promulgated regulations that would implement the changes created by the *ADA Amendments of 2008*.

Ironically, President Bush's father President George H. W. Bush signed the original *Americans with Disabilities Act* into law on July 29, 1990. That federal law and the implementing regulations required employers, public entities and places of public accommodations to discontinue a pattern and practice of discrimination and the exclusions of individuals with disabilities from society. As the first President Bush so eloquently stated, the ADA represented "...taking a sledgehammer to another wall, one which has for too many generations, separated far too many Americans from the freedoms that they could glimpse but not



Lawrence W. Berliner, Esq

grasp. With the fall of this wall we will not tolerate discrimination in America. Let the shameful wall of exclusion finally come down." Unfortunately in the years since the 1990 ADA's enactment, there were a series of United States Supreme Court decisions in 1999 and 2002 that erected barriers resulting in restrictions on

the scope of the ADA's coverage and protections. The Court had defined disability in a manner that was entirely inconsistent with the intent of Congress, resulting in the exclusion of individuals who should have been covered. Consequently, Congress took action to reassert its legislative authority to enact the laws and restated its 1990 intent on the definition of disability and the scope of the ADA's coverage and protections with the enactment of the *ADA Amendments of 2008*.

The U.S. Department of Justice had the responsibility to promulgate and enact the regulations for ADA Title II that covered public entities such as state and local government programs, activities and services. In addition, the Department had the responsibility to enact ADA Title III regulations that covered the programs, activities and services provided by private business and organizations. On September 10, 2010, the Department of Justice announced its final ADA Title II and Title III regulations with an effective date of March 15, 2011.

For parents of children with disabilities and students with disabilities enrolled in public or private schools, including post-secondary schools or colleges, these regulations will have a positive effect on ensuring equal access to the programs, services, and activities of public and private elementary, middle, high schools, and

post-secondary education programs at vocational schools, colleges and universities. For example, the *ADA Amendments of 2008* have created a "broad" presumption of coverage by the ADA. The law has redefined the definition of *disability* by adding to the phrase "*substantially limits a major life activity*" additional language to the original definition: reading, concentrating, thinking, and communicating. Previously, only the function of "learning" had to be substantially limited. Also, in evaluating whether an impairment substantially limits a major life activity, such an assessment is to be made without regard to "*mitigating measures*" such as the use of medication, low vision devices, prosthetic devices, assistive listening devices, assistive technology or medical equipment or supplies. In one case, the U.S. Supreme Court held that the use of "mitigating measures" took an individual outside the definition of disability and therefore, the ADA's coverage.

For high school students who are applying to college and/or college students who are taking college, graduate or professional school entrance exams such as the SAT, ACT, LSAT, MCAT, and GRE, the *ADA Amendments of 2008* have made it less onerous for the student to establish that they have a disability, that they need

see ADA on page 35

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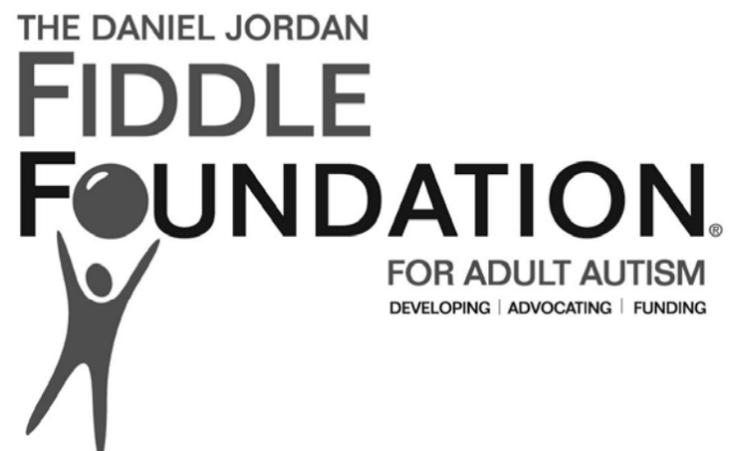
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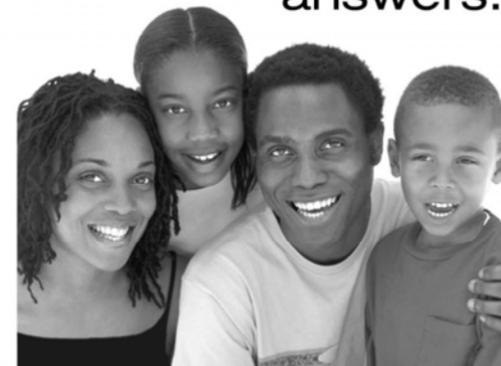


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Planning for Your Child with Special Needs

**By Stephen A. Ehrens, CPA, CLTC
Financial Representative
Northwestern Mutual Financial Network**



Stephen A. Ehrens, CPA, CLTC

One of the most challenging issues facing parents of children with special needs is planning for their child's future without them. Planning the finances for a child with special needs deserves special attention from the child's parents, grandparents and other relatives. With ever-changing laws and legal procedures, it's important for families to regularly revisit their financial plans to ensure their child with disabilities is well prepared for their future.

Careful planning is necessary to preserve eligibility for most publicly funded disability related programs, especially as the child reaches the age of majority (usually 18 years of age). Maintaining eligibility for basic government programs is important. As well, the family should understand that government benefits likely will not meet all the child's needs.

Special Needs Trusts

It is important to know that an inheritance may cause many problems for the child. An inheritance worth as little as a few thousand dollars could disqualify an individual with disabilities from

most federal benefits, such as supplemental security income (SSI) and Medicaid, as well as some state programs. This is an enormous loss for many, reports the National Information Center for Children and Youth with Disabilities (NICHCY), since critical services such as supported employment and vocational rehabilitation services, group housing, transportation assistance and personal attendant care could be jeopardized.

An effective estate plan would include a *special needs trust* – a legal document in which the family leaves chosen resources, such as money or property, to the trust. It is managed by a trustee on behalf of the person with the disability, who is given absolute discretion to determine when and how much the person should receive. There are many types of *special needs trusts* that serve different purposes and laws affecting trusts vary state to state. It is imperative that the family work with a knowledgeable attorney and a financial professional.

Funding the Trust

For some families funding a trust may require a reallocation of the assets they already have, while others may seek more assets to allocate. In this case, permanent life insurance may be a solution. Building a proper roadmap for all of the family's financial goals is extremely important. Grandparents and relatives may consider estate planning as an effective way to allocate assets to their loved one with special needs. Instead of designating their relative as a direct beneficiary, proceeds are left to the special needs trust.

Planning Considerations

There are important considerations parents can make when planning the financial future for special needs children. Here are a few suggestions:

Prepare, review and revise legal documents - Parents should regularly monitor legal documents such as wills, trusts, power of attorney documents and health-care proxies to make sure they are relevant and properly worded.

Develop a clear vision of how you want your child to live if both parents are no longer around - The family's planning efforts reflect their hopes, dreams and aspirations for their loved one.

Develop a written Letter of Intent that will assist future caregivers - Having a blueprint that provides vital information regarding the child's physical and mental status, likes and dislikes, medications, history, etc., will be invaluable to future caregivers... and the child.

Surround yourself with a team of knowledgeable professionals who have experience working with families with special needs - Core members of this team should include an attorney, a social worker and a financial professional. Together this group can help you manage the legal, government benefits, and financial solutions for your loved one with special needs.

Provide funding for quality of life for a lifetime - Special needs trusts should be regularly checked to make certain that

see Planning on page 41

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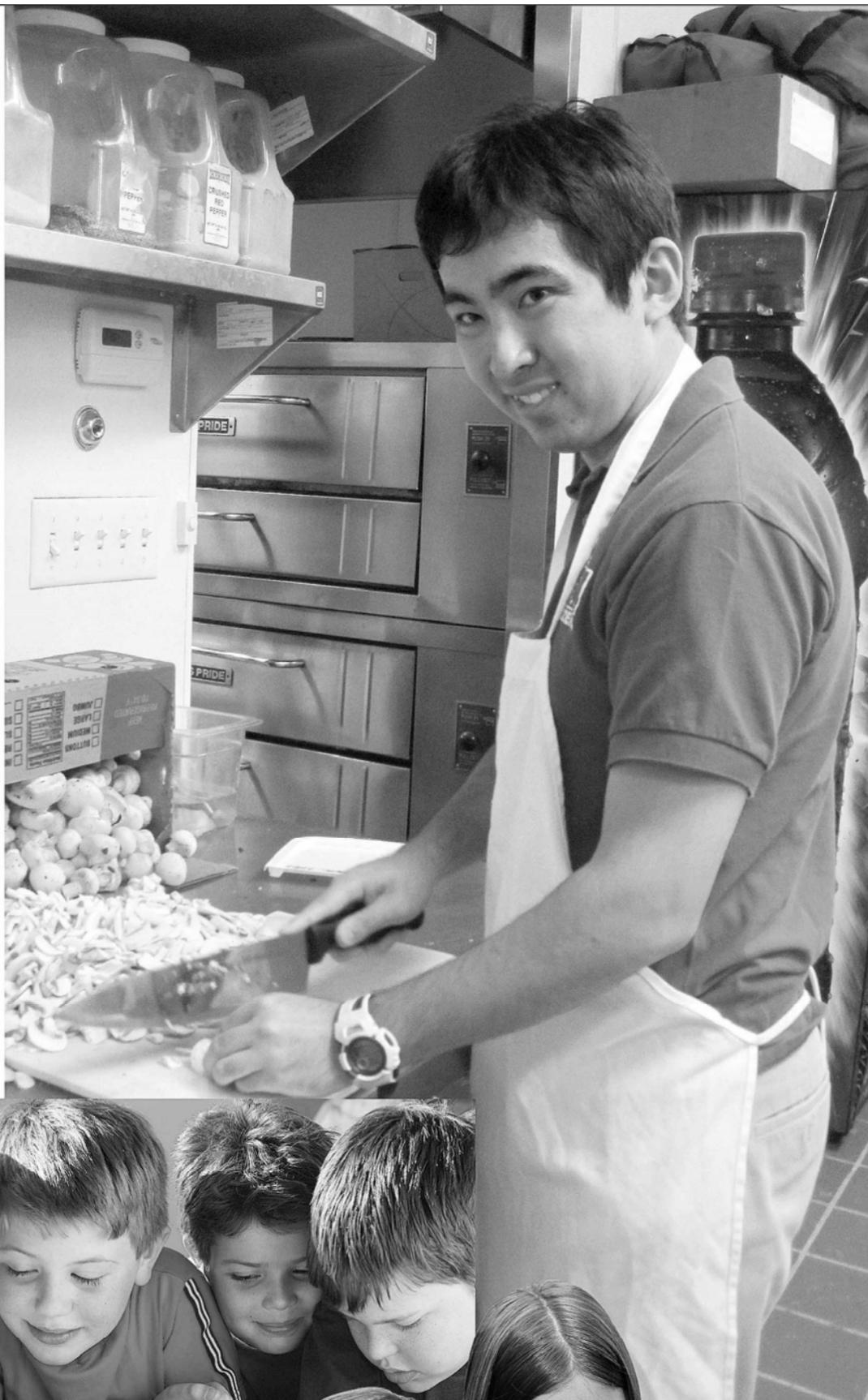
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Preventing the Plunge - Adults with Asperger Syndrome

By Susan Lesco, MS, QMRP
 Director of Program Partnerships
 Asperger Syndrome Training and
 Employment Partnership (ASTEP)

The Autism and Developmental Disabilities Monitoring Network (ADDM) and the Centers for Disease Control and Prevention (CDC) report that in 2002 approximately 10% of all 8-year-olds in the United States had an Autism Spectrum Disorder (ASD) (www.cdc.gov/ncbddd/autism/documents/autismcommunityreport.pdf - pg. 17). If these findings are correct, by next year 10% of all 18-year-olds in the United States will have an Autism Spectrum Disorder. The report does not account for the thousands of other people with ASD, in different age groups, who were not included in the study. Nor does it indicate where the study participants fall within the spectrum. However, the report does verify that an astounding number of adults with ASD are about to enter the workforce, enroll in college, look for adult services or fall through the cracks of a limited service delivery system. We must prevent the latter.

The first measure of prevention is to eliminate the all too common shock of learning that the rights of a student under the Individuals with Disabilities Education Act (IDEA) turn into a litany of eligibility criteria upon graduation from high



Susan Lesco, MS, QMRP

school or turning 22 years old, whichever comes first. All American school age children are entitled to a free and appropriate education in the least restrictive environment. Under the IDEA, students who have a wide range of disabilities, defined in the law's 13 categories, are entitled to receive the services or educational modifications necessary to complete their free and appropriate educational career. When school ends, entitlements end.

Another measure of prevention is to understand that laws, such as the Americans with Disabilities Act (ADA), are designed to ensure that people with disabilities are offered reasonable accommodations to access public places and activities. Albeit, according to the Keiser Commission on Medicaid and the Uninsured, the 1999 Supreme Court ruling in *Olmstead v. L.C.* required states to "provide services to persons with disabilities in community settings rather than institutions, if certain conditions are met" in order to comply with the ADA. However, the only people to meet "certain conditions" are those with severe disabilities, who need long-term services equivalent to institutional or nursing home care, and have Medicaid (www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13459). Adults with Asperger Syndrome are protected by the Americans with Disabilities Act, if they only require reasonable accommodations in college or their workplace, but are not entitled to the services they may need to succeed in those environments. Protection does not equal provision.

For example, if an adult with Asperger Syndrome needs assistance to get and keep a job, he/she must first qualify and then apply for specific, time limited, vocational services provided by his/her state's Vocational Rehabilitation (VR) agency. There are 80 state VR agencies, operating under the federal Rehabilitation

Services Administration, located throughout the United States. Each VR is funded by approximately 80% federal and 20% state money (www2.ed.gov/about/offices/list/osers/ras/products.html). They provide or pay for a range of vocational services, (such as job training, assistive technology, job placement, interest assessments, job coaching and so on), only if the person meets the following briefly outlined, basic eligibility criteria:

- The person must prove (with medical documentation) that he/she has a physical or mental impairment that substantially interferes in his/her ability to work.
- The person must prove that he/she needs vocational services to obtain and retain employment.
- The person must show that any VR service he/she is requesting and/or receiving must be directly related to getting and keeping employment.

The VR counselor who reviews the person's initial application for services is responsible for determining the applicant's eligibility and informing him/her of the decision. However, if the VR agency does not have the funding on hand to provide services to the people deemed eligible, the

see Plunge on page 33



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Divorce with a Child on the Spectrum

By Ernst O. VanBergeijk, PhD, MSW and Ron Hollander, Esq
New York Institute of Technology
Vocational Independence Program



Ernst O. VanBergeijk, PhD, MSW

Raising a child on the autism spectrum exposes a family to a whole host of stressors on top of the stressors normally associated with parenting. These stressors can overwhelm a couple and lead to marital dissatisfaction. In fact, there is some empirical evidence that families with a child on the autism spectrum are more likely to divorce than families with neurotypical children or children with other types of disabilities (Hartley, et al., 2010; Senechal & des Rivieres-Pigeon, 2009).

The goal of parents seeking the divorce should be to minimize the conflict, stress, and uncertainty for their children. If the parents can work together cooperatively and seek an amicable divorce, then they should seek an attorney who specializes in divorce mediation. This type of attorney works with both parents to arrange a mutually acceptable agreement in terms of custody, visitation, and child support. Recent research indicates families who used mediation have lower levels of ongoing conflict long after the finalization of the divorce (Sbarra & Emery, 2008).

The most common arguments parents have are over child rearing, sex, and money (Hitti, 2005). Many of these argu-

ments are identifying potential parental impairments in executive functioning or social skills. There is a great deal of evidence that autism is a genetically based disorder (Caglayan, 2010). It is possible that one or even both spouses may have an undiagnosed autism spectrum disorder or an associated condition such as attention deficit disorder (ADD) (Bolte, Knecht & Poustka, 2007). If the parents can reframe their spouse's objectionable



Ron Hollander, Esq

behaviors to perhaps signs of disability rather than willful behaviors, then this may lessen some of the acrimony associated with a divorce.

There is very little case law associated with custody cases where autism was a central issue. As with any other determination of custody, the sole concern, where a special needs child is involved, is a resolution that will best serve the interests of the child by pro-

moting the children's welfare, happiness, and optimum development (*Eschbach v. Eschbach*, 1982). Among the factors a court will usually consider to ascertain the interests of the child are the:

- Parenting ability and relative fitness of each parent;
- Love, affection, and nurturing given by each party to the child;
- Emotional bond between the child and each parent;
- Willingness and ability of a parent to put the child's needs ahead their own;
- Stability of the proposed custodial residence;
- Ability of a parent to provide for the child's emotional and intellectual development;
- Ability of each party to provide the child with food, clothing, housing, and medical care;
- Willingness and ability of each party to facilitate and encourage a close and optimum relationship between the children and the other party (*New York Domestic Relations Law § 240*, 2003).

see *Divorce on page 41*

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Sexuality, the “Double Vulnerability,” and Youth with ASDs

By Samara Pulver Tetenbaum, PhD
and Shana Nichols, PhD
ASPIRE Center

The social deficits of youth with Autism Spectrum Disorders (ASDs) place them at an increased risk of experiencing physical or sexual abuse, neglect or exploitation (Gabriels, 2007). However, these same social impairments can also increase their vulnerability to engaging in inappropriate behavior which can be interpreted by others as sexual or intentionally harmful (e.g., stalking, molestation). Engaging in such behaviors can lead to contact with the legal system as concerns are raised regarding the safety of others. Often, the behaviors have occurred not as a result of deviance, but rather because of the individual not knowing better. These youth commit what Dave Hingsburger and colleagues first called “counterfeit deviance,” or behaviors that are a result of a lack of sexual knowledge, social skills, or social naiveté (Hingsburger, Griffiths, & Quinsey, 1991). The unwritten social rules of sexual and relationship behaviors are highly complex and are often not explicitly taught, particularly to youth with ASDs. Social learning theory highlights the informal and incidental processes by which many concepts related to sexual interactions and behaviors are learned (Gagnon, 1991). These are mechanisms of



Samara Pulver Tetenbaum, PhD

learning that are not very accessible to youth with ASDs. Therefore, as more individuals with ASDs are becoming fully integrated into community life it is essential for socio-sexual rules to be taught explicitly as part of a comprehensive curriculum in order to prevent misinterpretation of behavior, negative interactions with the legal system, and the serious repercussions of such interactions (e.g., being labeled a youth sexual offender, jail time).



