

Managing the Financial Needs of Autism

Protecting the Financial Future of Your Child with Autism

By Bernard A. Krooks, Esq
and Sheryl R. Frishman, Esq
Littman Krooks LLP

Parents of children with autism know that just getting through day-to-day life requires careful planning. Many parents do not consider that financial planning for their child with autism also requires careful and special planning, especially when the child may not be able to support or care for himself when the parents are gone. The thought of ever predeceasing a child with significant special needs is frightening. So frightening that parents may do everything they can to try not to think about it. Who wants to face their own mortality? Who wants to face it especially when they are consumed with the day-to-day challenges that go into raising a child with autism? Nevertheless, there will most likely be a time when parents will predecease their child with autism, and it is absolutely essential that a financial plan be put in place to ensure that the child is cared for in the manner the parent wishes.



Government Benefits: While there are many government benefits that children with autism may qualify for, for the purpose of this article, we will review the two that are most widely used for people with

developmental disabilities and are available in all 50 states. These are: Supplemental Security Income (SSI) and Medicaid. It is imperative for parents to realize that eligibility for SSI and Medicaid are critical for

their child with autism. Eligibility for these two benefits is often necessary to be able to receive services as an adult. For example, in several states, group homes and other community residences are covered by these benefits; along with most day habilitation, some job training programs, and other essential adult services for your child.

Medicaid and SSI are in a category of government benefits that are called “means-tested” benefits. This means that in order to qualify for these benefits, not only does an applicant have to meet the criteria to be considered “disabled,” but must also have extremely limited assets and income. For example, for SSI, an applicant can have no more than \$2,000 in assets to be eligible. Because the income and asset threshold are so low, a parent or well-intentioned relative should not put money in, or leave money to, the child with autism. If the child has assets over the eligibility amount they will not qualify for these important benefits. If those assets are transferred out of the child’s name, then

see *Financial Future* on [page 20](#)

Autism Spectrum News to Honor Cartwright and Fiddle At First Annual Leadership Awards Reception

☆☆ You Are Cordially Invited to Attend! [Click Here for Details](#) ☆☆

Staff Writer
Autism Spectrum News

Autism Spectrum News is very pleased to announce that it will honor two outstanding and distinguished leaders of the autism community at its First Annual Leadership Awards Reception. The special event will take place on Wednesday, November 6th at 3:30 pm at the Crown Plaza Hotel in White Plains, New York. You are cordially invited! Please see our back page for more details on how to purchase tickets and support this important event.

Charles N. Cartwright, MD, is Director of the YAI Autism Center. He is an expert in the diagnosis and treatment of autism spectrum disorders in children, adolescents and adults. He is a board certified child and

adolescent psychiatrist and a faculty member in the Department of Psychiatry, Child and Adolescent Division, at the University of Medicine and Dentistry of New Jersey.

Linda Walder Fiddle is the Founder and Executive Director of The Daniel Jordan Fiddle Foundation (DJF), a national Autism organization focused on adults. The mission of the volunteer-run organization is to develop, advocate for and fund programs that create innovative ways for the diverse population of adults living with Autism Spectrum Disorders (ASD) to participate in and contribute to community life. The Daniel Jordan Fiddle Foundation Signature Programs developed and funded by the DJF Foundation can be found throughout the U.S. and include residential, vocational, educational and recreational opportunities that are blueprints for replication in grassroots communities throughout the world.

According to David Minot, Publisher of *Autism Spectrum News*, “We are so excited to be honoring two such outstanding leaders of the autism community at our first Leadership Awards Reception since *Autism Spectrum News* premiered in the fall of 2008. We hope everyone will come out and support this event, which will help us raise the funds needed to expand the free distribution of *Autism Spectrum News* and provide unlimited free access to our website that provides autism information and education to the entire autism community. I would like to give a special thanks to the members of our event planning committee, all of whom are dedicated members of the *Autism Spectrum News* Editorial Board: Susan M. Cortilet-Jones, MS, LMHC, Judith R. Omidvaran, Patricia Rowan, LMSW, and Dianne Zager, PhD.”

