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 obscenities 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, 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.

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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 setting.

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Deadline: June 15, 2011

Fall 2011 Issue:
“Understanding and Addressing the Unique Needs of Individuals with Asperger’s Syndrome and High Functioning Autism”
Deadline: September 15, 2011

Winter 2012 Issue:
“Science Matters: The Latest Advances in Autism Research”
Deadline: December 15, 2011

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“Transitioning into Adulthood: Navigating the Complex Changes Ahead”
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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 diagnosed children enter the system in order to receive the financial, medical, educational, etc. supports they may need during their lifetime, young adults 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 management plan will not guarantee good behavior, so it is important that parents know the systems that exist to protect their children.”

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 (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 or become involved 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 wallet card 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, firefighter, 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 characteristics 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, who parents become familiar with at school IEP meetings revolving around their child’s diagnosis, to her real-life son who has tales of住 here and foreign affairs, 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 limited verbal skills.” ‘Child needs visual cues to communicate’ ‘Child is self-directed.’ It wasn’t then 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 sprig him to life in all of his autistic glory.”

In addition to our featured 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 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.

As a nonprofit organization, we ship thousands of free copies of each issue of Autism Spectrum News to our growing family of autism and mental health organizations. For those who may not have the opportunity to pick up copies of each issue at our delivery locations, we post each entire issue for free on our website at www.mhnews-autism.org. On our website you can subscribe to receive your own personal hardcopy that will be mailed to your home or office address. You can also order our group subscription and receive 50 copies of each issue for your clients and staff.

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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Updated 2011 IACC Strategic Plan for ASD Research

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

The Intergency Autism Coordinating Committee

The Intergency 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 gaps 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 representatives of collaborations 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 Intergency Autism Coordinating Committee (IACC) is a federal advisory committee.

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

Lynda Geller, PhD, Founder of Spectrum 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 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 instruction 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 spectrum 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 intervention 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 will then 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 (Hornor, 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 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 individual 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 have 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.

References


Hornor, R.H., Carr, E.G., Halle, J., McGee, G., Odom, A., & Wolery, M. (2005). 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).

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.
Hope for People with Autism and Their Families

For more than 50 years, the YAI Network has provided comprehensive person-centered services to people with autism spectrum disorders and their families. Our new state-of-the-art YAI Autism Center combines our long tradition and expertise of serving people with autism with an early detection and treatment center; a school for children on the spectrum; family support and life planning services.

Our tradition of excellence make us uniquely qualified to serve your family.

yai.org/autism
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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 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 water. 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 due 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

For more information about our research or clinical program, please contact:

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CALL: 212-241-0961
VISIT: www.seaverautismcenter.org

The Seaver Autism Center for Research and Treatment is dedicated to discovering the biological causes of autism and to developing breakthrough treatments.

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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 Ceece 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 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 naivety, 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 must be taught and reinforced.

Privacy 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...
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” support. 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 Applied 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, Speak at the 32nd Annual YAI International Conference at the Hilton New York located at 1335 Avenue of the Americas, New York, NY on May 5, 2011 at 4:00 p.m.

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FEGS Day Habilitation and Residential programs are licensed and funded by the New York State Office for People with Developmental Disabilities. Additional services are also supported by The New York City Council, the New York City Department of Health and Mental Hygiene and the J.E. & Z.B. Butler Foundation through UJA-Federation of New York.
By Mary Riggs Cohen, PhD
Spectrum Services
Asperger Center for Education & Training

I n 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 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 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 naïveté and ineffective communication can lead to inappropriate behaviors that may be interpreted as stalking or unwelcome sexual advances (Debbaut, 2004). In his article, 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. Heraut (2005) has said that many adult ASD individuals are drawn to younger people because they feel that age expectations. 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 drawn to child pornography due to their obsessive compulsive tendencies, perseverative behavior and social isolation (Heraut, 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 dependency on pornography for sexual arousal and as a result become conditioned to be aroused by atypical images such as pornographic cartoons, hentai (Japanese animated pornography), child pornography or sadomasochistic 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

visit our website: www.mhnews-autism.org

Advice from a Neurotypical on Being Successful at Work

Barbara Bissonnette, Principal
Forward Motion Coaching

A n often quoted statistic is that 85% of adults with Asperger’s Syndrome (AS) are either underemployed or under-employed. Whether that number is accurate or not, clearly there are too many intelligent, college-educated individuals 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 jobs. They 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 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 individuals 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 (at his own request) to give him 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.