Shana Nichols, PhD

Little research has been conducted on the sexual behavior of youth with ASDs, however there are several recent studies which highlight the need for increased education. Stokes and Kaur (2005) examined the sexual behaviors of adolescents with high functioning autism and Asperger syndrome and found that these adolescents engaged in fewer privacy behaviors (e.g., seeking out privacy to undress and masturbate), had less knowledge regard-

ing privacy issues and displayed more inappropriate sexual behaviors (e.g., touching others inappropriately, touching themselves inappropriately, masturbating in public, disrobing in public and speaking about sexual activities in an inappropriate manner) than did their typically developing peers. In an earlier study, Ruble and Dalrymple (1991) examined parent reports of the rates of sexual behavior in their children, including school-aged children, adolescents, and adults. Sixty-five percent of individuals touched their private parts in public, 28% removed clothing in public, 23% masturbated in public and 18% touched the opposite-sex inappropriately.

These alarmingly high rates of inappropriate behavior are consistent with what we have observed in our clinical practice. We have worked with youth who engage in the following two kinds of behaviors: (1) behaviors which are *not* sexualized yet are interpreted as such. For example, youth whose sensory interests lead them to smell or stroke someone’s hair, to touch women’s legs and feel the texture of stockings, or to want to play with skin that wrinkles (e.g., elbows, knees). When these behaviors occur in young children, they are frequently tolerated or dismissed as cute; however, when an adolescent or young adult engages in sensory seeking of a socially inappropriate nature, their actions are

see *Sexuality on page 42*

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Compensatory Education is an Important Remedy to Consider

By Tracey Spencer Walsh, Esq
Senior Counsel
Mayerson and Associates

Compensatory education, an often overlooked remedy, is a legal term used to describe future educational services (or funds for services) that courts can award to a disabled student under the interpretation of the Federal IDEA statute. A compensatory education (comp ed) award is meant to *compensate* the student for the educational services he or she should have received but for the school district's *gross* failure to provide a FAPE (free appropriate public education). Comp ed is meant to remedy and "compensate" for the educational deficit created by an educational agency's failure to provide a FAPE.

The fact scenario comes up time and again, "The school district told us that our son, Jack would receive an hour of occupational therapy each week and his IEP mandates it - but the school doesn't have an occupational therapist!" Jack's mother asks several times, "When are you getting an occupational therapist?" The CSE chairperson replies, "There is nothing we can do about it - we have no control over staffing." During the time the school district has no occupational therapy, Jack receives none of his mandated occupational therapy services. Four months later, the school district



Tracey Spencer Walsh, Esq

finally hires a new therapist and begins to deliver the one hour per week of occupational therapy Jack was mandated on his IEP to receive. In this scenario, the student may be entitled to be "compensated" for the approximately 16 hours of occupational therapy, i.e., the therapy he should have received during those four months.

What happens if the school district refuses to make up the missed hours? Jack's parents must bring a due process proceeding seeking a comp ed award for the 16 hours of missed occupational therapy - the number of hours the student *should have received*.¹ An Administrative Law Judge (ALJ) can award a "bank" of occupational therapy hours that can be used in the future. If the school district begins to deliver the occupational therapy services, as mandated, after an award of compensatory education, the student can "tack on" the additional occupational therapy hours per week awarded as comp ed, in an effort to put the student back to where he would have been "but for" the school district's failure to deliver the occupational therapy during those four months. The idea is to "make up" for the services "lost" and give Jack an opportunity to get to where he would have been had he received the occupational therapy all along.

Let's consider a different scenario. Sydney, a 4 year old girl with an autism diagnosis, is evaluated privately by a reputable speech and language pathologist and neuropsychologist. Each of the evaluations make recommendations for Sydney including a twelve month school year, intensive speech therapy (5 hours per week), and 10 hours per week of home based 1:1 ABA intervention. Upon receipt of the evaluations and recommendations, Sydney's parents send all of them to the school district to consider.

At the IEP meeting, the IEP team rejects all the recommendations and offers only 2 hours of speech per week and no ABA services. The IEP chairperson tells Sydney's parents that "no child" in the district receives five hours of speech per week, and 10 hours per week of home based 1:1 ABA therapy is excessive, and by the way, we are not permitted to discuss "methodology" at IEP meetings.

After the IEP meeting, Sydney's parents write a letter to their school district and tell them that they do not agree with the IEP mandates and do not understand why their private evaluators' recommendations were ignored. The parents get no response. Sydney's parents are stunned but they do not know what to do about it (since the school district has never included parent counseling and training as part of the related services on Sydney's IEP and have not advised them of their rights) and they "wait and see" how it goes - after all, the school district does have Sydney's best interests at heart, right?

At the next annual IEP meeting, Sydney's lack of progress is discussed. Her teacher and parents report that Sydney has developed more interfering behaviors with greater frequency. Sydney's parents all but beg the team to incorporate the recommendations of the private evaluators. After Sydney's parents are completely exasperated, the IEP team "chairperson"

see *Compensatory* on page 42

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Sherri Shepherd
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How the AANE Wallet Disclosure Card Turned Around an Unfortunate Situation

By **Stephanie Loo, MEd**
Editor of the AANE Journal

K is a 32 year old adult with Asperger Syndrome (AS), has been a member of the Asperger's Association of New England (AANE) for about eighteen months. He participates in one of our weekly adult discussion/support groups, attended our adult summer conference ("Know Yourself: The Key to a Better Life"), and volunteers in our office. One thing he learned from people at AANE is that if you are a teen or adult on the autism spectrum, it's a good idea to fill out a copy of our wallet disclosure card and carry it with you whenever you go out.

K describes himself as a night owl. One weekday evening at about 11:00 p.m., K was in downtown Boston, hoping to hear some karaoke and grab a bite to eat. He walked by a McDonald's and a CVS, and turned down an alley, heading toward a bar that he knew had karaoke on Sunday



Stephanie Loo, MEd

evenings. When he got there, however, he found out there was no karaoke that night.

Well, he thought, I'm pretty hungry. I'll just head back around the corner to the McDonald's and pick up a burger. The lights in the restaurant were still on, and when he pulled the door, it opened. As he entered the restaurant, he heard an alarm ringing somewhere. Suddenly the lights went out. He backed out the door, thinking he would ask at the CVS next door whether the restaurant was in fact open. However, he found his way blocked by a Boston police officer. A cruiser was there, with its blue lights flashing. A second policeman appeared.

The officers escorted K back into the restaurant and asked him in a stern tone what he was doing. He felt afraid. They asked for his ID. K asked whether he could also show them his Asperger Syndrome wallet card.

Both policemen read the information on the card. Then they asked, "What is this 'Asperger Syndrome?'"

"It's a disability."

"How does it affect you?"

"It causes me to have concrete, black and white thinking."

The officers' tone changed. They seemed to realize that if they were interviewing a person with a disability, he might not be a thief or other kind of criminal. Nevertheless, they asked K to empty his backpack to ensure that he had not taken anything. They asked him what he was doing downtown, in a neighborhood considered dangerous this late at night, where he had been prior to entering the restaurant, and where he was headed. Finally, they gave him permission to leave.

K took the train to another neighborhood, where he knew the McDonald's stayed open until 2 a.m., and finally got his burger. He says, "I'm grateful that I had the AS wallet card with me that night. It really made a difference!"

For more information, please contact AANE at (617) 393-2824, or go to www.aane.org.

Wallet Card for Disclosure to First Responders and Law Enforcers

With Special Thanks to Dennis Debbaudt, Mary Fox, Debby Geheran, and Steffi Geheran

An important time for a person with Asperger Syndrome (AS) to disclose the fact that he or she has AS is when interacting with a "first responder" such as a police officer, fire fighter, or emergency medical technician. This kind of disclosure may be especially challenging, because the situation may be one in which the person may well feel threatened or unsafe. If you are an adult or teen with AS, we suggest that you carry a copy of the card below in your wallet at all times, to use in such difficult situations. Be sure to write on the card the names and telephone numbers of two people who know you and who explicitly agree to serve as emergency contacts for you if you ever find yourself in a difficult situation with a police officer or other first responder.

Some parents take their children to meet local police and disclose their AS in advance of any possible incident or emergency. Teens and adults could also make it a point to introduce themselves to local police, perhaps taking along a family member or trusted friend to facilitate the meeting. It is far easier to establish a mutually respectful relationship at a time when everyone is calm, than in the midst of an emergency or active law enforcement incident.

The expert on these issues is Dennis Debbaudt, who has kindly spoken at AANE conferences and trained law enforcement personnel and other first responders in New England on behalf of our community. You can receive his e-mailed "Autism Risk and Safety" newsletter by contacting him at ddpi@flash.net. AANE

staff members have developed this card based on models created by Dennis, and on his insights and teaching.

It is very important to ask a police officer for permission to reach into your pocket to get your wallet and the card yourself, or tell the officer exactly where you are carrying your wallet - purse, left side coat pocket, etc. - and ask the officer to please take out the wallet and look for the card himself or herself. For example, you could say, "Officer, I have a card in my wallet that explains my disability. May I please show it to you, or would you prefer to reach into my back pocket yourself?" If you just reach into your pocket suddenly, the police officer may think you are reaching for a weapon, and react in a way that could endanger you.

Directions

1. Cut out both the front and back sides of the card (www.aane.org/docs/resources_aane_wallet_card.pdf)
2. Fill out the front with your name, date of birth, and phone numbers of your two emergency contact people.
3. Cut a piece of card stock to the same size. Put it between the two sides of the card.
4. Laminate with contact paper or a clear lamination kit from a pharmacy, hardware, or stationary store.
5. Put the card into your wallet; carry it with you whenever you leave home.

To: A Law Enforcement Officer or other First Responder

I have a diagnosis of Asperger Syndrome.

My Name: _____

Home phone: _____ D.O.B. ____/____/____

In case of emergency, or to assist both you and me in communicating and in resolving this situation, please contact one of the following people:

1. Name _____ Phone: _____

2. Name _____ Phone: _____



Asperger's Association of New England

617-393-3824

www.aane.org

I have Asperger's Syndrome, a social/communication disability related to autism. Because of my Asperger's Syndrome, I may:

- Panic if yelled at, and lash out if touched or physically restrained.
- Misinterpret things you tell me or ask me to do.
- Not be able to answer your questions.
- Appear not to be listening or paying attention.
- Tend to interpret statements literally.
- Appear rude or say things that sound tactless, especially when anxious or confused.
- Have difficulty making eye contact.
- Speak too loud, too soft, or with unusual intonation.

I would like to cooperate. To help me cooperate, PLEASE:

- Clearly identify yourself as a law enforcement officer/first responder.
- **Call one of my emergency contacts.** (Please see reverse side of this card.)
- Do **not** assume that my Asperger's traits constitute suspicious behavior.
- Avoid touching me or restraining me.
- Speak to me in normal, calm, non-confrontational tones.
- Tell me exactly what I need to do politely, clearly, simply, literally, and step by step.

A Brief Overview of the Special Needs Trust

By Raymond J. Falcon, Jr, Esq
Falcon & Singer PC

You don't have to look too far to find reports on how medical costs have skyrocketed - and this is just for the general population. For persons with disabilities, medical costs are typically greater by an order of magnitude. Also, a child with severe disabilities may be unable to live independently. Group housing or long term care may be the only option when the parents get too old to care for their adult child with disabilities.

Few parents of children with special needs have the money to cover all these costs. The special child and her parents ultimately may have to look to the government for assistance, mainly to Medicaid, a joint federal/state program of medical insurance for the poor that is administered by the States. If the child qualifies for Medicaid, then most if not all of her medical expenses and possibly group home or long term care will be covered by Medicaid.

There's just one catch. Medicaid is a needs-based program for the blind, the disabled and the elderly. You have to be poor. In most States, poor means having \$2,000.00 or less in assets and a very low income (in New Jersey, the income level for a single individual is \$705.25 per month; other states have even lower income limits). While not all assets are



Raymond J. Falcon, Jr, Esq

counted toward the asset limit, most assets are counted. How will their special child survive on such a low income and limited resources? Parents want to give the child money to have a decent life. But, if they give the child money (by lifetime gift or inheritance), that money could cause the child to lose Medicaid. The child then has to spend down the money received from

the parents on medical and other expenses until she is poor again. The money was not used to improve the child's quality of life, contrary to the parents' wishes.

How to address this conundrum? The parents should consider setting up a Third Party Special Needs Trust (TP SNT) and putting the money into the TP SNT. Assets and income in a properly drafted TP SNT will not be treated as the child's income and assets, so will not affect her Medicaid eligibility. If the parents don't have much money but have their health, they can buy life insurance and have the death benefit payable to the TP SNT when they pass away. The money in the TP SNT can then be used to pay for things that Medicaid won't, thereby enhancing the child's life while preserving Medicaid and most other needs-based government benefits to meet the child's core survival needs.

What is a Trust?

First, what is a basic trust? Imagine a container with a spigot, like the 5 gallon jug of spring water sold in a supermarket. This trust container comes with an instruction manual (called a trust agreement) that tells what to do with the stuff in the container. You give the container and instruction manual to someone you trust (appropriately called the trustee). You tell the trustee, "I am giving you this container with the instruction manual. I may put something in the container now,

or provide in my Will for something to go into the container when I am gone. The manual tells you what to do with whatever is in the container. For example, for a typical trust set up for regular estate planning, the manual may say: Every year, open the spigot, pour out \$1,000 and give it to my son; and, once he turns 35, pour out whatever is left and give it to him. Unfortunately, the standard trust usually will not work for a child with special needs. Medicaid will often take the position that assets in typical non-special needs trusts are available to the child/beneficiary, thereby causing a loss of Medicaid. Use of a TP SNT can avoid this problem.

The Third Party Special Needs Trust

A Third Party Special Needs Trust is a container with a spigot, just like any other trust, and is usually set up by the parents. The key difference between a regular trust and the TP SNT is in the instruction manual. The TP SNT instruction manual contains very specific limitations on how the trustee can spend the money. For example, the trustee should not pay for something otherwise covered by Medicaid. Nor should the trustee give cash to the child. However, the trustee can buy the child a computer, or tickets to a play - things to make the child's life better. Moreover, the money in the TP SNT must not come

see Overview on page 34

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Executive Functions: Skills to Promote Success in School and Beyond

By Renee Soufer, MA, MEd and
Shuli Sandler, PsyD
Spectrum Services

Many children diagnosed with Asperger Syndrome (AS) and High Functioning Autism (HFA) struggle with impairments in executive functioning (EF). Executive functions are defined as “an umbrella construct defined as the control, supervisory, or self-regulatory functions that organize and direct all cognitive activity, emotional response, and overt behavior” (Isquith, Crawford, Epsy, & Gioia, 2005). These weaknesses impede their already compromised ability to function. A child with average or above-average intelligence will often present with less than optimal performance at home and at school because of deficits in these ancillary skills that are crucial for success in these environments.

Some examples of common Executive Functions include difficulty in the following areas:

Time Management - The ability to estimate accurate time periods for a task and stay within the time limit in order to meet deadlines and due dates.

Initiating Tasks - The ability to begin a task in a timely manner without procrastination or delay.



Renee Soufer, MA, MEd

Organization - The ability to create and follow a system for keeping track of materials, personal space, as well as information

Sustained Attention - The ability to maintain concentration on an activity or assignment without getting distracted frustrated or bored.



Shuli Sandler, PsyD

Response Inhibition - The ability to think before immediately responding to a situation or event, as well as the capacity to resist the temptation to say or do something inappropriate.

Emotion Regulation - The ability to manage emotions so that one can approach

tasks and successfully respond to an academic or social demand without becoming too overwhelmed without becoming emotionally overwhelmed.

Executive functioning, then, clearly impacts many different facets of day-to-day life including cognitive, social-emotional, and behavioral elements. Executive dysfunction (EDF) can manifest as poor planning and organization, difficulties with problem-solving, perseveration, and inflexibility (Anderson 1998). For example, children who have deficits in organizing their materials and initiating a task at school may otherwise appear unmotivated or oppositional to a teacher who is not aware of his or her difficulties. With regard to social situations, a child with EDF who has trouble regulating emotions or inhibiting responses to peers may have a harder time picking up social cues in the environment and, as a result, demonstrate poor social cognition and perspective taking (Anderson 2002). This can lead to significant amounts of frustration, anxiety, and disappointment for the child diagnosed with an autism spectrum disorder as well as his or her teachers, and family members.