Previously, Dr. Cartwright served as the Director of The Autism Center at UMDNJ

where he directed autism clinical, research and educational outreach activities. He ran a large clinical practice, lectured widely on autism-related topics, advocated for legislative and policy initiatives as a member of the New Jersey Governor’s Council on Autism, which enhanced autism clinical centers throughout the State of New Jersey, and conducted research in autism genetics, neuroimaging and psychopharmacology.

Dr. Cartwright completed a general psychiatry residency in Cape Town, South Africa, as well as fellowships in child and adolescent psychiatry at New York University/Bellevue Hospital and autism research at the Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine.

Linda Walder Fiddle is recognized as a “social entrepreneur” and has created and

see *Awards Reception* on [page 20](#)

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Deadline: June 5, 2014

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Deadline: September 5, 2014

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AUTISM SPECTRUM NEWS DESK

Mount Sinai Researchers Receive NIH Grant to Study Promising Treatment for Autism Subtype

By The Seaver Autism Center

Scientists at the [Seaver Autism Center](#) at the Icahn School of Medicine at Mount Sinai have received a grant from the National Institutes of Health (NIH) to study Insulin-Like Growth Factor-1 (IGF-1), a promising treatment for a subtype of autism called Phelan McDermid Syndrome (PMS). The grant will allow researchers to expand upon an ongoing study assessing the clinical benefit of IGF-1 in children with this severe type of autism.

IGF-1 is a commercially-available compound for growth deficiency that is known to promote nerve cell survival as well as synaptic maturation and plasticity. The primary aim of the study is to target core features of PMS, including social withdrawal and language impairment, which will be measured using both behavioral and objective assessments. So far, nine patients have participated in a pilot study to assess safety and feasibility of IGF-1. The Seaver Autism Center team hopes to enroll 18 more participants with support from the NIH grant, in order to establish statistically significant clinical benefit of IGF-1. The



Alexander Kolevzon, MD

NIH will provide more than \$750,000 over three years to study IGF-1.

With the grant, [Alex Kolevzon, MD](#), Clinical Director the Seaver Autism Center, will continue to enroll children ages 5 to 12 years old who have PMS in this double-blind, placebo-controlled crossover study. Patients will first receive three months of either active medication or three months of placebo. After a four-week break, patients who received active medication first will then receive three months of placebo, and patients who were first randomized to placebo will receive three months of active medication. Future trials are planned to explore the utility of IGF-1 in ASD without SHANK3 deficiency, the hallmark genetic mutation in PMS.

Dr. Kolevzon has also received a grant for \$25,000 from the [Autism Science Foundation](#) to study IGF-1 as a treatment for idiopathic autism.

“IGF-1 has the potential to be effective in treating Phelan-McDermid Syndrome and other types of autism spectrum disorder,” said Dr. Kolevzon. “We are very pleased that the NIH and the Autism Science Foundation have recognized this by providing us funding to continue our work in bringing this medication to our patients.”

The clinical studies with IGF-1 are supported by studies in a genetically modified mouse with a mutation in SHANK3. These studies carefully examined brain function in the mice when SHANK3 was mutated, and provided preclinical evidence for a beneficial effect of IGF-1. Deficits in nerve cell communication were reversed and deficiencies in adaptation of nerve cells to stimulation, a key part of learning and memory, were restored. These studies were reported the April 27th issue of *Molecular Autism*.

Side effects of IGF-1 administration include low blood sugar, liver function abnormalities, and increased cholesterol and triglyceride levels. Study subjects will undergo rigorous safety screening before they are enrolled in the trial, and will be carefully monitored every two to four weeks with safety and efficacy assessments.

About The Mount Sinai Medical Center

The Mount Sinai Medical Center encompasses both The Mount Sinai Hospital

[see NIH Grant on page 19](#)

Study Finds That Autism Genes are Surprisingly Large

By Virginia Hughes
SFARI.org

Enzymes called topoisomerases are crucial for the expression of extremely long genes in neurons, according to a study published 5 September in *Nature*¹. More than one-quarter of these genes are known autism candidates, the study found.

In the process of doing these analyses, the researchers stumbled on something surprising about autism genes in general: They're three to four times longer than the average gene expressed in neurons.