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.
Announcing the Opening of Spectrum Services

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- Spectrum Services is a cooperative of independent practices and organizations.
- All of our participants specialize in evaluation and treatment of children, teens, or adults with Asperger Syndrome and related conditions.
- Our services include specialized psychotherapy, social skills and pragmatic language groups, psychiatric services, speech and language, college coaching, executive function services, couples counseling, vocational assessment and support, social skills seminar, neuropsychological evaluation, individual and family support, certification course on college coaching, and a seminar series on autism spectrum issues.

Lynda Geller, Ph.D.  Founder of Spectrum Services and Psychologist
Mary Riggs Cohen, Ph.D.  Psychologist
David A. Cooperman, M.D. Psychiatrist
Enid Gort, Ph.D.  College Coaching
Rhea L. Hooper, M.A., CCC-SLP.  Speech and Language
Mitchell Nagler, MA, LMHC Mental Health Counselor
Shuli Sandler, Psy.D.  Psychologist
Ilene Solomon, Ph.D.  Neuropsychologist
Renee Soufer, M.A., Ed.M., Psychologist in training
Beth Yurman, Psy.D.  Psychologist

Asperger Center for Education and Training is a virtual center that disseminates information about AS and has nonclinical services available such as coaching, coaching supervision, educational consultation, and series of workshops and courses at www.aspergercenter.com

Asperger Syndrome Training & Employment Partnership (ASTEP) is a non-profit organization whose mission is to create and support programs that promote long-term employment for adults with Asperger Syndrome and high functioning autism.  ASTEP focuses on developing jobs in the corporate sector and training employers about the special talents and needs of adults with AS.  www.asperger-employment.org

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

Career and Employment Options, Inc., CEO is an award winning service providing transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities.  www.ceoincworks.com
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 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
The Simons Simplex Collection

Questions raised by AUTISM bring us together.
HELP US search for answers.

Strength in Numbers
Families connected by autism share a common bond. Their courage is inspirational, their questions are clear. What are the causes? Are there treatments? What does the future hold? Scientists hope to answer these questions with help from 2,000 families with one child on the spectrum.

13 Collection Sites Across North America

2,000 Families, One Mission
At 13 research sites across the country, eligible families with the following characteristics are answering our call for help.

- One child with an autism spectrum disorder (ASD), age four or older
- One or more siblings without ASD, age four or older
- Both biological parents willing to participate.

Can you help us reach our goal? Learn more at www.sfari.org
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 healthcare 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.

Special Child. Special Concerns. Special Solutions.

Preparing for the future of a child with special needs is a specialty of its own. It takes a professional with an understanding of the complexities of special needs and the ability to create a customized financial solution as unique as your family.

For a Five-Step Special Needs Kit contact:

Stephen Ehrens, CPA, CLTC
Financial Representative
(203) 256 - 2162
stephenehrens.com

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The Master of Arts degree in Disability Studies is preparing a new generation of service providers, researchers, advocates, and policy makers to be leaders in the field, in the classroom, and at the policy table. With a cross-disciplinary, holistic curriculum and an outstanding faculty, students have the opportunity to explore the phenomenon of disability from a variety of perspectives and disciplines.

To learn more or attend an upcoming Open House, visit www.sps.cuny.edu/madisability or call 212.652.CUNY (2869).

At Devereux, we understand the unique challenges facing families caring for individuals with autism. We live by the promise that every Devereux program and service must be of such superior quality that we would enroll our own child with complete confidence.

In our service to those living with autism, several factors make us outstanding:

1. Applied Behavior Analysis principles are used in all areas of programming.
2. Instruction occurs wherever necessary: in school, at home and in community settings toward the goal of less restrictive placement and a higher quality of life.
3. Goals and objectives are highly individualized and take the form of skill acquisition and positive behavior development.
4. Parents and guardians are critical team members, and we focus on parent education and support.
5. We focus on employment preparation and placement.