Executive functioning skills essentially aid in our problem solving abilities so that we can strategically approach a situation to achieve desired goals. They are necessary

see Executive Functions on page 40

Housing from page 1

While *Olmstead* is a powerful sword for people with disabilities who reside in institutions, it cannot be used to compel development of community based housing for those living in non-institutional settings. Thus, many states inspired by *Olmstead* have developed Medicaid home and community based waivers that cover Medicaid recipients in or at risk of institutionalization to help fill that gap. The Medicaid waiver program is one way to assist individuals with ASD “at risk of institutionalization” with supports needed for community based housing. Section 1915 (c) of the Social Security Act enables states to request a waiver of applicable federal Medicaid requirements to provide enhanced community services. Only Pennsylvania has a Medicaid home and community based waiver for adults with ASD at risk of institutionalization. All other waivers involving ASD are for children only.

Thus, *Olmstead* and the Medicaid waivers may ensure that a large number of people with ASD can secure supportive housing in the community. In 2009, the University of Minnesota’s Research and Training Center on Community Living reported that over half a million individuals with an ID/DD receive Medicaid Home-Based and Community Services, six-times the number of individuals in Intermediate Care Facilities. However, many people with ASD will not qualify because they are too high functioning and thus are not Medicaid eligible through SSI or are not at risk of institutionalization. Yet, to implement the spirit of *Olmstead* all people with ASD and other disabilities

should have the right to live in the community and the right to self-determination.

Pennsylvania has been a leading state concerning the development of housing options for individuals with ASD. Not only is it the only state to have the ASD adult waiver, the Department of Public Welfare’s Bureau of Autism Services has created the Housing Options Committee. This committee was charged with identifying housing options to ensure independence upon the transition to adulthood, through the concept of “accommodated living.” This general concept involves providing supports to individuals who wish to live as independently as possible and avoid institutionalization. Accommodated Living requires development of an individual plan with a person’s support team (house team, behavioral consultant, provider training). In April 2010, the Committee issued a Housing Report, identifying 22 housing models, with funding information that could be applied to individuals with a range of developmental and intellectual disabilities.

In addition to the Medicaid waiver, other funding options introduced to ensure affordable housing, include, but are not limited to: the Housing Choice Voucher; HUD Section 811 funding; Section 211 funding; rental subsidies; project based rental assistance; housing trust funds; and refinancing options. Public housing authorities, local government, and nonprofit organizations that receive federal funding can use these funds to develop rental housing or supportive programs to provide affordable housing for adults with disabilities. Under HUD’s Section 811 program, nonprofit organizations can develop rental

housing for low-income adults with disabilities and provide rent subsidies. To ensure the affordability of housing and community services, the HOME program was created in 1990 to support the state and local housing programs, and states also have the option of creating a housing trust fund in which revenues from taxes or fees are collected to develop and support affordable housing. Also, according to the Bureau of Autism Services in PA, people with disabilities generally have priority in receiving Housing Choice Vouchers. Furthermore, a low income housing tax credit is available to owners of affordable rental housing and provides incentives for creation of such units. (Bureau of Autism Services Housing Report, April 2010).

The challenges for developing housing options are not limited to funding, but also to ensuring that models address the specific needs of adults with a specific disability. For example, adults with ASD may require different housing structures than adults with conditions such as cerebral palsy or spina bifida: “Some adults with autism might require housing that limits light or noise to accommodate sensory sensitivity. Some might need relatively secluded housing to address socialization issues, while others may need shared housing to accommodate live-in aides or require ready access to public transportation or medical facilities.” (*Developing New Housing Options for Adults with Autism*, Pennsylvania Department of Public Welfare (Apr. 23, 2010)). One way to experiment with housing is through the development of pilot programs (e.g. Autism Pilot Program). Thus, efforts to create independent living housing (rather than group homes where people with dis-

abilities are only living with others with disabilities) continue.

As the population of adults with ASD skyrockets, the need for creative housing solutions will soar. Yet, *Olmstead* may only help a minority of these adults. Legislative, not litigative, solutions must be developed that capture the spirit of *Olmstead* and the ADA in state legislation. Only by creative advocacy can we create an array of housing options for all adults with ASD.

In addition to being a proud parent of an adolescent daughter with ASD, Sheryl Dicker, JD is Assistant Clinical Professor of Pediatrics and Family and Social Medicine at Albert Einstein College of Medicine, the Children’s Hospital at Montefiore, Rose F. Kennedy University Center for Excellence in Developmental Disabilities. Sheryl has been working for over three decades as an advocate on behalf of those challenged by developmental disabilities, poverty and the child welfare system. Sheryl was appointed by President Clinton to the President’s Committee on Mental Retardation and served as then Governor Clinton’s General Counsel of the Department of Human Services. Before joining the faculty at Einstein, Sheryl was the Executive Director of the NY Permanent Judicial Commission on Justice for Children (the nation’s first children’s commission based in the judiciary).

Kristina Majewski is the sibling of an adolescent with special needs and has a long history of advocacy for individuals with disabilities. Kristina is a law student at Cardozo Law School, Class of 2010 and is a LEND Law Student Fellow at the Einstein College of Medicine.

the lighter side of the spectrum: a mom's view

By Carrie Cariello



My Paper Boy

On paper, my son Jack looks like this:

- He was born on May 9th, 2004
- He stands 53" tall and weighs 62 lbs
- He takes a size 3 shoe
- His eyes are blue and his hair is light brown
- His left pupil is larger than his right; the result of a harmless congenital condition known as Horner's Syndrome
- He is diagnosed with autism

On paper his diagnosis looks like this:

- Limited verbal skills
- Little eye contact
- Lack of sociability
- Obsessive behavior
- Inability to interpret social cues from others



I remember attending Jack's very first IEP meeting in Buffalo, New York and listening to the entire group of therapists and teachers refer to him as "child." "Child has limited verbal skills." "Child needs visual cues to communicate." "Child is self-directed." It went on and on until I wanted to light each one of my eyelashes on fire and dart from the room. But what I wanted to do even more was shriek things like, "His name is Jack! He is two years old! He's really cute! And he loves Cool Whip!" From that point forward I resolved to never reduce Jack to a paper boy, but instead to spring him to life in all of his autistic glory.

What his paper description doesn't tell you is that he was born on Mother's Day after a fairly easy labor. He battled countless ear and respiratory infections from the time he was an infant, and eventually got tubes in his ear drums and his adenoids removed. (Also not on paper: when a child has their adenoids taken out and the doctors warn you they will have a terrible odor, it's true. He smelled like a squirrel crawled into his throat and died.)

As a toddler he used to laugh uncontrollably at a particular Baby Einstein video and became attached to a stuffed bunny - named Bunny - that he still

sleeps with today. His first word was "ball" and it came shortly before his second birthday. From very early on he was capable of sly - if skewed - manipulation ("Mommy, a cookie feels my throat better").

A paper explanation doesn't begin to describe what his diagnosis means in everyday life. That looks like this:

- *Limited verbal skills* - Throws enormous tantrums and rages until someone in the house figures out he wants juice. When he was a toddler this could take up to 45 minutes, countless tears from several people, and a lot of banging on the refrigerator.
- *Obsessive behavior* - As a baby he could trace the same grout line on a tile for 45 minutes. When he was a toddler he wanted to watch the same DVD over and over. Now he alternates fixations between cars, birthdays, and the wind chill factor.
- *Little eye contact* - He never seems to be listening when you talk, and as he gets older we spend a fair amount of time commanding him to look at us in the eye when we speak.

see *Paper Boy* on page 42

Accessing and Understanding SSDI and SSI Benefits

By Michael Guerriero
Social Security and SSI Consultant

One of the great mysteries in American governmental programs, second only to Medicare/Medicaid, is SSDI and SSI. While they are wonderful programs, keep in mind Congress implemented them - hence the confusing names and acronyms. I leave it to others to ponder if the confusion was on purpose or just accidental.

Social Security Disability Insurance

Social Security Disability Insurance (SSDI) is part of the Social Security Program. It is a social insurance program dating back to 1937. Funded by the beloved FICA tax, which all non-Federal workers have to pay. It is in effect a Social Insurance program. By paying income tax, workers contribute to it. If an individual (not the parents) has paid enough FICA tax through the years, and then becomes permanently disabled, he/she can receive SSDI benefits. The Social Security Administration also provides Retirement, Survivor and Medicare (not Medicaid) benefits.

The important point to make is that Supplemental Security Income is for people who have not paid social security taxes through work. Social Security Disability is for people who have worked,



paid taxes and collected enough credits to retire early due to becoming disabled.

If a parent is receiving Social Security Disability or Social Security Retirement benefits, then his/her child (under the age of 18) can also receive benefits, whether or not he/she has a disability. After age 18, the child can then apply as a disabled adult (if he/she has a qualifying disability) on the parent's record, if a parent is receiving a Social Security Benefit.

Supplemental Security Income

Supplemental Security Income (SSI) is provided by the Federal Government. This is a federal assistance program for

people who are disabled, blind or aged 65 or older who are US citizens or legal residents (green card holders only) who have little or no income or resources. Children under the age of 18 who have autism spectrum disorders, cerebral palsy, or other developmental disabilities are generally eligible for SSI benefits if their parent's income and asset levels fall within the federal poverty guidelines.

Here, the issue is not the child's disability, but the parental income. Parental income and resources (assets) are counted against the children in deciding their eligibility. Your assets and income are considered your child's income and assets.

Once your son or daughter reaches age 18, the rules change. Your children are considered adults under the program and your income and resources no longer count against them. Now, only their income and resources count. If they have no income and no resources then they are eligible to apply and the only issue is the disability issue. In this case the question becomes, "Does the condition they have meet the Federal standards for Disability?"

If your son or daughter is approved for SSI, he or she will be entitled to a monthly payment of \$472.00. Perhaps more importantly, Community/Managed Care Medicaid (not Medicare) coverage will be automatic. There will be no need for you to contact the county or go to any office. The Medicaid benefit card will be mailed out as soon as the SSI system notifies the Department of Social Services. Lastly, your child will receive a food stamp benefits card. The amount, I believe, is for \$25.00. So it is worth the time and effort to apply regardless of the bureaucratic process you have to go through (see below).

The Application Process

Now that you know all about the benefits, you probably want to know how to apply for SSI. You can begin with SSA's toll free number (1-800-772-1213) where you will receive some information from an agent over the phone. Or, you can go to the

see *Benefits* on page 37

Overview of Vocational Rehabilitation Services for Individuals with Autism

By **Scott W. Standifer, PhD**
Disability Policy and Studies
University of Missouri

There is growing anecdotal evidence of a lack of awareness within the autism community of available vocational rehabilitation (employment) services. Among those who do know about these services, there is also evidence of some misinformation and skepticism.

Vocational rehabilitation is a nationwide network of state agencies whose goal is to help individuals with physical or mental disabilities achieve career-oriented jobs (with competitive pay) and live independently in their community. These agencies provide or coordinate supports including counseling, medical and psychological services, job coaching, higher education, job training, job placement and other individualized services – anything to help the individual get and maintain employment. Research has consistently shown that for every dollar spent helping people with disabilities get employed and live independently, federal, state, and local governments get back \$7 in taxes and savings on other disability services.

Each state has a state VR agency and most cities and towns have at least one office of trained VR counselors. Nationally, VR agencies employ more than 9,000 staff. These offices, in turn, pay



Scott W. Standifer, PhD

for contracted support services from local community rehabilitation service providers to achieve the goal of helping people with disabilities get jobs. There are at least 8,000 of these providers nationwide, employing approximately 160,000 staff. Each year the VR system helps more than 200,000 people with disabilities find jobs.

This network is overseen by the Rehabilitation Services Administration, within the U.S. Department of Education, which monitors, advises, and partially funds the agencies.

The legislative basis for the VR system is the Rehabilitation Act of 1973. This act stands, with the ADA and IDEA, as a cornerstone of U.S. federal policy toward people with disability. In particular, the Rehabilitation Act states, in part:

“Disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society”

“The goals of the Nation properly include the goal of providing individuals with disabilities with the tools necessary to make informed choices and decisions; and achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self-sufficiency, for such individuals.”

It is the policy of RSA and VR that: All individuals with disabilities are presumed to be able to work, no matter how significant their disability. It is a matter of having appropriate supports. The appropriate outcome for a person with a disability

is employment in a career-oriented job; matching the person's interests and abilities, in a community setting, with non-disabled co-workers, and with competitive pay. Anything less is not considered a successful VR service outcome.

The Vocational Rehabilitation Process

Eligibility - VR services are available to any U.S. citizen with a significant disability who wants to work but finds opportunities limited because of a disability and who requires VR services to become employed. A significant disability is one which impedes activities of daily life and creates employment barriers.

Vocational Counseling and Guidance - Each person with a disability (the client) is paired with a vocational counselor. Together they identify a career goal for the person. RSA regulations require that this goal be a community-based job (preferably career-oriented) with a competitive salary, in a setting working with people without disabilities. The VR system does not believe that sheltered workshops are acceptable employment outcomes.

Based on the career goal, the counselor and client select the services the client needs to reach this goal. To determine what services the client needs, the counselor talks with the client about abilities,

see Vocational Rehab on page 39

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by hitting, kicking or knocking over furniture, or by walking out of a building. These children have poor social judgment as well as poor emotional control, so they use threatening language without appreciating the consequences. To formulate an appropriate response, the behavior needs to be understood in the context of the AS presentation, especially how the child is processing the situation. Behavioral plans focused on eliminating behavior through automatic application of increasingly negative consequences can have the impact of rigidity meeting rigidity, an ineffective way to teach cognitive flexibility and adaptive skills for self-control.

Bruce was in a 6th art class where several students frequently teased him. One day, the children were issued Exacto knives for an art project. When the teacher left the room, the teasing grew intense. Bruce gestured with the knife to a girl near him. The teacher learned of this gesture and told Bruce not to repeat it. A few days later, the same situation recurred. When some other students started talking, Jason assumed it was about him, held up the knife and said something that was taken as threatening. This second time resulted in a warning. Bruce's mother was told that the school was calling in an expert to deal with the situation so that it would be handled appropriately. The next day, however, the teasing started again. This time, Bruce told the girl nearby, “You don't have to worry. If I were going to kill anyone, it would be me.” The girl again felt threatened and



Marcia Eckerd, PhD

reported the incident to her father, who pressed the school to file charges. Bruce was charged with the felony of Risk of Injury to a Minor, as well as two misdemeanors. The Juvenile Prosecutor agreed to a non-judicial disposition of the charges, taking into account Bruce's disability, but stipulated that if Bruce faced charges again within the year, the original charges would be reinstated. This is exactly what happened when the school reported Bruce to the police for making threatening statements again, after a day of what he perceived as harassment from his teachers.



Andrew Feinstein, Esq

With both Jason and Bruce, the child's inability to understand and navigate the social situation was met by the school's inability to understand and manage a student with Asperger's Syndrome. Teachers may know that a student is diagnosed with AS, but fail to understand that behavior in the classroom is not primarily attention seeking or oppositionality. A student can be very concrete in his questions or blunt with his comments, which can be seen as having an “attitude.” There may be a myriad of triggers: feeling shamed, being told to do a particular kind of task, such as writing, or the actions of another student,

even those not intended to be provocative, such as tapping a pencil. A student can tolerate something one day and not the next because he's tired, hungry, upset by some prior event, or simply having a bad day. This variability can be perceived as proof the behavior is intentional and provocative. Teachers may not understand the hypersensitivity of students with AS to treatment that they perceive as unfair and humiliating. They do not get the tendency of these students to perseverate on the idea that the teacher hates them. Many AS students face an academic Catch-22; they're twice exceptional, very bright but also learning disabled. They find resource rooms beneath them, which they take as condescension, but feel humiliated when they cannot perform at their intellectual level in regular classes, especially if the teacher points this out in class.

These students usually perceive the behavior of others with concrete, “black and white thinking,” failing to appreciate the viewpoint of others. Once they believe someone is against them, they cannot let go. Teachers can become frustrated with these behaviors and at times respond critically in front of the class, fueling the fire of the student who feels unfairly singled out and humiliated. The AS student may have little understanding of the role his own behavior plays and of the applicable social norms.

Federal law guarantees children with disabilities a free appropriate public education in the least restrictive environment. For any child with a suspected disability, the school needs to evaluate, determine

see Kids on page 34

The Man Who Understood Autism When Nobody Else Did

A Tribute to Leo Kanner

By Irene Slovak Kleiner, MS
Mother of an Adult with Autism

In 1956, my younger son was born. He was about five years old before we finally found a name for the problem he had. We had visited many professionals and asked them to diagnose his condition and tell us what we could do.

"There is no name," most of them said, "and the only thing to do is to put him into a State Hospital." We refused to do that.

But there was a man who was doing something in those years. We did not know about him at the time - nor who he was or what he was doing. But he had a profound effect on our lives and on the lives of every family with an autistic child. He was the first researcher who understood autism as a distinctive brain-related syndrome, and his work was the basis of all subsequent research and practice in helping individuals with autism develop and live independently. He was also the man who popularized the word "autism" to refer to this syndrome, and thereby distinguished it enough that people could focus on specific treatments for it. His name was Leo Kanner, MD

Kanner was born on June 13, 1894 in Klekotow, Austria. He grew up in a Jewish community, in which his primary edu-



Irene Slovak Kleiner, MS

cation took place at a Cheder (traditional Jewish school), as well as an ecumenical secular school. He was an extraordinary student and began to write poetry when he was about 10 years of age. He received his MD degree in 1921 from the University of Berlin.

Because of the growing political instability in Germany, a friend persuaded Dr. Kanner to accept a position in the United States as Assistant Physician at the State Hospital in Yankton, South Dakota. He arrived in 1924. During the next few years, he studied the English language in order to publish some of his thoughts on psychiatrics.

In 1928, Dr. Kanner applied and was accepted for training as a psychiatrist. At the end of his three year fellowship he was given a position at Johns Hopkins University Hospital. He set up and oversaw a child psychiatric unit - this started the changes that brought a completely different perspective on the relationship between a doctor and a child patient.