“It's pretty remarkable that, at least to my knowledge, no one had noticed this before,” notes Benjamin Philpot, associate professor of cell biology and physiology at the University of North Carolina, Chapel Hill, and one of the study's leaders. “But the genes are definitely much longer. It's very striking.”

The findings suggest that defects in topoisomerases — whether caused by genetic mutations or environmental influences — may contribute to some cases of autism and other developmental disorders, the researchers say.

If it's true that long genes are preferentially affected in autism, “the implications are really quite fascinating,” notes James



Benjamin Philpot, PhD

Sutcliffe, associate professor of molecular physiology and biophysics at Vanderbilt University in Nashville, Tennessee, who was not involved in the research.

In genetic sequencing studies, for example, mutations found in long genes tend to be discounted in statistical analyses. That's because the longer a gene is, the



Mark J. Zylka, PhD

more likely it is to harbor a mutation just by chance. But the new study suggests that mutations in long genes should be considered more carefully.

“This raises a really interesting question of whether we may be correcting away something that's inherent to disease risk,” Sutcliffe says.

Transcription Targets

Topoisomerases are found in all cells and are known to play a role in unraveling knots in DNA.

“When a cell divides, the DNA gets tangled up, and these enzymes cut the DNA to unwind it,” says Mark Zylka, associate professor of cell biology and physiology at the University of North Carolina, Chapel Hill, who led the new study along with Philpot.

Drugs that inhibit these enzymes gum up that process, preventing DNA replication and, as a result, cell division. Because of this, these drugs have been used to treat cancer for four decades.

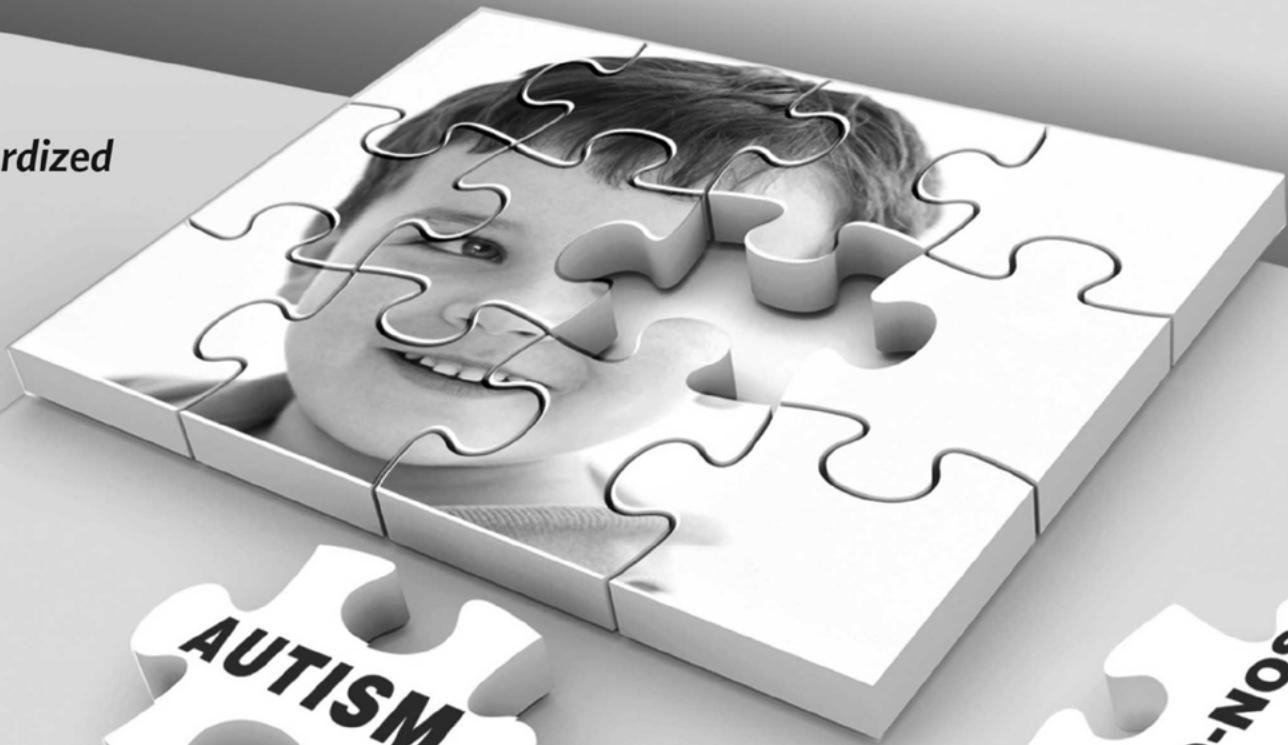
In late 2011, Zylka and Philpot reported in *Nature* that in spinal cord neurons, a topoisomerase inhibitor called topotecan activates the normally silent copy of UBE3A, the gene that is damaged in Angelman syndrome, a developmental disorder related to autism. Duplications of UBE3A are also thought to cause some cases of autism.