For more information, call one of the following autism-specific Devereux programs:

**Devereux Connecticut, Glenholme School**
81 Sabbaday Lane
Washington, Connecticut 06793
(860) 868.7377

**Devereux New Jersey**
220 Mantua Grove Road, Building #4
West Deptford, New Jersey 08066
(856) 599.6400

**Devereux New York, Millwood Learning Center**
14 Schuman Road
Millwood, New York 10546
(914) 941.1991

**Devereux Pennsylvania, Kanner Center**
390 East Boot Road
West Chester, PA 19380
(610) 431.8100

**Devereux Center for Autism Research and Education Services**
620 Boot Road
 Downingtown, PA 19335
(610) 873.4930

**Devereux Community Adult Autism Partnership Program**
150 E. Pennsylvania Avenue
Suite 400
Downingtown, PA 19335
(610) 269.5318 x 224

Or contact our National Referral Office at 800.345.1292.

www.devereux.org

Devereux offers programming and services in 11 states – Arizona, California, Colorado, Connecticut, Florida, Georgia, Massachusetts, New Jersey, New York, Pennsylvania, and Texas.
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 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/ersa/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
By Ernst O. VanBergeijk, PhD, MSW and Ron Hollander, Esq
New York Institute of Technology
Vocational Independence Program

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 arguments 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 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 promoting 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
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 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 offender, jail time).

Samara Pulver Tetenbaum, 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 regarding 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 Dalyrymple (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

Shana Nichols, PhD

see Sexuality on page 42
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 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. 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”
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 karaoke on Sunday that he knew had karaoke on Sunday night. He turned down an alley, heading toward a McDonald’s and a CVS, and was in downtown Boston, hoping to hear karaoke on Sunday night. He walked by a McDonald’s and a CVS, and was in downtown Boston, hoping to hear karaoke on Sunday night. He turned down an alley, heading toward a McDonald’s and a CVS, and was in downtown Boston, hoping to hear karaoke on Sunday night. 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 night. 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?”

“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 likely cooperate. To help me cooperate, PLEASE:

- Clearly identify yourself as a law enforcement officer/first responder.
- Tell me 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.

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.
- Tell me 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.

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

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 laminating kit from a pharmacy, hardware, or stationary store.
5. Put the card into your wallet; carry it with you whenever you leave home.

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.

A n 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.

Wallet Card for Disclosure to First Responders and Law Enforcers

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

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

Directions
1. Cut out both the front and back sides of the card.
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 laminating kit from a pharmacy, hardware, or stationary store.
5. Put the card into your wallet; carry it with you whenever you leave home.
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 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...
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.

**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.

**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.

Inability 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 institutional settings, it cannot be used to promote the 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 independance 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 disabilities 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 Joint Commission on Juvenile Rehabilitation 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.
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 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 dash 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 removed 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 great 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 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 Security 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 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 go be a career that they can pursue through reasonable accommodations. The counselor works with the client to achieve that goal, 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.
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.

Kanner was born on June 13, 1894 in Klekotow, Austria. He grew up in a Jewish community, in which his primary education 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. 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
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 devastat-ing 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 appropriate 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 psychologist 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 school’s 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.”

So we realized that this school district 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 immedi-ately 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 advo-cating 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 recommen-dations 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 dis-trict. Reimbursement cases are analyzed under the Burlington/Carter 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 consider-a-tion 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.”2

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 becoming 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 co-operate at all stages of the IEP development process. At the same time, you must remem-ber that YOU are the expert of your child. Many times, you know better than anyone else at the IEP meeting what your child re-quires in order to make meaningful pro-gress. With evaluations and recommendations from your professionals supporting your position, you can feel comfortable po-lisely 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.

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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 thou-sands of children with autism, there are simply not enough publicly funded appro-priate placements and programs available.
Parental 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 then other 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.

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 trying to apply to the New York State 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 coordinating 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 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, with a focus on Community Health and Patient Education, from Stony Brook University Health Sciences Center.

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 (ASTE3P), 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.