In 1935, Kanner wrote his first book, *Child Psychiatry*. This was the first English language text book on child psychiatry. His book emphasized a need for a full description of the child within the context of family and environment - before suggesting diagnoses and interventions. This gave clinicians a method with which to understand the problems of an autistic child.

A child psychiatry service within the pediatric hospital was set up for Dr. Kanner. The examining room was equipped with a washstand and table for an office. The doctor then set out to work with young children who had behavioral problems.

Dr. Kanner found a group of 11 children between the ages of 2 and 8, and saw them periodically for the next twenty-eight years. At the beginning, Dr. Kanner set the interview with each child individually, and established a rapport between patient and Doctor. The two carried on a conversation where the child was at ease and could speak without criticism.

After choosing and working with his initial small group of 11, he brought together a larger group of 55 children from whom he could get a wider range of information. Later, he found other large groups of children from whom he would monitor behavior patterns and other information. He worked steadily as a researcher until his death at age 86 in 1981.

Over time, Dr. Kanner created a new methodology for working with these types of children. In treatment, he spoke directly to the child, using the child's words to formulate any definitive diagnoses. Dr. Kanner used the child's exact words in naming the symptoms.

He also made a great contribution in his writing. Dr. Kanner kept notes on each of the children. He referred to each by the case number in his notes. The final report that carried material regarding each child was entitled, *Autistic Disturbances of Affective Contact*. He ultimately wrote eight books and 300 articles about his work. Most of his books are still being used as

see Kanner on page 43

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FIFTY YEARS WITH AUTISM

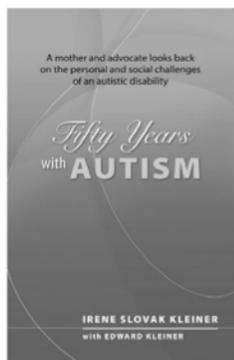
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The IEP Process Through a Parent's Eyes

By Amanda Watson, MSW

My daughter was diagnosed on the spectrum while I was studying for my Masters in Social Work. As for all parents who receive this seemingly devastating diagnosis, we had to cope and learn what this meant for our daughter and our family. As I was enrolled in a Master's program, I took it upon myself to begin teaching myself as much as I could about the diagnosis and treatment. I was able to use my schooling as a way to educate myself and my family about our daughter's diagnosis. The information that I have gathered has been invaluable but also enlightened me to what it feels like to be on both sides of the equation.

Free Appropriate Public Education (FAPE) is mandated by federal law and is typically termed Special Education. The two laws that mandate FAPE for all children are Individuals with Disabilities Education Act (IDEA) 1975 and the No Child Left Behind Act (NCLB) 2002. These laws state that school aged children with disabilities are entitled to adequate and individualized specialized education at no additional cost to the parent or guardian.

A specialized education is guided by an Individualized Education Plan (IEP), but what does Individualized Education Plan (IEP) really mean? Parents are usually told that it is the way to obtain appro-



Amanda Watson, MSW

priate educational services for their children. This isn't a lie, but also not the whole truth. I will discuss our experiences in two different school districts regarding the IEP process in hope of enlightening families and professionals about what the IEP process should be.

The following is an account of our first IEP meeting regarding our daughter who is on the spectrum. Hopefully this account

is foreign to most, and not the status quo. The meeting consisted of the following individuals: School Psychologist, School Social Worker, our daughter's teacher, my husband and myself. The school psychologist briefly discussed his impressions of our daughter and made suggestions of what the school could offer her. He then handed my husband and I each an eleven-page document, briefly explained it, and told us where to sign.

The goals were cookie cutter goals such as: Child will meet kindergarten grade standards for reading habits. Looking back on this I am angry with myself for having signed off and not advocated more effectively for our daughter. However, this was our first meeting and we did not know what to expect. At the end of the meeting, I stated that I was concerned that our daughter would not be receiving occupational therapy. I was told that we had to request an Occupational Therapy evaluation and only the child's pediatrician could make that request. This meeting took place in October 2009. That same day I had our pediatrician fax a request for OT evaluation. It was not until February 2010 that our daughter was finally evaluated. I called the school psychologist almost weekly regarding the delay in the evaluation and was always told the same thing, "There are just so many children to evaluate; she will be evaluated as soon as possible."

We soon realized that this school dis-

trict was not the place for our daughter. We began to look elsewhere within the state for better school districts and began the process of relocation. Our daughter finished her Kindergarten year in this school, and luckily through the hard work of her teachers and my husband and I, she graduated kindergarten. We relocated during the summer months and began the process of enrolling her in a new school that we had researched and felt very comfortable with.

After registering our daughter for school and supplying the district with all of her evaluations and prior IEP, I received a call from the Assistant Coordinator for Special Education who stated that our daughter would have to go to a different elementary school in the district as the school we are zoned for did not have enough room in the Collaborative Teaching Classroom for our daughter. I immediately responded that we did not want our daughter to go to a different elementary school and asked if there was anything else that could be done. He called back within a few hours and stated that he had arranged a meeting with the desired school's principal and asked if we would be able to attend.

During our meeting with the principal and the Assistant Coordinator for Special Education we were able to present our daughter and highlight her strengths and

see *Parent's Eyes* on page 43

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IEP from page 14

Get a Feel for the "Temperature" of the IEP Team

If, during the IEP development process, the IEP team is meaningfully considering your requests and the recommendations from your child's providers, congratulations! You are in an excellent position to continue advocating for your child's needs. Continue to rely upon your evaluations to request all of the services and supports in the IEP.

Always Remain Open-Minded and Willing to Consider the District's Recommendations

Some school districts are not willing to consider additional services or recommendations for your child. In New York City, for instance, students diagnosed with autism spectrum disorders who require a full-time 1:1 ABA program and placement are rarely, if ever, offered such placement.¹ For NYC children, this means one of two things. On one hand, parents can place their child in a placement and program that is not appropriate. On the other hand, some parents elect to "unilaterally" place their child in an appropriate placement and program and sue the school district for reimbursement for tuition

and educational related costs.

During this "due process" lawsuit, the judge or hearing officer will analyze parental cooperation with their school district. Reimbursement cases are analyzed under the Burlington/Carter² analysis and address three questions. *Prong 1*: Did the school district offer the student a free appropriate public education (FAPE)? *Prong 2*: Is the parents' unilaterally chosen placement and program "reasonably calculated" so that their child can make "meaningful progress?" and *Prong 3*: Do the "equities" favor an award for the parents?

Recently, more than ever before, hearing officers and judges have placed a higher emphasis on Prong 3 – the consideration of the "equities" – in determining whether parents will prevail. Among other things, the hearing officer will look at whether the parents cooperated and acted reasonably with the school district. In fact, with respect to Prong 3, the U.S. Supreme Court has expressly held that "[C]ourts retain discretion to reduce the amount of a reimbursement award if the equities so warrant."³

Accordingly, this "equities" burden weighs quite heavily on parents who may need to sue their school district. No matter what happens during your IEP meeting, you

should always remain open-minded and cooperative with the IEP team and your school district. You can disagree without being disagreeable. If you sense that the IEP team is not meaningfully considering your child's evaluations and recommendations, you still must remain cooperative and act reasonably with your school district.

IEP season is, perhaps, the most critical time of the year for parents of students with autism. As parents, you must comply with your school district, act reasonably and cooperate at all stages of the IEP development process. At the same time, you must remember that YOU are the expert of your child. Many times, you know better than anyone else at the IEP meeting what your child requires in order to make meaningful progress. With evaluations and recommendations from your professionals supporting your position, you can feel comfortable politely but firmly advocating for your child and advising your school district what your child really needs. Cooperation may be time-consuming and tedious, but at the end of the day cooperation is key.

Maria C. McGinley, MST, JD (New York Law School, '10) is an Associate at Mayerson & Associates, a New York law firm dedicated to representing children

and adolescents on the autism spectrum, and assisting families in accessing the education and related services necessary and appropriate for students. Prior to practicing at Mayerson & Associates, Ms. McGinley taught students with autism spectrum disorders when she was a special education teacher for the New York City Department of Education.

Footnotes

1. In New York City, there is only one school that offers students full-time 1:1 ABA support. The New York Center for Autism Charter School admits students strictly by lottery, and very few students in New York City (less than 50) are fortunate enough to be selected. For a city with *thousands* of children with autism, there are simply not enough publicly funded appropriate placements and programs available.

2. The "Burlington/Carter" analysis is derived from Sch. Comm. of Burlington, Mass. v. Dept. of Educ. of Mass., 471 U.S. 359 (1985) and Florence County School District Four v. Carter, 510 U.S. 7 (1988).

3. Forest Grove Sch. Dist. v. T.A., 129 S.Ct. 2484, 2496 (2009).

Support for Parents and Progress for Children with Autism

By **Brian Goldberg, PsyD, BCBA-D**
Founder
United Supports for Autism



Brian Goldberg, PsyD, BCBA-D

Parents of children with autism are at the front lines of the challenges posed by autism. They are confronted with added responsibilities associated with parenting a child with autism. These parents are in the seemingly unending position of helping their child learn vital skills (e.g., social, language, etc.) and, in some instances, decreasing problem behavior. This task can appear insurmountable, while also tending to everyday household tasks such as making meals, doing laundry, cleaning the house, and shopping in the community. As a result, parents of children with autism can have increased stress levels. This stress can have a negative impact on parents, such as fatigue, heightened emotional responses, and giving “easy” responses to child problem behavior (e.g., giving a child candy in the supermarket when he begins to get upset). Stress can also affect the entire family. The anticipation of child problem behavior can lead to changes in daily plans or a restricted range of family activities. Autism has been recognized as breaking up marriages, draining bank accounts, and disrupting parents’ sleep. For parents, the circumstance might seem daunting, the challenges might seem great, but with

support, optimism, and collaboration with professionals, the potential for improvement is great for the child and the entire family.

Parents are in the best position to confront autism when they have support and they are not facing it alone. Support can come from a number of different sources, including family members, friends, support groups, religious affiliations, daycare,

and professionals. These supports can serve different purposes. The primary role of professional support is to teach children skills, address a problem area (e.g., behavior), and pass skills on to parents. There are often many professionals working with a single child with autism, both at home and at school. In order to work successfully with a child parents must be involved and incorporated on some level. Unfortunately, these efforts are sometimes uncoordinated. For example, teachers and/or other professionals often work with a child at home. When these professionals leave that child’s home, parents remain with their child. When parents are unaware of programs and the accompanying teaching procedures, learning opportunities will be lost. A united front between all stakeholders can bring about greater and faster success for a child with autism and his family than professionals and parents working separately.

We know that parents spend more time with their child than anyone else. We also know that children with autism have difficulty applying skills to other aspects of their life (generalization) and holding on to skills over a period of time (maintenance). Taken together, parental engagement as an active “teacher” throughout the day, every day, is critical for their child’s success. Parents need to be equipped to teach their child new skills, to practice recently acquired skills, and to decrease problem behavior. Behav-

ioral parent training helps parents manage the difficulties associated with autism by empowering them with tools to help their child become increasingly independent and to reduce their child’s problem behavior (if necessary). Based on behavior analysis, behavioral parent training provides parents with essential tools such as prompting, reinforcement, and fading. With proper knowledge and guidance, parents can use these tools to develop and implement needed supports to help their child without relying on a professional. For example, parents can develop and implement visual activity schedules and/or positive reinforcement systems after learning how to do so from behavioral parent training. Behavioral parent training would also enable parents to implement teaching procedures when their child returns from school or after professionals have left their home. The net result is that parents are active agents in teaching new skills and promoting generalization and maintenance of learned skills. Sure, parents playing an active role as a “teacher” can seem like another burden placed on an already full plate. In the short term, parents are likely to experience an added stressor to “teach” their child. In the long term, however, the payoff is great. Parenting is like an investment. The more time and effort put in now, the greater the returns later.

see *Support on page 43*

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agency will implement an “Order of Selection,” (known to most as a waiting list), based on three categories of need: priority one includes eligible people with 2 or more significant disabilities; priority two includes eligible people with one significant disability; and priority three is for people with non-significant disabilities (dwd.wisconsin.gov/dvr/knowledgebase/rsa_oos_fact_sheet.htm). An eligible person with strong intellectual abilities, who has Asperger Syndrome, may not get the time limited vocational services he/she needs to succeed. Eligibility for services does not equal obtaining services.

More and more young adults with Asperger Syndrome and college degrees have been told that they are too intellectually superior to qualify for adult developmental disabilities services, while at the same time, too socially impaired to get and keep a job independently. These young men and women are faced with entering the federally defined poverty level to apply for social services and Medicaid, or taking their chances as unemployed and uninsured citizens. Somewhere in between lays the crack.

Our current economic crisis and shortage of appropriate vocational services for people with Asperger Syndrome have provided new impetus to find and design other means of prevention. Newly formed and existing consumer driven groups, such as the Asperger Syndrome Training and Employment Partnership (ASTEP), are combining forces with voluntary agencies, universities, philanthropic organizations, foundations and civic minded companies to create jobs for motivated and able people who have an ASD.

ASTEP is taking a unique approach in creating employment opportunities for people with ASD by focusing on the significant benefits to corporations and other large employers. ASTEP’s primary goals are to train national employers about the benefits of expanding their diversity policies to include people with ASD and to work with companies to hire highly qualified job candidates with ASD into appropriate professional positions. ASTEP is looking towards vocational training/rehabilitation providers, and college support programs, to identify and prepare adults with ASD to fill these positions, and provide job site training for the employees’ natural sup-

ports (i.e. company managers/co-workers, etc).

ASTEP will draw on the extensive corporate and professional Autism support experience of its staff and advisory board to help national employers increase their bottom line, reduce costly turnover and recruitment rates, and enhance quality production by employing focused, dedicated, professionals who happen to have an Autism Spectrum Disorder. Innovation begins to fill the crack.

Susan Lesco has worked with people who have Autism Spectrum and other developmental disorders, and their families, for more than 25 years. She is currently the Director of Program Partnerships at the Asperger Syndrome Training & Employment Partnership (ASTEP), based in New York City. During her most recent tenure as the Director of Family Support Services at Stony Brook University Hospital Cody Center for Autism, Ms. Lesco developed, implemented and directed their first NYS Medicaid Service Coordination program; wrote and co-directed grants including the Doug Flutie Foundation summer camp

inclusion program for children with Autism Spectrum Disorders; coordinated, wrote and presented curriculum for phase one of Parent Partners in Health Education, a demonstration project of the NYS Council on Graduate Medical Education and the NYS Department of Health, funded by the NYS Developmental Disabilities Planning Council; and participated in developing and directing the Stony Brook University Resource Center for Autism, funded by the Matt and Debra Cody family in 1998. Ms. Lesco also participated in developing and co-directing a unique college support program for community college students with ASD in Suffolk County, NY. She has published numerous articles, presented parent and professional training sessions, worked as a vocational rehabilitation instructor, parent support group leader, and residential program director. Ms. Lesco holds a Bachelor of Science in Community and Human Services, and a Master of Science in Health Policy and Management, with a focus on Community Health and Patient Education, from Stony Brook University Health Sciences Center.

Spectrum Services from page 9

CCC-SLP, Mitchell Nagler, M.A., LMHC, Michele Robins, Ph.D., Shuli Sandler, Psy.D., Ilene Solomon, Ph.D., Renee Soufer, M.A., Ed.M., and Beth Yurman, Psy.D.

In addition to this group of highly experienced professionals, three organizations also contribute their expertise to this effort. 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. Nicholas Villani, CEO and President, has long taken a leadership role in developing innovative services for adolescents and adults on the autism spectrum in the world of work and independence.

Asperger Syndrome Training & Employment Partnership (ASTEP) is a foundation whose mission is creating and supporting programs that promote employment for adults with AS in the corporate sector and training employers about the advantages and challenges of employing such individuals. After years of corporate experience in the

financial world, Marcia Scheiner, CEO, founded this effort and developed the concept of matching highly qualified individuals with AS to appropriate positions in concert with their abilities. By creating support for employers and partnering with community vocational support agencies, ASTEP creates a linkage that has not before existed. Michael John Carley, Executive Director, and Susan Lesco, Director of Program Partnerships, are building the new program.

Since 1988, Asperger Syndrome and High Functioning Autism Association

(AHA) has provided support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. The vast experience of this organization in developing creative supports and activities contributes to Spectrum Services' overarching goal of coordinating multiple approaches to improve the lives of those on the spectrum through increased awareness, knowledge, and evidence-based services.

To obtain information or contact the participants of Spectrum Services, please see the website at www.spectrum-services.com.

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from the special child herself, but only from third parties - parents, grandparent, other relatives - either by direct gift to the trust or an inheritance in a Will specifically naming the TP SNT as beneficiary.

It is also a good idea to let other family members know about the TP SNT. This way, if they planned to make a gift to the special child, or to leave something to the special child in their Will, instead they can make the gift to the TP SNT or name the TP SNT as a beneficiary in their Wills so as to avoid negative effects on the special child's eligibility for Medicaid.

The Self-Settled Special Needs Trust

Unfortunately, sometimes, the parents don't plan properly and the special child receives a gift or inheritance outright, causing her to lose Medicaid eligibility. In that case, it is too late to use a TP SNT; the child already has the money. However, all is not necessarily lost. It may be possible to set up a Self-Settled SNT, which is another specific type of SNT (sometimes called a d4A trust or a payback Trust) that can be used to hold the special child's own assets. The Self-Settled SNT is similar to the Third Party SNT except for two key differences: it should only be funded with the special child's own assets; and, when the child

passes away, Medicaid must be paid back from whatever remains in the Self-Settled SNT before distributions to the child's heirs (the so-called Medicaid payback requirement). The Self-Settled SNT can only be set up by a parent, grandparent, legal guardian or a court. Once set up, the child's funds are transferred into the Self-Settled SNT and the assets are no longer counted red as the child's assets and income, just like in the TP SNT.