It was a shock to find out that topotecan had this affect in neurons, Zylka says, because neurons don't divide. “So we wanted to figure out what the heck these enzymes were doing there.”

Some studies had shown that, in addition

[see Autism Genes on page 31](#)

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Funding Home Programs and Private Schools - Possible, Yes! Easy? Not Exactly

By Tracey Spencer Walsh, Esq
Partner
Mayerson & Associates

You have learned that your child requires intensive intervention and educational services. A school district may provide your child with the services your child requires on the IEP. To help support your request for an intensive (and what is oftentimes, costly) educational program, provide your school district with “quality” recommendations and ask the IEP team to consider the recommendations made for your child’s education. If the school district refuses, all hope is not lost – you may have to retain an attorney to protect your child’s rights under the Individuals with Disabilities Education Act (IDEA) (20 U.S.C. § 1400 *et seq.*). Obtaining funding from your school district can be what makes the difference in your child’s life.

The first step to securing funding for the services your child requires is presenting the IEP team with recommendations from an esteemed professional who has evaluated your child in the area of his disability. An unhelpful recommendation is one that reads: “John requires an intensive level of intervention.” It is too vague and open to interpretation. A much more helpful recommendation is specific, for example: “John requires an intensive level of inter-



Tracey Spencer Walsh, Esq

vention with no less than 40 hours of 1:1 ABA therapy and 4 hours a month of ABA program supervision with a Board Certified Behavior Analyst (BCBA).”

The next step is to share the evaluation and recommendations with the school district and request that the IEP team consider including those recommendations in your

child’s IEP. It will also inure to your benefit to have the professional who performed the evaluation participate in the IEP meeting, either in person or by telephone. This will allow the IEP team to ask questions about the recommendations.

Next, once you receive a copy of the IEP, read it to determine whether it provides an educational program that will meet your child’s unique and individual needs. If the IEP does not provide the educational services that will help your child make “meaningful” progress (progress that is meaningful to *your* child), then you should reject the IEP, in writing, and give reasons why you find it inappropriate. For example, “We just received John’s IEP. As we expressed at the IEP meeting, John requires a far more intensive level of services than is recommended in the IEP. Dr. Jacob’s report recommended that John receive 40 hours of 1:1 ABA, yet the IEP provides for no ABA intervention, and only one period per day of 1:1 teaching time. This is completely inadequate to appropriately educate John.”

What can a parent do next? It is now clear that the school district is not going to meet John’s needs for the upcoming school year, either because the district does not agree with the recommendation, or cannot provide the program in-district for a variety of reasons. Sometimes even the most caring school district professionals who want your child receive the intensive level of services he needs, simply do not have the power or

authority to make that happen. At this point, parents should consult with an attorney who specializes in special education law for advice and plan of action.

Two options available to the parents are to: (1) fund the program and seek reimbursement from the school district; or (2) sue the school district to seek funding for the appropriate program going forward. It is preferable for parents to fund the program, if at all possible, so that the child is benefiting from the program while the litigation is in progress - then the outcome is “only” about the money. The second alternative requires that the child wait until the outcome of the litigation before the educational program is put into place. Attorneys who specialize in special education law can provide parents with strategies to help them and their child reach the desired outcome.

If there is no private school that is either available or that is appropriate to meet your child’s needs, parents may consider implementing a home program and seek reimbursement for the services implemented in the home. (This is not the same as a “home-school” program and you should discuss with your attorney or advocate how to phrase what you are seeking before you contact your school district).