ASTE3P 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 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 supports (i.e. company managers/co-workers, etc.).

aste3p 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, professional volunteers 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 (ASTE3P), based in New York City. During her most recent tenure as the Director of Family Support Services at Stony Brook University Hospital, she was elected to the New York State 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 coordinating 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 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, with a focus on Community Health and Patient Education, from Stony Brook University Health Sciences Center.
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from the special child herself, but only from third parties - parents, grandparents, other relatives - either by direct gift to the intestate or by a will naming an heir. 3. A trust created by the special child during her lifetime, such as a payback trust, can be used to meet the same ends. The advantage is that the child can control the trust, whereas the guardian would control a payback SNT.

After years of corporate experience in the financial world, Marcia Scheiner, CEO of the Autism Asperger Advocacy Foundation, founded the organization in 1997 to provide support to families of special children. The organization has provided support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. The Autism Asperger Advocacy Foundation is a non-profit organization and is a 501 (c) (3) organization.

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 specied trust created by the special child to hold all the child’s assets. The advantage is that the special child can control the trust, whereas the guardian would control a payback SNT.

The Self-Settled SNT is similar to the Third Party SNT, except that it can only be used for paybacks and Medicaid. A Self-Settled SNT cannot contain a Medicaid payback provision. The Medicaid payback requirement of the TP 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 and then spend it or pay it back to Medichild first. An ounce of prevention is 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 specific behavior interventions and supports.

Misbehavior is an inherent part of disability and particularly of children on the autism spectrum. Congress passed the predecessors to the IDEA in 1975 to ensure that states could not exclude children with disabilities from their neighborhood schools. In 1988, the Supreme Court held that “Congress meant for school children on the autism spectrum to be integrated into the general education setting. This was the intent of the law, and it was the purpose of the law scientifically measured with success rate data.”

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 and then spend it or pay it back to Medichild first. An ounce of prevention is worth a pound of cure.

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 NLData.com, a member of CT Association on Education 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 as an attorney at the University of 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 preeminent national special education advocacy organization and an adjunct professor of special education law at Central Connecticut State University. Attorney Feinstein is also a member of CT Association on Education for Children with Learning Disabilities and Smart Kids with LD, a member of the Council of Parent Attorneys and Advocates (COPAA). He is a member of the Council of Parent Attorneys and Advocates (COPAA). The A. Feinstein’s practice is currently located in Mystic, Connecticut.

To obtain information or contact the participants of Spectrum Services, please see the website at www.spectrumservicesnc.org.
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 us 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.

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 valid 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 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 Tool Kit (www.autismspeaks.org/community/family_services/transition_kit.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 preparation, 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, with or without the help that 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 support 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 gathered by experts in the field. We 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.
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.

Furthermore, we must alter our behaviors from page 13

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

Furthermore, we must alter our behavior depending on situational and social context. 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 Assemblywoman 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 Nutley, New Jersey. The law sponsored by Assemblywoman 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 must then complete a knowledge verification 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 responders, is 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 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 understanding the special needs of all their residents. If the first responders know in advance who is residing in their catchment area they can then provide a more comfortable and safe 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 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 walk through your home to give you suggestions on safely securing you 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 feel comfortable to 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 responder to inquire whether they have 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 community. Unfortunately, we are all too often medicated as a result of what we are witnessing and this does not allow 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. The officers in the field are often the first to arrive at an incident and must act swiftly and decisively. Ultimately, the behavior is occurring. They also report feeling uncomfortable with the course material. 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 where 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 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 Autism Spectrum Disorder Training 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

Behaviors

Strategies for Addressing These Issues

Dealing with sexuality in persons with ASDs is a complex undertaking. From a legal perspective, there is no significant body of law which provides guidance on how to respond to a range of sexual behaviors. Individuals with ASDs must be provided accurate and concrete information regarding their sexual identity, training in the social nuances associated with sexual behavior and sexual expectations. There is growing evidence that individuals with autism spectrum disorders do have unique sexual identities and expressions. 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 time and attention. Introducing concepts and programs in late childhood or early adolescence will ensure opportunities to teach across many different and important subjects.

• Teach concretely - it’s important to clearly define appropriate and inappropriate behaviors. It is also necessary to focus on self-awareness and maintaining skills - some individuals with ASDs have difficulty maintaining skills and
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 counters periods when he is overwhelmed by compulsions.