Conclusion

Remember that, unlike the Self-Settled SNT, the Third-Party SNT would not contain a Medicaid payback provision. The Medicaid payback requirement of the

Self-Settled SNT makes it a much less desirable option than the TP SNT. It is far better to create the TP SNT to receive gifts and inheritances from third parties, rather than having the special child receive the money outright, then scrambling to set up a Self-Settled SNT with the Medicaid payback requirement. By proper use of the TP SNT, Medicaid eligibility is preserved from the outset, and then whatever is left in the TP SNT when the special child passes away can pass to anyone specified in the TP SNT (such as the child's siblings or a favorite charity), without having to pay back Medicaid first.

An ounce of prevention is truly worth a pound of cure.

Kids from page 30

the child's areas of need, draft measurable annual goals to address those areas of need, and provide educational programs and related services to meet those goals in a document called an Individualized Education Plan (IEP). Where the child has behavioral issues, the IEP should mandate a functional behavior analysis (FBA) leading to a behavior intervention plan that uses positive behavior interventions and supports.

Misbehavior is an inherent part of disability and particularly of children on the autism spectrum. Congress passed the predecessor to the Individuals with Disabilities Education Act (IDEA) in 1975 to ensure that states could not exclude children with disabilities from their neighborhood schools. In 1988, the Supreme Court made it plain that "Congress very much meant to strip schools of the unilateral authority they had traditionally employed to exclude disabled students, particularly emotionally disturbed students, from school" (*Honig v. Doe*, 484 U.S. 305, 323 (1988)). Simply put, disabled students are not supposed to be punished or expelled for their disability.

School response to misbehavior of an AS student should be proactive rather than reactive. An FBA looks at the antecedents to the behavior, both interpersonal and environmental, as well as the effectiveness of consequences imposed. A good FBA generates hypotheses as to the triggers or the function of the behavior to the child. The accuracy of the hypothesis is determined by measuring the success of the intervention by manipulating antecedents. The FBA should result in a behavior intervention plan that both minimizes triggers and equips the student with adaptive skills. The reality, sadly, is that few school districts are capable of administering an FBA, opting to fill out meaningless checklists instead. The statutory mandate for positive behavioral interventions and supports is frequently violated as school administrators think that increasingly severe sanc-

tions, such as suspension, expulsion, or police referrals, are the way to extinguish maladaptive behavior.

Due to inadequate resources, schools often lack trained personnel to supervise situations where provocations are taking place, to design nuanced accommodations of classroom demands or to embed coaching in self-calming or social skills to help the student develop more appropriate behaviors. In Jason's case, the behavioral consequences that were supposed to extinguish unwanted behavior exacerbated them. In Bruce's case, the lack of appropriate supervision set him up for predictable failure. Both children suffered the trauma of being subjected to police intervention and the juvenile justice system.

Honig v. Doe held that a school could not expel or change the placement of a disabled student without parental agreement or a court order. In 1997 Congress added a manifestation determination process to the IDEA. If suspension for longer than 10 days or expulsion were to be considered as a consequence for misbehavior, the child's IEP team needs to meet to determine whether the behavior was a manifestation of the child's disability. Even for children not identified as eligible for special education, the school district has to hold such a meeting if it had reason to know that the child might have a disability. The IEP Team (including the parents) must review all relevant information to determine if the conduct was caused by or had a direct and substantial relationship to the child's disability, or if the conduct was the direct result of the school's failure to implement the child's IEP. If so, the child should not be subject to discipline in the same manner as a non-disabled child. For children on the autism spectrum, the expert opinion of a psychologist or psychiatrist is needed to determine if the behavior was a manifestation of the child's autism. This is critical for parents to understand: in a manifestation determination, parents need a strong and articulate expert.

In Bruce's case, the police were called due to the "three strikes you're out" rule

concerning threatening behavior. Bruce should not have been subjected to the same disciplinary rules as a non-disabled child. The school should have identified triggers to his behavior and provided safe options when he was provoked.

By calling the police and referring a child to the juvenile justice system, schools circumvent the manifestation determination requirements. Generally, police, prosecutors and juvenile judges disapprove of these referrals except in the most serious cases of personal injury or property damage. Sometimes, juvenile probation officers are willing to work with the family to press the school to provide needed services for the child, because such services are unavailable to the court. Parents whose children are arrested need to stress their child's disability and the obligation of the school to deal with it.

In dealing with schools, parents should be careful to communicate in written form so there is a clear record. Email works wonderfully because it is not as formal or off-putting as a letter, but still makes a permanent date stamped record of all correspondence. Parents need to rely on mental health professionals to make an explicit connection between the child's behavior and the disability. Schools should have stronger educational programs for school staff so that these connections are better understood and behavior plans are better devised. Increasingly, the challenge is insufficient resources.

Parents should be aware that misbehavior is a predictable part of being on the autism spectrum. Children should not be punished for having a disability. None of us want children to be explosive, rude, and misinterpret the behavior of others. Yet, we have the right to demand that the school has sufficient understanding to reduce the triggers for misbehavior and to teach the student how to adapt. This is a long-term process and results depend on both the interventions and the child. With

education and understanding, the risk can be reduced and positive development enhanced. However, even the best behavior plan will not guarantee good behavior, so it is important that parents know the systems that exist to protect their children.

Dr. Eckerd is a licensed psychologist working for over 25 years with children, teens and adults with Asperger's Syndrome, Nonverbal Learning Disabilities and PDD NOS. She provides therapy, neuropsychological evaluations, social skills coaching, and consultations for parents, schools, advocates and attorneys. She is a licensed psychologist on the National Register of Health Service Providers in Psychology, a resource clinician on OASIS/MAAP (Aspergers.com) as well as NLDline.com, a professional board member of CT Association for Children with Learning Disabilities and Smart Kids with LD, a member of the Council of Parent Attorneys and Advocates (COPAA). Her blog, "People Skills" is found on PsychologyToday.com.

Andrew A. Feinstein has represented children with disabilities and their families pursuing appropriate educational programs for the past fifteen years, first in Hartford with David C. Shaw, and since 2008, as a solo practitioner in Mystic, Connecticut. He is co-chair of the Amicus Committee for the Council of Parent Attorneys and Advocates (COPAA), the pre-eminent national special education advocacy organization and an adjunct professor of special education law at Central Connecticut State University. Attorney Feinstein was graduated from Wesleyan University in 1972 and the New York University School of Law in 1975. He completed the Senior Manager in Government Program at the Kennedy School, Harvard University, in 1983. He has served as a professional staff member of the House Committee on Armed Services and Chief Counsel of the House Civil Service Subcommittee.



Robin's Voice

A Resilient Mom's Commentary on Autism

Your Child is Approaching Adulthood - Navigating Transitions

By Robin Morris
Freelance Writer

There is an old adage that I do not subscribe to: "Little kids, little problems; big kids, big problems." My faith in human nature and the power of trial and error gives our typical children the ability to decipher what's right and wrong. They may confront some significant bumps along the road, but there is certain buoyancy implicit in growing up. It is what our children choose to do with that gift that can make the difference.

There are certainly no guarantees, however having a "leg up" is simply a profound gift.

The autism community has navigated a less traveled road, for many years. Thousands of parents have been pioneers, searching, experimenting and ultimately begging for advice. What happens to the "bigger" children with autism? Does the old adage apply in this arena? It is a bigger problem, because there is no precedent for the growing population of children with autism.

Autism Speaks has made it a priority to guide parents along this tenuous journey. The 100 Day Kit (www.autismspeaks.org/community/family_services/100_day_kit.php) is a valuable tool in helping parents move



Robin H. Morris

forward, during the most critical days following diagnosis. The School Community Tool Kit (www.autismspeaks.org/community/family_services/school_kit.php) was designed to support administrative staff in helping students on the autism spectrum, both academically and socially, as they interact with the community as a whole.

Finally, Autism Speaks has now launched the "leg up" for individuals with autism, as they transition from adolescence to adulthood. The Transition Toolkit (www.autismspeaks.org/community/family_services/transition.php) can be downloaded for free. Be mindful that although the journey may be quite different for each family, the goal is the same. An excerpt from the introduction draws you in, as a parent, an advocate and a hopeful partner in ushering your child towards independence:

"We know that the future can seem uncertain for an adolescent with autism. After years of intervention, you are not alone in hoping that the autism diagnosis may have been altered by now. As a parent or guardian, it may be hard for you to imagine your child out in the world, or what he or she will do once the school bus is no longer arriving each morning. Some parents find the thought of the transition process overwhelming. Like many parents or caregivers, you have worked hard to obtain services and supports for your child with autism. Many families have spent years researching, negotiating, and advocating for these services and supports in order to maximize their child's potential. The thought of doing this again with a whole new system can

seem daunting. It is at times such as this that you may want to take stock, look back, and calculate all of the strides that your child has made. It is also important to take the time to reflect on how much you have learned and how vital it is to be proactive. It is with this energy that you will move forward in the transition to adulthood.

Before you begin the journey into the transition process, it may be helpful to recognize that others have traveled this road. A significant amount of information has been collected, and while the process may have been trial and error for some families, valuable information has been gleaned. Additionally, experts in the field have researched and investigated the process. We have compiled a great deal of this information and many of these resources into this kit. The best news is that autism awareness is continuing to generate more opportunities for growth in the transition process, which can lead to more opportunities for young adults with autism to live independent and fulfilling lives."

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

ADA from page 18

auxiliary aides or services, or require reasonable accommodation for that examination such as a time extension, alterative test format, alternate test setting, or other accommodations. For example, a college and test organizations such as the College Board, can request documentation of a disability if that request is reasonable and limited to the need for the requested test or exam modification and/or request for a reasonable accommodation. Such documentation could include a student's recent IEP, Section 504 Plan, and/or a history of receiving past accommodations, modifications, or auxiliary aides and services in the test or exam setting.

The author had recently represented a medical student with some mild to moderate learning challenges who had requested a reasonable accommodation in the form of an alternate test setting and time and one-half for a medical licensing exam. The student had received these accommodations since he was a student in high school and he had them in place at his college and medical school, as well as receiving these accommodations on the SAT, and MCAT exams. However, the private organization that administered the medical licensing exam had questioned whether the student had a disability and whether

he demonstrated any need for any accommodation, despite several evaluation reports and letters from the student's high school, college, and medical school that supported the applicant's request for test accommodations. Nevertheless, the organization wanted even more information and when the applicant had submitted a current assessment report establishing his disability and need for test accommodations, his request was still denied. Clearly, if the Department of Justice's regulations had been in effect, the student would not have encountered the obstacles outlined and his request would have received more favorable consideration by the private test organization.

Other changes in the *ADA Amendments of 2008* and revised regulations include the requirement that public or private entities, such as public and private schools, and post-secondary institutions, must allow an individual with a disability to take their service animals into such facilities provided that the service animal is under the control of its owner or handler and that the animal is "housebroken." In addition, public or private entities must allow a person with a disability to utilize manual and powered mobility devices such as walkers, manual wheelchairs, power wheelchairs, etc., absent legitimate safety concerns, that is, a legitimate safety

concern that is based upon an actual risk and not speculation. A public or private entity has to ensure that its communication with individuals with disabilities is as effective as the communication provided to individuals without disabilities. This requirement also applies to telecommunication equipment. Therefore, the public or private entity cannot request the individual with a disability, their companions, or family members to provide interpreting services, as a form of accommodating the individual's communication needs.

Public and private entities have been obligated to provide auxiliary aides and services to individual with disabilities since the 1990 ADA enactment to ensure an equal opportunity to participate or access the programs, activities, and services. However, with the *ADA Amendments of 2008*, the public or private entity must now give *primary consideration* to the request of the individual with a disability for the type of auxiliary aides and services that are to be provided, rather than providing what is available.

There are many changes to the ADA that are too numerous to cover with this article that will ensure physical, programmatic, communication, and other forms of equal access to employment, places of public accommodations and public entities and eliminate most forms of discrimination and unequal access.

The U.S. Department of Education is also reviewing the *ADA Amendments of 2008* in order to determine if the Section 504 regulations require any revisions in order to ensure that federal fund recipients such as public schools, local and state governments agencies and private schools and colleges, are covered by both sets of federal laws and regulations.

If you or a family member believe that you have been a victim of discrimination or that your rights are being denied by an employer, public entity, or place of public accommodations due to the existence of a disability, then do not delay and you should contact a knowledgeable attorney or any local, state or federal civil rights agency for information on your rights that are applicable to a specific set of circumstances, and if appropriate, whether to file a complaint in order to protect your rights. The *ADA Amendments of 2008* and the implementing regulations have restated the Congressional intent from 1990 on the individuals who should be covered by this law, the protections from discrimination, and the obligations of public and private entities to accommodate the needs of individuals with disabilities and to remove barriers that exclude or tend to exclude people with disabilities

see ADA on page 43

Training from page 12

- Do not apply pressure to the individual's back while prone
- Most importantly, do not keep this individual face down

There is a dynamic and ever changing landscape for individuals with autism. As individuals with autism are successfully integrated into community life, the first responder will undoubtedly be called to service and face situations of direct interaction with individuals on the autism spectrum.

According to The Center for Disease Control and Prevention (CDC), the current prevalence of autism in the nation is 1 in 110. In New Jersey that statistic is 1 in 94 and it is startling and worrisome to know that in New Jersey 1 in 67 boys will be diagnosed with an autism spectrum disorder.²

The reality on the ground is that first responders of all types (police, firefighters, EMT's and paramedics) will be on the front lines responding to calls for service which involve individuals on the autism spectrum.

Another part of first responder training which is vitally important to highlight is that, in any group of first responders, there will be those who are, or will become, parents of children with autism. In any training, it is vital to talk about the early warning signs of autism and give first responders the facts of what to look for in children. Whether we are welcoming new children into the world or we are welcoming grandchildren into our lives some of us will be caring for children with autism.

New Jersey Assemblyman Fred Scalera (D-Essex) sponsored Bill (A-1908) to establish an autism awareness training course that emergency medical technicians, police and firefighters are required to take. Scalera is also a fire chief in Nut-

ley, New Jersey. The law sponsored by Assemblyman Scalera required Department of Health and Senior Services (DHSS) to create an autism awareness training course and curriculum. Prospective emergency medical technicians are required to complete the Office of Emergency Management (EOM) administered course prior to receiving certification. Current emergency medical technicians are required to complete a continuing education course in "autism recognition and response techniques," as a requirement for recertification.

Bill (A-1908) was signed into law and authorized the development of a training program to assist first responders when encountering an individual with autism spectrum disorders. The online program, which is mandatory for all first responder's to complete by February 2012, can be found at www.njlearn.com. The online program is an important first step, but all first responders are also encouraged to continue their learning with a face-to-face course as well. In the face-to-face presentation the first responders can ask questions to the instructor and get more comfortable with the course material.

One aspect of first responders training which cannot be overstated is the importance of community outreach. It is important for all first responders in a community to take a proactive approach to identifying the special needs of all their residents. If the first responders know in advance who is residing in their catchment area they can then be proactive in providing a safer resolution to the call to service. However, this process of outreach must go both ways. Families caring for loved ones with special needs, including autism, must be responsible partners as well and take the time to identify the special needs of your loved one to the first responders in your community. For example, if you have an eloper (someone who wanders

away), have you asked the Fire Marshall to do a walk through in your home to give you suggestions on safely securing your home and property? Have you informed the fire department that you have a child or adult with special needs and detailed how they may react in an emergency situation? Have you taken your child to the police and fire station to introduce him/her to the officers to allow your child to recognize, know and trust the first responders in your community? Do the first responders know you and your family? If you have a child or adult with autism living in your home, go to the first responders and inquire whether they have taken any training courses in autism recognition and response techniques. If they have not, request that they do so.

There are many facets of first responders training which go beyond the recognition and response to emergency situations that need to be covered in any training program. Individuals with autism are not only often medically frail, but they may also be emotionally and physically vulnerable. These vulnerabilities make our loved ones amongst the most vulnerable in our society. Individuals with autism may be unduly influenced to commit an act which is unlawful as they try to please and be accepted by unscrupulous "friends." They may not recognize their rights under the law, especially in interrogation or the administration of Miranda rights. They may want to end a situation, such as an interrogation, and falsely incriminate themselves by admitting to crimes they did not commit. There are many areas in which the first responder must be aware of regarding the unique profile of individuals on all areas of the autism spectrum. Continuing training which deals with all aspects of emergency response and law enforcement must be provided in an ongoing and comprehensive manner.

In the State of New Jersey, meaningful

change happened when first responders were trained in the appropriate recognition and response techniques for individuals with ASD. This type of change is only possible when grassroots family-driven efforts are brought to bear on the legislative process. The delivery of service in a state can be affected in a thoughtful and positive manner, but only when stakeholders work together with their legislators to develop and utilize a well defined plan and process. Success means that the entire community participates in, and benefits from, these efforts.

Whether it is an eight year old boy with autism in Idaho or a 22 year old adult with autism in New Jersey, one person who is disregarded, handled improperly causing injury, falsely imprisoned or even caused to die is simply one too many.

B. Madeleine Goldfarb, MA is the Founder/Director of The Noah's Ark Children's Association and conducts First Responder's training in Autism Spectrum Disorders throughout the State of New Jersey. Ms. Goldfarb also serves of the New Jersey governor's Council on Research and Treatment of Autism. You may contact Ms. Goldfarb at noahsarkmail@gmail.com.