In addition, you should find experienced therapists to work with your child and their services should be within “market rate” in

see [Funding on page 27](#)

This is what success looks like...



This is what an adult living with autism looks like!

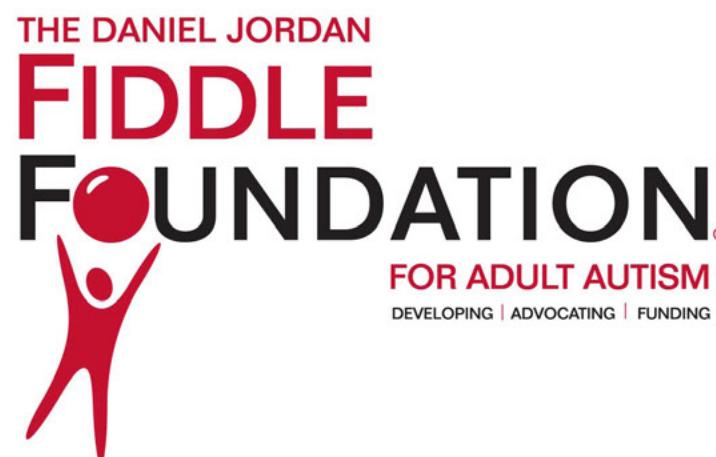
Building successful futures for adults living with autism takes innovative program development, advocacy, funding – and a belief in their strengths, talents and promise.

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Positive Psychology in Autism Spectrum Disorders

By Jill Krata, PhD
Manager of Clinical Services
YAI Autism Center

Using a positive psychology approach in working with individuals with an autism spectrum disorder can help them lead a fuller and a more enriched quality of life. Optimism, resilience and kindness are some of the key traits at the core of positive psychology. Through positive psychology, we can promote these and other character strengths not only to enhance an individual's quality of life, but also to help a person develop new assessment and intervention strategies that focus on positive problem solving.

Positive psychology, at its very core, seeks to identify and understand human strength. It involves looking at what characteristics help a person be resilient in the face of adversity and it looks at what goes right, even in the face of bad situations. Researchers define it as an umbrella term for the study of positive emotions and character traits, and focuses on what is healthy and strength-oriented within people and how these elements help us not only to cope more effectively, but also to flourish and become more adaptable in a world of challenges (Seligman, Steen, Park, & Peterson, 2005).

The unique perspective of positive psychology is that it functions from a strength-



Jill Krata, PhD

based rather than a deficit- or pathology-based foundation, where the primary focus is on augmenting positive personal traits to maximize meaning and engagement in life, as well as positive emotional states.

Traditionally, professionals who work with individuals with autism and developmental disabilities rely on a deficit-based model, focusing on a person's challenges, opposed to strengths. This approach often focuses on external observable behavior.

In positive psychology, the main targets for change are internal behaviors, which are not observable. These internal behaviors are the thinking patterns, self-images, attributions and cognitive constructs that lead an individual to feel happy, fulfilled and therefore, an increased self-esteem and well-being. By incorporating both these external and internal behaviors, parents, educators, caregivers and therapists, may be able to address more of the many aspects that create a higher quality of life and a sense of well-being in people with autism and developmental disabilities.

Programs and services in our field are typically designed to decrease inappropriate behaviors and increase desired behaviors. By developing practices which foster positive traits, we can shift the emphasis from specific targeted behaviors to focus on enhancing intrinsic values. By looking at intrinsic values, programming and interventions can be expanded to enhance these character strengths within a wide range of therapeutic techniques that incorporate positive problem solving by utilizing multi-sensory procedures as traditional programs do.

Treatment and programming can continue to focus on basic principles of behavior modification while incorporating visual supports, repeated practice, high levels of reinforcement, while including a positive problem solving approach to allow for opportunities for people to become more

independent and fulfilled. For example, if a person with autism consistently destroys community property, in addition to a program targeting property destruction, professionals could also focus on a long-term value of being a productive and integrated member of the community. To achieve this, interventions might reinforce kind, empathetic and courageous behavior as well as teaching optimistic thinking.