David is very self-aware: he does not want to engage in any compulsive behavior 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 “Silent Journey.”

Sandy’s forthcoming book of poetry, many poems on or about David, is available at www.finishinglinexpress.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 esteemed faculty at Columbia University and has participated in the development and implementation of an effective strategy-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 more 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.

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.
Some autism spectrum disorders are caused by the improper expression of a gene termed UBE3A. Having duplications or deletions 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 autism-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 Tenerbaum and Stephen Shenkoff
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 language 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 Koeleg
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. Linguistic measures 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-child education component will also be incorporated allowing for the evaluation 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 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 its 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 structure and function of 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.

I’m not sure we’re ready for this: Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. Social Work in Mental Health, 8, 72-91.


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.

Dr. Mary Riggs Cohen, PhD is a Licensed Psychologist at the Asperger Center for Education and Training. To learn more, visit www.aspergercenter.com. Dr. Cohen can be contacted at mc@autismsrc.org.

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 can 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.

Dr. Scott Standleifer is an Adjunct Professor for the Disability Policy & Studies office (DPS) at the University of Missouri. He is the author of Adult Autism & Employment: A guide for vocational rehabilitation professionals, and of the online Handbook of Disabilities. He was an organizer of the Autism Works National Conference, March 3 & 4, 2011, and will present on Current Trends in Autism Employment at the Autism Intervention Conference held by The Thompson Center for Autism and Neurodevelopmental Disorders, April 15, 2011. He can be contacted at standleifer@missouri.edu or through his website www.dps.missouri.edu/autism.html.

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

Sociization and Life Skills Group For Asperger’s Syndrome and High Functioning Autistic Adults

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

For further information contact the facilitators:
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Dates for 2011:  4/10,  5/22,  6/12

Westchester Arc
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Executive Functions

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 Functions (EF) may manifest in multiple environments and impact children differently, depending on their developmental and cognitive abilities (Dawson & Guare, 2010).

Children with EF problems, parents may notice that their children have difficulty with ongoing routines such as getting ready for school and organizing their homework. 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. This can often be an arduous task, as children with executive function deficits typically forget to bring their home worksheets from the previous 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 up in class or resist exiting the classroom. Deficits in EF result in a student who is unable to prioritize different homework assignments and instead, becomes overwhelmed and tasks are left undone, avoiding 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, empty the laundry, wash dishes, 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 be 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. Additionally, planning and organizing executive functioning. Organizing a calendar, time management, and juggling different extra-curricular activities are other areas of potential difficulty. Preparing for college and tackling the many steps towards transitioning 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 and development, the expectancies 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 declines during adolescence, with growth spurts in frontal lobe development lasting through the beginning of adolescence (Anderson 2002). This can present an overwhelming challenge for a student who has difficulty with or transitioning to a new academic environment, a teacher can help the child break tasks into smaller steps to make the classroom intervention more manageable. The teacher can also take note of those situations that trigger EF 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, when 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 to 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 been developed in the home environment which may include taking deep 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 that is overwhelming 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 overwhelmed. The Incredible 5-point scale (Buran & Curtis, 2003) uses a rating scale where children can rate their feelings on a scale of 1 to 5 for different situations 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.

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.
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. Parents’ respective roles while living in the family 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 that parents 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.

A resource to help you identify local legal professionals for your family is www.nationalcareadvisors.com

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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-government organizations and websites that provide 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.nichey.org
- Special Needs Alliance
  www.specialneedsalliance.com
- 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.

Should the custody dispute devolve into an adversarial scenario, then a forensics 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 concept of a child on the autism spectrum and the social behaviors characteristic of the child 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 examiners, and guardians ad Litem be trained to recognize children with a copy of the custody evaluation of ASD.

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 (Ahrons, 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 parent’s home is more likely 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 educations and interventions are best. ASD is present.