Footnotes

1. Pickett J.A., Paculdo D.R., Shavelle R.M., & Strauss D.J. (2006). 1998-2002 update on – "Causes of death in autism." *Journal of Autism and Developmental Disorders*, 36, 287-288.

2. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators; Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders--autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *MMWR Surveill Summ*. 2007 Feb 9; 56(1):12-28.

Behaviors from page 13

is important to consider that many sexuality rules are hidden or unwritten, making instruction even more complex.

Furthermore, we must alter our behavior depending on situational and social contexts. It is permissible to be naked at times, for example. Similarly, it is sometimes acceptable to be physically affectionate toward another person, but only if it is consensual. For individuals with ASDs for whom making discriminations in their behavior across settings and situations is already challenging, this added layer of complexity in navigating veiled social norms presents a whole new realm of difficulty.

When Things Go Awry

The worst circumstances encountered by individuals on the spectrum generally involve public displays of sexual behavior. It may be that individuals with ASDs are more vulnerable to these issues because of few other outlets, a tendency toward self-stimulatory behaviors, and poor social understanding (e.g., Dalldorf, 1983; Ruble, 1992). When socially unacceptable behaviors are persistent, serious consequences can result. Realmuto & Ruble (1999) reported on a case of an individual with autism who masturbated in front of children, which resulted in po-

lice involvement. Ultimately, the behavior was treated with hormone reducing medication and criminal charges were avoided but such cases raise ethical issues and concerns. How do we balance community protection and individual freedom? When may it be appropriate to restrict access to preferred sexual materials or activities?

A recent review of cases of offenders with Asperger Syndrome in the UK revealed that their experiences in the criminal justice system were very negative (Allen et al., 2008). The processes of arrest, investigation, and trial can be extremely challenging for anyone, let alone persons with limited insight and communication deficits. Difficulties may include misinterpreting what is told to them, misjudging what to reveal in a formal interview, sticking with an erroneous or incomplete description of what occurred once it has been presented, and misusing words to their disadvantage (Allen et al., 2008). These individuals have also been described as difficult to integrate into the prison environment and more vulnerable of exploitation once there.

Self-reports of offenders with Asperger's indicate being overwhelmed with information and unable to process all that is occurring. They also report feeling unsupported, disbelieved, and generally confused. Fairly universally, these individuals did not feel that their disability was considered by the justice system. Allen

et. al. (2008) summarize some strategies that could reduce the extent to which the legal process is negative and incomprehensible. These include presenting information about the process visually instead of verbally.

Perhaps most importantly, there is an urgent need to better educate law enforcement and corrections personnel regarding the unique needs and characteristics of persons with ASDs. Suggested adjustments in how such personnel interact with individuals include talking directly and without sarcasm or innuendo, giving the person time to respond, and approaching him or her in a non-threatening way (Debbaudt, 2002). Furthermore, several have suggested the importance of having a person familiar to the individual and an autism expert on site for all proceedings.

Strategies for Addressing These Issues

Dealing with sexuality in persons with ASDs is a complex undertaking. From a prevention perspective, individuals with ASDs must be provided accurate and concrete information regarding their sexuality, training in the social nuances associated with sexual behavior and sexual expression, and monitored for adherence to societal expectations and norms. These are long-term and multi-layered goals. In addition, we must also train the community that will encounter these individuals,

especially law enforcement personnel. In this context, it is imperative to explain the ways in which such behaviors represent the disability of the individual and should not be automatically characterized as deviant. This may result in more compassionate and humane treatment of those individuals with ASDs who engage in counterfeit deviant sexual behaviors.

Sexuality Education Strategies that may help:

- Start early - as mentioned previously, sexuality education is a complex and multi-layered subject, thus requiring significant effort and time to teach. Introducing concepts and programs in late childhood or early adolescence will ensure opportunities to teach across many different and important subject areas.

- Teach concretely - it's important to clearly define appropriate and inappropriate behavior across various settings and contexts. Offer multiple examples to increase discrimination skills.

- Revisit previous teachings periodically to check for maintenance of skills - some individuals with ASDs have difficulty maintaining skills and

see Behaviors on page 38

Navigating the World of Autism and Deafness

By **Sandy Rochelle Schachter**
Parent, Advocate, and Filmmaker

My lovely son, David is both autistic and deaf: he is in a Group Home and Day Habilitation Program in Staten Island run by "On Your Mark."

Although David is non-verbal he is very social – he is adept at sign language, both receptive and expressive.

David and I are always in the community on his weekends home from Staten Island, New York.

We live in the small town of Edgewater in Northern New Jersey very close to Manhattan and we travel by Ferry to Manhattan every weekend.

David loves it and he is barely in the door when he is signing Ferry Boat.

We spend time in various locations including: Greenwich Village, Battery Park and Central Park.

David encounters periods when he is overwhelmed by compulsions.

David is very self-aware: he does not want to engage in any compulsive behav-



Sandy Rochelle Schachter

iors that threaten to sabotage his good time: he will sign: "I am sorry" "Please forgive me" "I will stop" and "I love

you." This only contributes to breaking my already fractured Heart.

I hold on remembering that all things good and bad pass and I sign: "I know you are trying to control yourself and I love you" and for the most part David does gain some control.

David is often recognized since I produced a documentary film about David called "Silent Journey." The goal of the film is to honor and celebrate David and to inform, educate and give hope to parents who are in the midst of the autism struggle.

People recognize David from the film and they ask me, "Is that David?" and David will turn around and shake their hands, and they respond, "Happy to meet you David."

I am thrilled for David and I hope that he will not in any way do anything that will embarrass him and change any one's impression of him from the film.

David's social life is full with us at home and with "On Your Mark."

David vacations both with us and with his agency; a yearly cruise with the agency where we tag along.

David delivers Meals on Wheels, is involved in horticulture and many parties, dances and social events, especially during the holiday season.

His agency spends time in the community every day: they purchased the local Jewish Community Center and turned it into the Independent Community Center – for all things recreational: they also run a café for disabled and non in the local Staten Island Community.

David is well known and appreciated in our New Jersey Community.

We believe that answers for autism will come from research and we are involved in the Seaver and New York Autism Center of excellence for Research at the Mount Sinai School of Medicine.

So, we enjoy the blessings and overlook the challenges and know that they will pass.

David's Documentary Film Silent Journey is available at www.nationalfilmnetwork.com - search for "Silent Journey."

Sandy's forthcoming book of poetry, many poems on or about David, is available at www.finishinglinepress.com.

Jill Krata, PhD, Joins YAI Network's Premier HealthCare and YAI Autism Center

By **The YAI Network**

The YAI Network is pleased to announce that Jill Krata, Ph.D., has been named Associate Chief of the Premier HealthCare Autism Research and Treatment Institute and Manager of Clinical Services at the YAI Autism Center.

Dr. Krata holds a doctorate degree in intellectual disabilities and autism from Teachers College, Columbia University and master's degrees in clinical psychology, counseling psychology and special education. She has worked in the field of intellectual disabilities for more than 15 years and has both clinical and academic experience. Her area of expertise is working with individuals with autism and various genetic disorders such as Williams syndrome and Fragile X syndrome.

"Jill is an outstanding clinician," said Dr. Peter Della Bella, Medical Director of Premier HealthCare. "I look forward to Jill's expertise taking our programs to the next level."

Throughout her career, Dr. Krata has collaborated on research projects with



Jill Krata, PhD

esteemed faculty at Columbia University and has participated in the development and implementation of an effective strat-

egy-based curriculum for abuse prevention and empowerment for women with intellectual disabilities.

Dr. Krata had previously worked at the YAI Network from 1994 through 2000 in a variety of managerial positions in the residential and clinical and family services departments, including YAI's Center for Specialty Therapy.

"I feel like I'm home. I feel like this is home. I'm really looking forward to working with families with children on the spectrum and reconnecting with my colleagues from throughout the YAI Network."

Dr. Krata is affiliated with various professional organizations, including the American Association on Intellectual and Developmental Disabilities, The National Association for the Dually Diagnosed, The Council for Exceptional Children (CEC) and the Division on Autism and Developmental Disabilities of the CEC.

Premier HealthCare, which provides comprehensive and coordinated medical, dental, mental health, rehabilitation and specialty care to 10,000 patients with developmental and other

disabilities, has been designated a Patient-Centered Medical Home by the National Committee of Quality Assurance. Recognized by the U.S. Surgeon General as a national model for the provision of health care for people with intellectual and other developmental disabilities, Premier HealthCare is a leader in the field. Premier HealthCare was cited in a 2009 National Council on Disability (NCD) Research Report to President Obama, as one of only four examples of effective health care programs for people with developmental disabilities nationwide.

The YAI Autism Center, headed by Dr. Charles Cartwright (www.yai.org/agencies/autism/dr-charles-cartwright.html), combines the YAI Network's tradition and expertise of serving people with autism with an early detection and treatment center; family support and life planning services.

For information about Premier HealthCare or other services available through the YAI Network, call 1-866-2-YAI-LINK or visit yai.org.

For more information about the YAI Autism Center call 1-888-YAI-Autism or visit yai.org/autism.

Benefits from page 29

web site www.ssa.gov where you will find a lot of information that has been designed to be easy to understand. You will also find the many forms needed for the application process here. You can get an idea if you will qualify for SSI benefits by filling out the Benefits Eligibility Screening Tool (B.E.S.T.) on the web at www.benefits.gov/ssa.

The basic SSI application consists of 21 pages and 58 questions regarding family composition, income for your adult child, resources, living arrangements and other issues. The Disability Report addresses the applicant's disabling condition. It consists of 9 pages. It asks for information about the disability, names of treating sources, medications, tests and asks how the condition affects the applicant's ability to work. There

are also other forms involving the release of medical information, private health insurance and who will be payee for the applicant if he/she is incapable of managing money. You can request these forms and try to complete them yourself, or contact your local Social Services Office to see a representative who will assist you. This can be done in person or by phone. They do make appointments but they often need to be made two or

three weeks in advance. Or, you can just go in and wait to see someone. Either way be prepared to be at the office a while - set aside at least half a day, and bring a book and sustenance.

This article was originally published in the Fall 2010 issue of AHA's On The Spectrum newsletter. To learn more, please visit www.ahany.org.

Awards from page 9

Dr. Portia McCoy and Dr. Ben Philpot
University of North Carolina
*Ube3a Requirements for Structural
Plasticity of Synapses*

Some autism spectrum disorders are caused by the improper expression of a gene termed *UBE3A*. Having duplications of the *UBE3A* gene is strongly associated with autism, while deletions of the *UBE3A* gene cause the severe intellectual disability "Angelman Syndrome". Both disorders are characterized by cognitive, sensory, and behavioral deficits thought to arise because connections between brain neurons (synapses) form improperly during critical periods of development. However, little is known about how changes in *UBE3A* expression alter the wiring of neurons in the brain. This study aims to determine the role of *UBE3A* in the structural plasticity of synapses during critical periods of brain development. By filling this gap in knowledge, this study will not only reveal the synaptic structural dysfunction leading to improper circuit formation in *UBE3A*-related forms of autism, but may also serve as a model to help with therapeutic testing.

Dr. Haley Speed and Dr. Craig Powell
UT Southwestern University
*Identifying Impairments in Synaptic
Connectivity in Mouse Models of ASD*

Impaired communication between neurons, or synaptic transmission, is thought to underlie autism-associated behaviors. The goal of this research project is to identify specific deficits in synaptic transmission as novel targets for future therapy. Shank3 is a postsynaptic scaffolding protein required for normal synapse maturation and function, and mutations and

copy number variations in the Shank3 gene have been directly implicated in heritable autism with mental retardation in humans. Our laboratory will use genetic mouse models of autism containing regional deletions of the Shank3 gene to 1) Understand how the structure and function of hippocampal synapses are impaired by region-specific mutations in the Shank3 gene, and 2) Determine if each mutation contributes to autism-associated deficits in learning and memory. This thorough, interdisciplinary strategy will identify subcellular mechanisms that will immediately translate into pre-clinical studies for treatment of autism-associated behavioral deficits.

Drs. Elena Tenenbaum and Stephen Sheinkopf
Women & Infants Hospital at Brown University
*Attentional Distribution and Word
Learning in Children with Autism*

This study will investigate how children with autism attend to information when learning new words and how that attention might affect their language development. We know from previous research that children with autism tend to look at social scenes differently than their typically developing peers. Recent research with typically developing children suggests that the way a child looks at social scenes can predict successful language development. To explore the possibility that attention to social scenes among autistic children might be affecting their language development, we will conduct an eye tracking study of visual attention in a word learning task. Children will watch videos of a person labeling new objects while we track their attention to the scene. We will then test the child's recognition of the newly learned words and compare their success to their patterns of attention to the word learning scenes. We will also investigate whether their ability to learn new words in the lab relates to their lan-

guage development outside of the lab. It is our hope that the information we obtain in this study will lead to the development of new interventions for facilitating language learning in children with autism.

Jessica Bradshaw and Dr. Robert Koegel
University of California at Santa Barbara
*Prelinguistic Symptoms of
Autism Spectrum Disorders in Infancy*

This Pre-Doctoral Fellowship research project aims to enhance the understanding of prelinguistic symptoms of autism spectrum disorder in infants less than 12 months of age through the assessment of preverbal social and communication behaviors in the context of a pilot treatment program. Infants between 9-12 months of age exhibiting signs of ASD will be enrolled in a pilot treatment program designed to increase social engagement and decrease overall symptomology. This intervention will be a modified version of Pivotal Response Training, a validated manualized naturalistic intervention utilizing developmental and applied behavior analysis approaches. A parent-education component will also be incorporated allowing for families of infants at risk for ASD to better understand autism and learn effective therapeutic techniques. Despite research showing early signs of ASD in infancy, intervention resources for infants exhibiting early symptoms remain limited. This study aims to address this gap by assessing social-communicative gains made subsequent to the implementation of a comprehensive treatment program.

Christie Buchovecky and Dr. Monica Justice
Baylor College of Medicine
*Identifying Genetic Modifiers of
Rett Syndrome in the Mouse*

Rett Syndrome is an autism-related disorder that affects primarily girls and has a prevalence of 1 in 10,000 births.

Restoring function of the gene responsible for Rett Syndrome, *Mecp2*, to mutant mice allows them to live normal, healthy lives, even after symptoms have developed. This is hopeful news for patients, highlighting a potential for reversing the disease by pharmacologic means. Unfortunately, *Mecp2* is not a promising drug target, as a genetic trick that would be impossible in humans is required to restore function in mice. Our lab has undertaken a genetic screen in which we randomly mutated a second genomic site in *Mecp2*-mutant mice to locate more pharmacologically targetable genes. From this screen, we have identified five lines carrying inherited suppressors that increase lifespan and decrease other Rett Syndrome related symptoms in *Mecp2*-mutant mice. This Pre-Doctoral Fellowship project focuses on characterizing the two mutations present in the line that show the greatest degree of rescue - one of which, we believe, provides great therapeutic promise. In the process of assessing the degree of rescue for each line, we will evaluate the brain structures altered in Rett Syndrome to determine the degree to which neuronal maturation deficits are rescued. Furthermore, we will use established mouse behavior tests to assess the extent to which the suppressors alter cognitive ability and motor function. Understanding the suppressors at a functional molecular level may provide an avenue for development of therapeutic compounds applicable to multiple types of autism spectrum disorders.

Alison Singer is President of the Autism Science Foundation. Visit www.AutismScienceFoundation.org to learn more about the Autism Science Foundation. Ms. Singer can be reached at asinger@autismsciencefoundation.org.

Behaviors from page 36

information over time and will benefit from periodic review of previously taught material. It is important to avoid assuming that once a topic is covered once, especially given the complexities of this topic, no further instruction or review is needed.

- Break topics down into smaller components and teach methodically

Systems/Community Intervention:

- Educate law enforcement and corrections personnel about ASD
- Teach professionals effective ways to de-escalate a person with ASD

- Teach professionals effective ways to communicate with a person with ASD

Survival Skill Education:

- Teach individuals with ASDs about behaviors with social and legal consequences
- Teach self-advocacy skills to persons with ASDs

Summary

Individuals with ASDs are at risk for legal difficulties. Individuals with intense interests and significant social impairments are at highest risk. Behaviors may be misinterpreted and consequences can be severe. It is imperative that educators address sexuality education, identify at-risk individuals, and treat such dangers as real. Effective collaboration with families must include making the discussion of these issues explicit. It needs to be dealt with as an essential area of education and treatment. Furthermore, law enforcement and legal personnel must be educated about the unique challenges that may be encountered with this population, so that compassionate solutions are possible.

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Internet Crime from page 16

one less than seventeen is considered "promoting sexual performance" and also a felony. Most offenses involving computer transmission of child pornography (distribution) have a minimum sentence of five years in prison and a maximum sentence ranging from ten to twenty years. Whenever images are

downloaded from a server it usually involves "crossing a state line" and is therefore a federal offense. File sharing is particularly problematic because it is considered a distribution offense. In regard to sexual chat with minors, there are many sting operations that law enforcement has employed to catch adults who are conversing inappropriately with minors online. These conversations are

turned over to a law enforcement officer who poses as the child and then leads to an arrest of the adult. As a result, the socially naïve ASD individual is at risk using the internet without a full understanding of the ramifications of certain behaviors. Parents, family members, and clinicians must educate ASD adults about the risks of inappropriate internet activities and help provide structure and

monitoring to help reduce the commission of internet crimes and prevent the incarceration of those with ASD in the future.

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Vocational Rehab from page 30

interests, past experiences, concerns, and accommodation needs. Medical and other documentation is important, but the key source of information is conversations with the client and/or client's family.