The five main character traits in positive psychology are: optimism, humor, self-efficacy, kindness and resilience. In the field of psychology, optimism has been a topic of research for many years. Researchers believe optimism has something to do with maintaining a positive outlook, expecting that positive things will happen and behaving as if anticipating a good outcome. Most of the research has been done on the level of optimism people have when faced with difficult situations or stressful life events. Human responses to familiar life challenges, such as caring for a loved one, going through a major life change, have been studied extensively. In general, the results of these studies have shown that optimistic people tend to enjoy better psychological health, use more coping strategies, feel that they have fewer barriers in fulfilling their goals and benefit more from social support in times of stress.

Promoting optimism in people with an

see *Psychology* on [page 24](#)

yai.org/phc

We salute our colleague Dr. Charles Cartwright

You combine brilliant clinical insight with great sensitivity for every single patient and family in your care.

You are always encouraging, never unrealistic, and in many other ways an inspiring teacher to all of us fortunate enough to work with you.

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Five Steps to Help Young Adults Transition to Independence

By **Elise Hahn Felix, LCSW**
 Director, Jewish Child Care
 Association's Compass Project

There are many services for children with Autism Spectrum Disorders, but Jewish Child Care Association's Compass Project is unique because we specifically target the period when an adolescent/young adult transitions from high school to the next step. While school districts support families and individuals in high school, there is often a huge cliff awaiting families once their child graduates. Compass helps them avoid the cliff and find a path toward a productive life that is right for them.

Starting with Questions

Compass helps the family and individual understand their choices, rights, and options. Families need help facing and allowing their young adult or adult child to begin to advocate for themselves. This is easier said than done.

Can the child go to college? And which college program is the right fit? Compass/Bridges has staff on the campuses of 10 different metropolitan colleges and universities (including Adelphi, Queensborough Community College, FIT, and Pace in Manhattan) helping students advocate for themselves with their professors as well as



Elise Hahn Felix, LCSW

participate in various clubs and activities. College is not just an academic experience, but the opportunity to forge new friendships, which is often the biggest challenge for these individuals.

Internship Opportunities

For students who want to test the waters and see what an entry level position would be like, we have internships in the summer and throughout the school year. We pro-

vide career assessments to determine suitable career choices. This can occur while the student is in high school or throughout this transition process.

Perhaps the student wants to do a little bit of work and take several college classes. We can help design the best fit. We are also an ACCES VR vendor. This means that once the young adult child graduates high school, New York State offers some supports to attain a job, with coaching for a certain period of time.

Building Social Skills

We know that getting a job and keeping a job are two very different issues. JCCA's Compass Project offers resume writing, interviewing workshops, and role playing. More than that, we offer social skills building through Club Compass, where individuals go on outings to the city, learn travel training, go out to dinners, and take several overnight trips, including Washington, D.C. and Montauk. Brian M. says of a recent trip, "I had fun walking around town with my friends and buying souvenirs, since I had never been to Montauk before. I also liked having time to sit at the pool and spend time with my friends." Participants practice their skills and parents get some respite. This January, we will be offering our fourth Birthright trip to Israel. This trip includes participants who are neuro-typ-

ical siblings as well as individuals who have never been to Israel and are interested in the health field.

Getting and Keeping a Job

Compass helps participants get jobs. Preston Burger was diagnosed with Asperger's Syndrome at the age of four. He attended Princeton University and then pursued several careers. But after losing five jobs in five years, he decided enough was enough. "I realized I was going to need an extra source of support if I wanted to make it in the professional world," he says. "That's when I contacted Compass."

He started working with Evan Oppenheimer, Compass Project Coordinator.

"Evan helped me get to the heart of what I really value and how I can create this in a job situation. We have open-ended discussions about my future goals and also discussed specific skill-building, like practice interviews and resume revision." Preston now has a job counseling students that he enjoys very much.