References


Dr. Ernst VanBergeijk, is the Associate Dean and Executive Director of New York Institute of Technology’s Vocational Independence Program. Holland E, Esq. is an attorney who specializes in matrimonial and real estate law.
Sexuality from page 24

often interpreted as sexual, which unfortu-
nately can result in significant legal reper-
cussions. The second kind of behavior
appropriate for youth with ASDs and therefore any behaviors perceived to be
sexual and inappropriate in nature are
not taken lightly. The most suitable inter-
vention 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 treat-
ment requirements has not been an option,
resulting in 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 com-
pared to their typically developing peers
due largely to limited access to available
and appropriate educational resources
(Koller, 2000); there is little material spe-
cifically geared towards teaching sexual-
ity and relationships to individuals with
ASDs. Typically developing youth have a
great deal regarding sexual behavior
through social observation of peers, fam-
ily, and media and sharing that informa-
tion within their peer groups. As dis-
cussed earlier, youth with ASDs often
don’t have 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 education additionally
incorporates social skills training and so-
cial thinking concepts, because healthy
sexuality is embedded within the social
environment. It is essential that any sexu-
ality 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 oth-
er). There are a surprisingly large num-
ber of social rules that govern our sexual
behavior. Many of these rules are unwrit-
ten and requires that parents and educators
focus on teaching these rules to youth with
ASDs who struggle with social understanding.

Compensatory from page 25

agrees to “up” Sydney’s speech services
by a half hour per week - still two and a
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 par-
ents continue to see a lack of progress, and
despite the “extra” half hour of speech, Syd-
ney is losing language skills, i.e., she is re-
gressing. In November, Sydney’s speech
therapist goes out on maternity leave and is
out the entire month. 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 pa-
tiently wait for the school district to help
them - they need to find out what Sydney’s
education plans are and consult with a lawyer who specializes in
special education law.

After consulting with their lawyer, Syd-
ney’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. Syd-
ney’s parents learn that this is the first time
Sydney has viable claims for the missed
speech sessions that were man-
dated 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
need, and advocates should keep in mind whenever a school district fails to
deliver or recommend appropriate services.

Tracey Spencer Walsh, JD (Fordham University School of Law, ’94) is the Sen-
or Counsel at Mayerson & Associates, a
New York law firm dedicated to repre-
senting children and adolescents on
the autism spectrum and their families in
accessing the education and related ser-
dices necessary and appropriate for stu-
dents. For six years, Ms. Walsh worked as
an educator and served as an Upper
School Dean of Students at an independ-
ent 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
could be argued to the court that the student
was not offered the services necessary 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 gonna grow up?”

• rocks the chair, squirms in his
squirming subject’s 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

He has a crush on his first grade
teacher, Mrs. Cushman

His nickname is Jack-a-boo or Kan-
garoo Jack

Jack’s paper version makes me feel like this:

• Sad I have a child who is special needs

• Anxious that he’ll need live with us
forever

• Frustrated that the reading load ahead of us

• 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

and learning about appropriate expression
of affection is crucial to prevent both vul-
nerebility to being sexually exploited and
views of aspergians helping others. By pre-
paring 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 sys-
tem, of the unique experiences of indi-
viduals 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 con-
tinue to experience negative and often
traumatic interactions with the legal sys-
tem that are fraught with harmful misun-
derstandings.

For more information about the “ASPIRE Center” and our sexuality edu-
tation programs, please contact Samara
tetebam, PhD, Psychology Fellow at
 ASPIRE at 631-923-0923 or spanga-
re@gmail.com. You may also visit our
Support from page 33

Parents must take care of themselves before they can take care of their 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., a specific extra curricular activity, 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 decrease 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 quite a bit 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 related to autism and, in turn, be better able to teach their child’s skills that will serve him throughout his life.

References


Dr. Brian Goldberg is a psychologist and consultant in school districts on Long Island. He is the founder of United Supports for Autism, which is an organization to support families with a child with autism. To learn more about United Supports for Autism, visit www.unitedsupportsofautism.com.
Helping families understand and cope with a child on the spectrum can only be achieved by providing them with information that is based upon the best scientific research and medical evidence.

Autism Spectrum News provides vital news, information, education, advocacy, and resources in the community that adhere to our strict evidence-based standards.

Contact us today at (508) 877-0970 and visit our website www.mhnews-autism.org to learn how Autism Spectrum News can help provide your organization or community group with an affordable and trusted source of autism education.