VR Services - Together the client and counselor decide which supports and services the client needs to reach the career goal. The specific services a client receives will vary widely, depending on the client's career goal and personal support needs. The chosen services and career goal become the Individualized Plan for Employment (IPE). The IPE is not complete until the client signs his or her name to indicate that she or he 1) was an active participant in its creation and 2) agrees with the services, responsibilities, and goal listed. This insures that clients have a central and determining voice in the type of services they receive. The IPE is a working document which can be revised later if necessary.

Types of VR Services include any goods or services needed to help the client find employment. As mentioned, services can vary widely depending on individual circumstances, community resources, and career preferences. Services can include, but are not limited to:

Assessment Services - These focus on a person's abilities and support needs, not on barriers. This is NOT a qualifying assessment for services, but a clarifying tool. This is also NOT a career filtering tool – assessment results clarify the support needs a particular career choice might require.

Counseling and Guidance - This is the ongoing relationship between the client and counselor. As a team they review

evaluation results and develop a realistic employment plan.

Treatment - In some instances, specific medical treatment (such as surgery or counseling) may increase a person's career potential. This is NOT for ongoing medical needs, but a focused intervention to improve employment options.

Job Training and Education - This covers skill acquisition, including post-secondary education, to improve employment potential (see discussion below).

Other Support Services - This addresses secondary needs key to job retention, including development of transportation options, buying tools or equipment, or support for independent living.

Job Placement - These are services to help a client locate job opportunities and become hired. It can include specific job hunting skills (interviewing, resume writing, etc.) but can also include services from job placement specialists who market a client to local employers.

Supported Employment Including Job Coaching - (see discussion below)

Independent Living Services - This includes referral to local community resources, help with self-advocacy, help with money management, etc.

Assistive Technology Services - Some clients need a specific device or piece of equipment to improve employment options.

More on Vocational Rehabilitation Services

Supported Employment - Ideally, supported employment (the use of an on-site job coach to help a client navigate job

tasks and responsibilities) should be a temporary, transitional support which fades out. However, a few individuals need supported employment on a long-term basis. Because the goal of VR services is the achievement of employment, there must be a cut-off point at which the client is determined to be securely employed and services are complete (usually 90 days after employment). Funding for supported employment services is time limited and long term job support must come from another funding source.

Ideally, the counselor and client will address this issue during the planning stage and identify other sources for supported employment on a long term basis, if needed. This is an ongoing area of attention from RSA.

Training and Education - These are some of the most common VR services. There is no time limit on how long the training may take, as long there is reasonable progress toward the employment goal. Training options include short-term training such as specific job skills courses or training at a vocational technical college, or advanced degrees at a university. VR frequently covers the cost of short-term training, and a significant portion of advanced degrees. This is not an open-ended scholarship, but does have a flexible time scale as long as activities are focused on the career goal.

Self-Employment Services - There are several subtypes of self-employment, including small business owner, contract worker, and equipment ownership.

Transition Services - Many new clients for VR agencies are young adults completing high school. All VR agencies have extensive outreach efforts for transition planning and services.

Protection and Advocacy

Like all service networks, VR agencies are not perfect and do not always achieve their own ideals, despite their best efforts. All state VR agencies are required to have an internal appeals process. If any client feels his or her counselor is denying appropriate, necessary VR services, these processes can provide a review by an external "impartial hearing officer." Federal regulations also require each state to have a Client Assistance Program (CAP) to advise and support VR clients who need help with advocacy. These CAP offices provide advice on rights and responsibilities under state and federal regulations and policies. CAP offices can refer clients to appropriate service agencies or, if necessary, to legal services. Some CAP offices can provide direct legal representation.

Many state VR agencies are recognizing a need for more informed services for clients with autism. Our Autism Works project at the University of Missouri is working to achieve this with interested agencies. The autism community can help by actively seeking VR services (when appropriate) and vigorously engaging state agencies in dialogue about service needs.

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

The focus of the support group is to assist families in understanding the complex issues related to their adult child impaired with Asperger's Syndrome or High Functioning Autism. At many of our meetings, we have speakers address various topics of importance related to these syndromes.

For further information contact the facilitators: **Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com**

Socialization and Life Skills Group For Asperger's Syndrome and High Functioning Autistic Adults

Focused on: Employment & Vocational Issues, College Coaching & Supports, Socialization Self-Advocacy, Dating, and Relationships

For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 - Patrowan@bestweb.net | Susan Cortilet, MS, LMHC - (845) 406-8730 - Susan.cortilet@gmail.com

Dates for 2011: 4/10, 5/22, 6/12

Westchester Arc
The Gleeson-Israel Gateway Center
265 Saw Mill River Road (Route 9A)
Hawthorne, NY 10532

Executive Functions from page 28

for many of the daily tasks we encounter such as prioritizing our responsibilities, organizing our behaviors to meet long-term goals, and persisting on a task. Additionally, these abilities assist us in regulating our emotions and monitoring our reactions. Deficits in Executive Functioning manifest differently across multiple environments and impact children differently, depending on their developmental and cognitive abilities (Dawson & Guare, 2010).

In school-aged children with EF problems, parents may notice that their children have difficulty with ongoing routines such as getting ready for school in the morning or preparing for bedtime. Without constant verbal reminders from a parent, children often delay getting dressed, brushing teeth, and packing their bag packs. At school, the teacher typically finds it necessary to repeatedly prompt these students to begin an assignment or follow directions. These tasks require such EF skills as organization, initiation, shifting, and working memory. Additionally, homework is often an arduous task, as children with executive function deficits typically forget to bring home their worksheets from class or resist completing the work that is assigned. The weekends can also present as a challenging time for the child with executive function difficulties who cannot respond flexibly when plans are unexpectedly changed.

In middle school, there are many areas for students to utilize EF skills. Students need to learn to raise their hands before speaking, inhibit their emotional responses so that they are not making inappropriate comments in class, transition from preferred to non-preferred activities, and attend to group instruction without becoming distracted by external stimuli. Children who are lacking organizational skills may be unable to consistently write down assignments in a homework planner. In the home environment, time management skills become crucial. Deficits in EF result in a student who is unable to prioritize different homework assignments and instead, becomes overwhelmed and tantrums or, alternatively, becomes avoidant and refuses to complete homework assignments. Deficits in initiating and transitioning between tasks in the home are commonly seen with children who are expected to complete such chores as "clean your room." Without having the ability to break down that task into smaller steps (throw out garbage, make the bed, put laundry in hamper, etc.) the child is not able to follow through on these responsibilities.

High School can present a significant increase in those challenges placed on an adolescent with EF deficits. Many assignments such as term papers and projects require long-term planning and the ability to break down assignments into smaller chunks. This can present an overwhelming challenge for a student who has difficulty understanding how to brainstorm ideas, create an outline, and organize different thoughts into a coherent thesis statement, all skills requiring executive functioning. Organizing a calendar, time management, and juggling different extracurricular activities are other areas of potential difficulty. Preparing for college and tackling the many steps towards tran-

sitioning to a new academic environment requires many executive functioning skills that these adolescents may not be adequately equipped to address. Daily living skills (chores, hygiene) as well as money management are additional areas that are necessary for this age group to master so that a gradual sense of independence can be fostered.

Executive Functions are mediated by the prefrontal cortex of the brain; however, it is likely that input is received and organized from other areas of the brain (Anderson 1998). Research suggests that EF develops throughout childhood, with growth spurts in frontal lobe development lasting through the beginning of adolescence (Anderson 2002). Childhood and adolescence are ideal times for an intervention, so that the brain can accommodate newly learned skills in the area of executive functioning. If we can understand the particular deficits that are impacting a child's functioning in childhood, parents and teachers can help to target those specific skills to ensure academic and social success. As a result, this information can help inform how much structure and support the child will need as they mature into adolescence and adulthood (Dawson & Guare, 2010).

In the early stages of development, parents and teachers undertake the role of setting guidelines and concrete steps and thus, act as the control center for the child's executive functioning. However, as a child develops, the expectation is that he or she will be able to make more independent decisions and self-monitor behavior without the consistent guidance of adults (Meltzer, 2010). However, for children and adolescents with executive functioning deficits, these underdeveloped skills require continued support and teaching before they can become more fully independent. Such support can be provided by environmental modifications as well as specific skill development.

Some specific strategies to remediate the deficits in EF include both individual and group interventions that highlight specific deficits for each of the participants and include goals that are based on the personal needs and strengths of the individual participants. It is recommended that parents of a child on the autism spectrum look for a program that not only addresses the specific executive functioning deficits but also keeps in mind the unique needs of the child. Additionally, it is essential that the parents or caregivers are included in the treatment so that the skills learned in the group are practiced, supervised and generalized to the home environment.

When considering appropriate interventions, the therapist needs to work with the parent to conduct a thorough assessment of the child's executive functioning profile. A comprehensive assessment is typically based on the child's performance at school as well as the home. Therefore, it is necessary for the treating therapist to collect assessment information from a variety of sources, including parent interviews, classroom observations, work samples, behavior checklists and formal assessment procedures. When prioritizing which executive functions are the most primary to address, a specific behavioral goal should be identified along with a measurable way to track progress. This

creates a more successful outcome for the child. By creating a collaborative approach with the teacher, parents and therapist, the child is then placed in a consistently supportive environment where the intervention and the goals are clearly stated and encouraged.

For example, a child may present with deficits in the area of organization. At first, the therapist attempts to understand the nature of this deficit and how it manifests particularly for this child. Feedback is elicited from both teachers and parents to target specific areas of concern. An intervention is designed that reflects these deficits and includes measurable goals to adequately measure progress. The teacher can answer the question, "In order to increase (student's name) organizational skills, what are two behaviors, if targeted, that would lead to more academic success for this student?" The therapist then works with the child to create gradual steps that will enable the child to achieve those goals. Often, it will include a behavioral plan with parental involvement in which a child will be reinforced for positive behaviors to facilitate success. The child is taught to compensate for organizational difficulties as well, for example, by using color-coded folders that match textbooks or having a visual/written prompts placed near the locker or desk to remind the student to bring home specific books for homework. In the classroom, the teacher can use consistent classroom routines for elementary students so that the skills become more automatic. Routines can be established for managing supplies, turning in homework, entering/exiting the classroom, and writing down assignments from the board. Teachers can also use cueing (or prompting) that helps to guide the student to approach tasks in a consistent and thoughtful way. Teachers can cue by asking a student questions that help them prepare for the task, such as "What materials are you going to need to finish this assignment?" or "How will you know when you are finished?" Communication is fostered between the parents and the teachers using email or a notebook. Progress is tracked and continuously reinforced. In this way, the child's difficulty with organization is gradually improved.

Modifying the environment to facilitate success is often an important consideration when developing a successful intervention for a child with EF deficits. By creating a physical and social environment that matches the student's skills and needs, the child is in a better position to perform and behave in more successful ways. Such environmental modifications may include preferential seating to reduce distraction, modification of class assignment so that the long-term project is broken down into smaller tasks. Furthermore, modification of the social demands can be achieved by strategically pairing a child, during group work, with appropriate peers who can model the necessary skills and provide opportunities for the child to practice his/her skills. EF treatments that occur in a smaller group setting often use a modeling approach to facilitate improved EF skills for the student. In this way, the teacher or peer mentor can use the skill in front of the student and, at the time, explicitly teach how it can be successfully used in the classroom or at home.

When thinking about a child on the autism spectrum who is specifically chal-

lenged by an emotional regulation deficit, success will be maximized when there is a team approach. This provides the child with more of an opportunity to practice these new skills across different settings. For example, this can be seen in a middle school child who tends to melt down suddenly and without warning. The first step in addressing this behavior is identifying the triggers leading up to the meltdowns and defining the replacement behavior in each environment. For example, these triggers may occur in class when the child is asked to complete certain academic tasks and during recess when the child tends to get easily over-whelmed by group activities or social gatherings. After these difficult situations are identified, there are specific strategies that teachers, parents, and caregivers can use to help the child manage his or her emotions. These strategies can enable the child to complete the task, control emotional responses and successfully cope with the academic or social demand. In the school environment, a teacher can help the child break tasks into smaller steps to make the task more manageable. The teacher can also take notice of those situations that are triggers for emotional regulation problems (i.e. quizzes, tests, etc) and give the child breaks during those specific tasks when he or she starts to show signs of becoming upset (fidgeting, pacing, wringing fingers, etc). Similarly, a parent or teacher can model the practice of positive self-talk that is encouraging and supportive. For example, the parent may model to the child a statement such as "I know this activity is going to be hard but I am going to keep trying and when I am confused, I can ask for help." Providing the child with a script to follow during certain situations can lessen the anxiety and enable the child to feel prepared to face a demanding social situation. For younger children, it can be helpful to use literature or social stories to teach emotional control. A parent can teach the child specific coping strategies that have worked at home which may include breathing exercises or even raising one's hand to ask an adult for a break from the specific situation (family dinners that are very noisy and crowded, homework time when the child is working on a difficult assignment). Using a rating scale to help children identify and cope with their feelings can also foster a feeling of better control because it teaches the child that they have options when feeling overloaded. The Incredible 5-point scale (Buron & Curtis, 2003) uses a rating scale where children can rate their own behavior according to the severity of their feelings in a situation. In this way, the child, along with various members of his or her team, can become better equipped to handle these challenges through simultaneously shifting the child's thought process and lessening the environmental triggers to maximize success.

Choosing the best treatment for children is crucial for continued independence and success as they grow and mature. Through empowering children and adolescents to overcome deficits in executive functioning, they are more likely to develop an increased awareness of their learning style, an improvement in their self-confidence, and a sense of internal motivation to succeed in the school, work or social environments.

Divorce from page 23

The courts do not have special rules when dealing with custody in the cases where there is a special needs child in the home. The focus on the above factors are made "...in light of the totality of the circumstances, including each parent's past performance, relative fitness and their abilities to maintain a stable home and provide for the child's special needs (*Tennant v. Philpot*, 2010). When a special needs child is involved, the courts decisions are grounded in the above factors, "including the parties' respective home environments, behavior toward each other and the child, parenting skills with particular reference to the child's special needs, care of the child over his lifetime, willingness and ability to foster a relationship between the child and the other party..." (Lionel E. v. Shaquana, 2010).

The most common custody arrangement is one in which the children move back and forth between the homes of the parents. This model has been considered outdated and not supported by empirical literature according to some authors (Kelly, 2007). In order to reduce anxiety among the children, it is important to give them plenty of advanced warning of the pending change in the family structure. The main message the children need to hear is that the divorce is not their fault. Often children blame themselves for their parents' divorce. To further help reduce anxiety and give the children a sense of control, parents can engage the children in helping select a new place to live, which new bedroom will be theirs, and help select decorations for the new home.

Providing a sense of predictability, stability, and structure will be critical in helping a child on the autism spectrum cope with the change in family structure. One easy intervention is to provide the school-aged child with a copy of the custody/visitation schedule in a visual form. A copy of a calendar for the month with color coded weeks indicating at which parent's home the child will stay can be placed in the child's binder. Additional copies can be posted on the refrigerator doors at the respective parents homes. By providing a copy of the custody schedule in an understandable form to the child, parents will help the child gain a sense of predictability and help reduce anxiety.

Continuing with previously established family rituals can also help increase the child's sense predictability, stability, and structure. Family dinners with all the family members in the new configuration at the same time as was previously held will help. Bedtimes and associated rituals (e.g. bathing, reading a story, etc.) should be kept the same as prior to the separation if

possible. The children should also continue their extracurricular activities if at all possible. Cancelling the children's extracurricular activities will compound their sense of loss and will remove them from their support network.

Instituting new structure and rituals can also help the family cope with the transition of a divorce. Covey (1997) describes the concept of family meetings where family members can review the week, celebrate successes and acknowledge accomplishments, as well as discuss issues and develop mutually acceptable solutions. The institution of this ritual not only provides the family with ritual and routine, but also serves to teach and model pro-social behaviors such as listening, waiting one's turn to speak, and compromising. Covey (1997) also champions the concept of having one on one time with each child. One on one time is where the parent spends alone time with each of the children individually in an activity chosen by the child. The one on one time is done on a weekly basis. This is especially important for the siblings not on the autism spectrum because they often feel that family life revolves around their sibling with the disability.

Prior to any disagreements, if the parents can establish a mechanism to resolve conflicts, this will help decrease tensions and improves the long term outcomes for the children. One mechanism to consider is hiring a family therapist who is acceptable to both parties and is trained in working with families who have a child on the autism spectrum. The professional should be neutral and should be considered as the last word on helping decide critical issues. Prior to engaging this professional both parties should agree, in writing, that this person will truly be neutral and be used only for mediating conflict, i.e., both parties must agree not to subpoena this person in a custody dispute. The family therapist can work with the family in a variety of constellations depending on the family's current need.

Unfortunately, some families are not able to come to an amicable or mutually acceptable dissolution of the marriage. The most frequent sticking point revolves around the education and medical treatment of the child with the ASD. Often one parent embraces the notion of the child having an ASD while the other rejects the notion wholesale. This is particularly true when the child is "high functioning" and has a diagnosis of PDD-NOS or Asperger syndrome. The parent who is resistant to the label may focus on only one aspect of the child's disorder or agree to a more socially acceptable label such as attention deficit disorder (ADD). This can lead to educational and behavioral interventions that do not address the core issue with ASDs which is social in nature.

Should the custody dispute devolve into an adversarial scenario, then a forensic custody evaluation may be ordered by the court. The court will then appoint a guardian *ad Litem* or law guardian on behalf of the children. This attorney or other professional's role is to protect the interests of the children separately from the interests of the parents. Both the guardian *ad Litem* and the forensic evaluator ought to be sensitive to how the children's social disability will affect their ability to understand and answer questions. They need to be aware of the concrete and literal nature of some individuals on the autism spectrum. They also need to be aware of how some individuals on the spectrum may be scripted. They or the family members may inadvertently or even intentionally script the individual on the spectrum to give answers that would be more favorable to one parent or another during the custody proceedings. Furthermore, legal professionals should be sensitive to the fact that ASDs are inheritable and consequently, one or both parents may have an undiagnosed ASD or features of a co-morbid disorder associated with ASDs. A reasonable accommodation under the *Americans with Disabilities Act of 1990* would suggest that forensic evaluators, and guardians *ad Litem* be trained in dealing with families where an ASD is present.

Who should be granted custody? The best long term outcomes for children of divorce occur when there is a minimal amount of conflict. Children do the best when their parents protect them from the daily machinations of the legal proceedings. If the parents can truly co-parent in a cooperative manner and not attempt to micromanage what occurs in the ex-spouse's new home, then children are less likely to suffer serious long term effects from the divorce (Ahrns, 2007). If the divorce is high in conflict, then custody should be granted to the parent who can incorporate the developmental needs of all their children into account when making decisions. This person needs to be cooperative and willing to learn new parenting techniques. He or she will need to know that children on the autism spectrum have unique needs, and what educational and behavioral interventions are empirically indicated to fill those needs. Finally, custody ought to be awarded to the parent who can provide all of the children with a sense of predictability, stability, and security.

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Planning from page 20

they are adequately funded for quality lifetime care and quality of life.

Resources for Parents

There are many government and non-profit agencies to contact for more information on planning for the financial future for dependents with special needs and related issues. Following are some starting points for identifying local contacts:

- **The Arc of the United States**
www.thearc.org

- **National Dissemination Center for Children with Disabilities**
www.nichcy.org

- **Special Needs Alliance**
www.specialneedsalliance.com
A resource to help you identify local legal counsel with expertise in special needs

- **National Care Advisors**
www.nationalcareadvisors.com

A consulting firm that provides quality of life planning necessary to meet the challenges of living with special needs.

Whether a family has substantial means or few assets, a young child or adult child with disabilities, planning for the financial future of a loved one is critically important. The fact is, how parents and the child's family leave their assets after death may greatly affect the quality of life for their family member with special needs.

Article prepared by Northwestern Mutual with the cooperation of Stephen A. Ehrens. Stephen A. Ehrens, CPA, CLTC, is a Financial Representative with Northwestern Mutual Financial Network, the marketing name for the sales and distribution arm of The Northwestern Mutual Life Insurance Company (Northwestern Mutual)(NM), Milwaukee, Wisconsin, its affiliates and subsidiaries. Stephen A. Ehrens is an insurance agent of NM based in (Fairfield, CT). To contact Stephen A. Ehrens, please call 203-256-2162, e-mail him at stephen.ehrens@nmfn.com, or visit his website at www.nmfn.com/stephenehrens.

IACC from page 8

committee that was created by Congress in an effort to accelerate pro-

gress in autism spectrum disorder research and services. The IACC works to improve coordination and communication across the Federal government

and work in partnership with the autism community.

The committee is composed of officials from many different Federal agencies

involved in autism research and services, as well as people with ASD, parents, advocates and other members of the autism community.

Sexuality from page 24

often interpreted as sexual, which unfortunately can result in significant legal repercussions. The second kind of behavior youth can engage in is (2) socially inappropriate sexual behavior that is misinterpreted as *intentional or deviant*. For example, we have worked with many youth who do not know how to appropriately express romantic interest; their advances are at times inappropriate in nature. Additionally, rigidity and limited social understanding can prevent some youth with ASDs from accepting rejection by a desired partner, or a fixation can develop related to having someone as their romantic partner. These behaviors are often identified as *stalking* and the ramifications are often severe. We have seen teens expelled from school, banned from community social groups, and tried as juvenile sex offenders. The legal system, including police officers, lawyers, judges, and parole officers, is not equipped to understand the behaviors of youth with ASDs and therefore any behaviors perceived to be sexual and inappropriate in nature are not taken lightly. The most suitable intervention for neurotypical youth (e.g., a standard juvenile sex offender course), is likely not appropriate for youth with ASDs. Though we have communicated

these concerns to the courts on a number of occasions, flexibility in fulfilling treatment requirements has not been an option, resulting in a very difficult experience for our clients with ASDs.

Due to the social impairments of ASDs, adolescents may lack insight into comprehending or recognizing whether their behavior is socially inappropriate (Stokes & Kaur, 2005). Adolescents with ASDs have less sexual knowledge compared to their typically developing peers due largely to limited access to available and appropriate educational resources (Koller, 2000); there is little material specifically geared towards teaching sexuality and relationships to individuals with ASDs. Typically developing youth learn a great deal regarding sexual behavior through social observation of peers, family, and media and sharing that information within their peer groups. As discussed earlier, youth with ASDs often lack a peer group and struggle with social observation, thus preventing learning via implicit observation.

A focus on punishment of sexually inappropriate behaviors can prevent teaching opportunities for an individual to learn more responsible behavior (Hénault, 2003). As children with ASDs grow, it becomes increasingly important to help them understand which behaviors are ac-

ceptable and which are not (Lang, 2005). Importantly, sexuality education should not focus only on sex and anatomy. A comprehensive sexuality plan additionally incorporates social skills training and social thinking concepts, because healthy sexuality is embedded within the social environment. It is essential that any sexuality education curriculum comprises a strong social skills component and that concepts related to sexuality (e.g., where to be naked) are not taught in isolation from their social context (e.g., *why* you can be naked in some places and not others). There are a surprisingly large number of social rules that govern our sexual behavior. Many of these rules are unwritten and therefore must be explicitly taught to youth with ASDs who struggle with social understanding. Through comprehensive sexuality education, adolescents with ASDs can learn to recognize *what* is appropriate and to understand the reasons *why*, so that they do not endanger themselves, or others, and unfortunately receive the label of "sexually deviant."

We believe that sexuality education should be viewed as a critical part of a teen's educational plan. Creating a comprehensive plan that includes goals in the areas of enhancing teen's knowledge of body parts, differentiating between public and private, identifying clear boundaries,

and learning about appropriate expression of affection is crucial to prevent both vulnerability to being sexually exploited and unintentionally exploiting others. By preparing a child and his or her family for their journey through adolescence and into adulthood, healthy and safe sexuality can be achieved.

At the same time, effort is needed to educate law enforcement personnel and individuals working within the legal system, of the unique experiences of individuals with ASDs. Collaborative efforts are necessary in order to determine if a person with ASD has engaged in true deviant sexual behavior, has acted in a socially inappropriate and uneducated manner, or whether their behavior in fact serves a completely different purpose (e.g., sensory). Without this joint effort, youth and adults with ASDs will continue to experience negative and often traumatic interactions with the legal system that are fraught with harmful misunderstandings.

For more information about the "ASPIRE Center" and our sexuality education programs, please contact Samara Tetenbaum, PhD, Psychology Fellow at ASPIRE at 631-923-0923 or spataspire@gmail.com. You may also visit our website at www.aspirecenterforlearning.com.

Compensatory from page 25

agrees to "up" Sydney's speech services by a half hour per week - still two and a half hours short of the recommendation and no ABA services. Sydney's parents again write a letter to the school district and continue their request for additional speech and 10 hours of 1:1 ABA therapy.

After a couple of months, Sydney's parents continue to see a lack of progress, and despite the "extra" half hour of speech, Sydney is *losing* language skills, i.e., she is regressing. In November, Sydney's speech therapist goes out on maternity leave and is not timely replaced. Sydney's parents learn for the first time that Sydney has not been receiving her mandated speech services during a February parent-teacher confer-

ence, when the classroom teacher "slips" and reveals that Sydney was not getting any of her speech services. Sydney's parents realize at this point they can no longer patiently wait for the school district to help them - they need to find out what Sydney's educational rights are under the law and consult with a lawyer who specializes in special education law.

After consulting with their lawyer, Sydney's parents put the school district on notice that they will provide Sydney with 5 hours of speech therapy and 10 hours of home-based 1:1 ABA, and will look to the school district for reimbursement. Sydney's parents then file a demand for due process. Sydney has viable claims for the missed speech sessions that were mandated on her IEP and to be "compensated"

for the services the school district never mandated in the first place, but should have. Of course, the evidence will need to support these claims to get an award of comp ed. Compensatory education is an important "equitable" remedy that parents and their advocates should always keep in mind whenever a school district fails to deliver or recommend appropriate services.

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an educator and served as an Upper School Dean of Students at an independent school in Westchester, New York.

Footnotes

1. Depending on the facts of the case, the demand may seek more than 16 hours of occupational therapy comp Ed. While 16 hours were missed, because of the gap in services, the student may have regressed, and additional time may be required to get the student back to where he was prior to the discontinuation of services. So while 16 hours are the actual hours missed, it may now take more than 16 hours to get the student back to where he would have been "but for" the school district's gross failure to deliver the services.

Paper Boy from page 29

- *Lack of sociability* - People make him nervous. I could write an entire book about this bullet point.
- *Inability to interpret social cues from others* - He loves to ask questions like "How old are you?" and follow it up with the zinger "And when do you think you're going to die?" oblivious to his squirming subject's red face and sputtering. Apparently people don't like to have their mortality questioned by a 7-year old.

In April of 2007 we moved to New Hampshire and I was relieved to discover his new team was warm and loving. In our very first meeting together they asked to see a picture of him, and "Child" was

replaced by "Jack." Together we laughed over his quirks and looked hopefully towards his year in pre-school. At last, people who could see beyond the paper boy.

Jack's paper diagnosis fails to capture the beautiful gifts of his autism. He has an uncanny capacity to retain information and a remarkable memory. He interprets much of the world differently than we do.

Some other interesting things about Jack:

- He loves pancakes
- He's terrified of dogs
- He's a very good bowler
- He's proud to ride the big bus to school
- He's soothed by music

- He has a crush on his first grade teacher, Mrs. Cushman
- His nickname is Jack-a-boo or Kangaroo Jack

Jack's paper version makes me feel like this:

- Sad I have a child who is special needs
- Terrified of the long road ahead of us
- Anxious that he'll need to live with us forever
- Angry that he wasn't born normal

My real-life Jack makes me feel like this:

- Hopeful he can overcome some of the obstacles his autism presents

- Inspired by how hard he works
- Anxious that he'll need live with us forever
- Fascinated by how his mind works
- Lucky to know him

In moments of panic about his issues and our future it's easy for me to diminish my son to his paper version. But autism is a diagnosis, and that's all. Although it's as much a part of Jack as the two freckles on his nose and his love of Scooby Doo, it's just one mere aspect of his whole extraordinary being.

He's beautiful inside, outside, and even on paper.

Carrie Cariello lives in New Hampshire with her husband and five children.

Kanner from page 31

textbooks or reference works today.

Dr. Kanner dealt, from the beginning, with a topic that remains very controversial today: the causation of infantile autism. Unlike many observers of his day, he seemed to believe in both environmental and organic factors. His explanation for this complex attribution was a note on the importance of "not reducing all mental disorders to a few basic conflicts." He saw autism as the outcome of many different forces - biological, developmental and environmental.

Dr. Kanner was also a strong voice

in favor of ending the terrible conditions at state mental hospitals. His interest in this started with the 11 children whom he studied in his first group. They came from families that were affluent, and in some cases very controlling. Some of the parents lost their confidence in him at one point; feeling that too little of their children's behavior had changed; they placed these children into a state psychiatric hospital, where mentally disabled and retarded children were sent. But the parents soon discovered that the children got even worse in the state hospital and took them out. Dr. Kanner's

methods were the only methods known, at that time, which could help children from sliding into a less capable, less communicative state.

After Dr. Kanner observed what was happening to the individuals placed in state hospitals, he expressed a great deal of concern about the usual treatment that the mentally retarded children received. His voice was among those that helped bring an end to the poor treatment of the individuals in mental hospitals, and an eventual end to the hospitals themselves.

In all of these ways, Dr. Kanner's contribution to child psychiatry was

numerous. Most importantly, his ever-broadening work with children with autism formed the basis for a new field of research. He made an immeasurable contribution to the lives of people who were and are still being diagnosed as autistic. This includes my son, who was able to be diagnosed early in his life because Dr. Kanner showed the way. All of the achievements that my son made, I can show direct correlation to the good doctor.

My thanks to Mr. Robert Q. Kreider, President and CEO of the Devereux Foundation.

Parent's Eyes from page 32

weaknesses. At this meeting we were allowed to take a very active role in our child's educational planning. As a group we began to tailor a specific educational plan for our daughter that was specific to her needs. After this meeting I realized how our previous school district had been lacking and felt very positive about our decision to transfer our daughter.

Our first IEP meeting at the new, now current school district was intimidating, mainly because I was unprepared for how many professionals would be attending the meeting. The meeting consisted of the following: Assistant Coordinator of Special Education, School Psychologist, Special Education Teacher, Occupational Therapist, Speech Therapist, and our daughter's regular classroom teacher. In this meeting our daughter's transfer to the district was discussed and plans were made to ensure that the school would be able to accommodate our daughter and provide her with the necessary services. Again I was given an opportunity to discuss her strengths and weaknesses and state what I felt were some appropriate goals for

her. The meeting ended with the understanding that we would all reconvene in two months to discuss her progress and make any necessary changes.

A few days after the meeting, I received a letter in the mail detailing the meeting with a list of her goals and how the district planned on helping her to attain the goals. The goals were very specific to our daughter. For example: Child will learn to use adequate pressure when writing for at least ten minutes. Since then, each quarter we are provided with a progress report discussing her progress toward her goals.

Hopefully the account of our second IEP meeting is what most families encounter. Nevertheless, it was stressful and intimidating. I often wonder as I am going through this journey with my daughter about the other families out there. How are they coping? Are their children receiving appropriate services? Do they have an advocate to help them?

I found that neither of the school districts that our daughter has attended thus far has employed a parent advocate to help with such matters. I have found that if you require advocacy you need to speak to a special education lawyer, or find an

agency within the community who employs such advocates. Unfortunately, as these can be expensive options it is not always possible for every family.

One of the most important pieces of information I found while exploring the IEP is this: a student can still graduate high school with a local diploma or a regent's diploma despite his or her IEP status. However, there is an increase in the amount of students graduating with an IEP diploma. This diploma means that the student has met the goals outlined in the IEP not necessarily high school coursework and may not have passed the regents. Students are usually eligible for this diploma once they have already completed 12 years of school or exceed the age requirements. This IEP diploma is not enough for entry into a 4-year college or university and some 2-year colleges. The IEP diploma and the local school diploma are not the same. Parents are often led to believe that this is the best for their children and because they want the best for their children, they consent. Many times, this educational plan for the student to graduate with an IEP diploma is already drafted early in public school years that the child has no opportunity to work to-

wards the local or regent's diploma. Each state has different standards and it is important for families to find out the standards in their state and school district.

What does this mean for our children's futures? How can we expect and hope that our children on the spectrum will reach their potential if from early on they are not being given the opportunity to succeed as most children? I truly believe that our daughter has a much better opportunity to succeed to her fullest potential in the new school district, as the IEP process is so very different. It is so important for parents and guardians to be given the opportunity to be fully involved in the IEP process, most children will only benefit from this. From a professional standpoint, if the families are more involved they will feel more "ownership" over the IEP and will cooperate with the school in implementing the IEP. Parent advocates are a wonderful way to help facilitate this collaborative process, but unfortunately with school and state budget cuts, most schools cannot afford to have a parent advocate on staff. As professionals and as parents we have to build this relationship for the benefit of our children's futures.

Support from page 33

Parents must take care of themselves before they can take care of their children. To do this, parents must recognize when they experience stress, how it is manifested, and its possible sources. All parents, especially parents of children with autism, can then benefit from outlets to relieve that stress. Sometimes, it is difficult to find time to relieve or reduce stress. Other times, the typical outlets (e.g., listening to music, exercising, going out with friends, etc.) to relieve stress are simply not enough. In many cases, parents can benefit from learning stress reduction and relaxation techniques from professionals, like deep breathing exercises, breaking down expectations/ goals/ tasks, and cognitive restructuring. We know that thoughts we tell ourselves can increase or de-

crease stress, depending on the nature of thoughts, and affect our behavior. "The Little Engine that Could" was able to accomplish quite a bit more when she believed with confidence that she could complete the seemingly insurmountable task. Due to its likely impact on parent behavior, the thoughts parents tell themselves can have an impact on their child's future development. Recent literature (Durand, Hieneman, Clarke, & Zona, 2009) indicated that parents who had negative thoughts about their parenting skills, and not the severity of problem behavior or the child's cognitive deficits at age 3, was the best predictor of problem behavior three years later. Cognitive restructuring, a component of cognitive behavioral therapy, can relieve parents' stress levels by changing dysfunctional or unrealistic thought patterns. Cognitive restructuring can also look to improve

parenting behaviors by modifying the thoughts parents tell themselves. For example, instead of being rendered inactive by believing thoughts such as, "nothing I do will improve my child and his skills," "I don't have time to teach my child new skills," "my child will be dependent on me forever," or "my child is like this because of me," it would serve parents well to view their situation and parenting abilities/potential from a more favorable perspective. Doing so would not only empower them to be even more active in their child's development, but would also make the involvement more positive and productive.

In summary, by taking care of themselves, parents will be more capable to care for their child, thereby allowing them to manage daily routines. With a united effort between parents and professionals, parents can learn to deal with stress re-

lated to autism and, in turn, be better able to teach their child skills that will serve him throughout his life.

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ADA from page 35

from full and equal participation in all aspects in their schools, colleges, businesses, and employment opportunities.

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