Independent Living

Finally, after going to college, possibly living in dormitories, or working part or full time and becoming independent, Compass offers two separate independent

see *Independence on page 19*



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- Workshops to help adjust to life
- Social and recreational activities
- Paid summer internships
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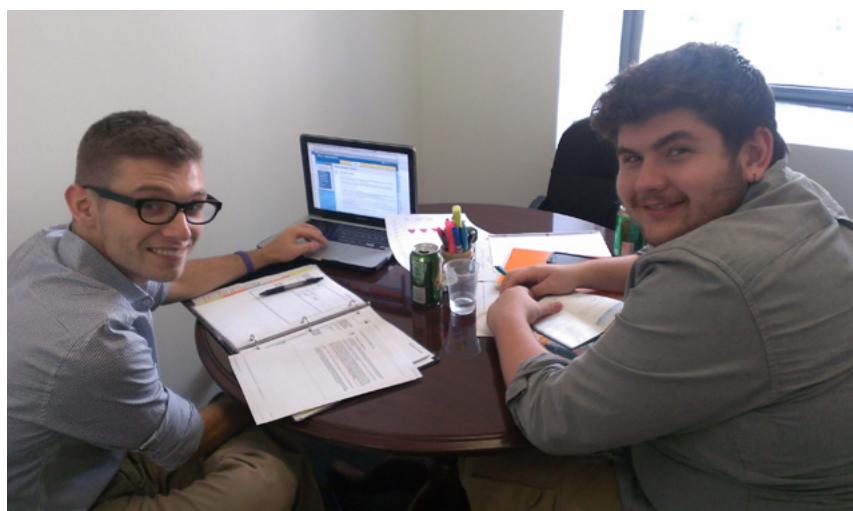
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New York State Autism Insurance Law

“No One Said It Would Be Easy”

By Patrick D. Paul, CPA
Chief Operating Officer
Anderson Center for Autism

On November 1, 2011 New York State became the 29th state to require regulated health insurance plans to cover “medically necessary” services for the diagnosis and treatment of Autism Spectrum Disorders (ASD) for both children and adults. The legislation was intended to help families afford the expenses related to providing services for family members with ASD. This article focuses on one area of the new law requiring coverage of Applied Behavior Analysis (ABA). Many families believe this is the most important change resulting from the new law. This law applies only to State-regulated insurance companies and does not apply to employers who are self-insured.

On October 31, 2012, one day before the autism insurance law went into effect, the New York State Department of Financial Services (NYSDFS), in consultation with the Department of Health and the State Education Department, promulgated emergency regulations identifying the credentials needed by providers to be authorized to receive insurance reimbursement. These regulations essentially changed the



Patrick D. Paul, CPA

requirements and standards of ABA service providers as legislated by the new law thus, drastically reducing the number of qualified providers from approximately 700 to as little as 50 for the entire state. This change made it virtually impossible for families to

find an ABA service provider whose services would be reimbursed by insurance.

In the new autism insurance law, a Board Certified Behavioral Analyst (BCBA) was identified as the credential needed by service providers to deliver ABA services. BCBA's are currently not a licensed profession in NYS. This appears to be the reason why the NYSDFS issued contrary emergency regulations requiring that Board Certified Behavioral Analysts (BCBA's) also hold a license issued pursuant to New York Education Law Title VIII in order to be qualified to provide services, or to supervise assistants that could provide ABA directly to individuals with ASD. One positive outcome of the emergency regulations was the establishment of qualifications and standards for ABA aides that could provide ABA services under the supervision of a qualified BCBA.

In response to complaints from families and advocacy groups, two intervening emergency regulations were issued, culminating in a third emergency regulation issued on July 25, 2013. The July emergency regulation eliminated the requirement for dual licensure/and BCBA certification. It also added licensed providers whose scope of practice includes ABA such as: licensed psychologists, mental health counselors, social workers and certified providers such as teachers and school psychologists. The

revision also provides for Board Certified Assistant Behavioral Analysts (BCaBA) under the supervision of a BCBA, entitling them to insurance reimbursement.

We at Anderson Center for Autism (ACA) have been providing autism insurance education since the law's initial passage. We continue spreading the news about the availability of autism insurance. We speak with advocacy groups, parents, educators and medical providers throughout the state in presentations and continue to provide updates on our website. We began discussions with insurance companies early in 2012. Most companies knew very little about the new autism insurance law and did little to prepare for its implementation. We found that behavioral health organizations were better prepared having administered these services in other states. We worked with many of these organizations setting up our initial administrative and service provision infrastructure. Since NYS law was different than other states, and since the regulations have changed every 90 days since October 1st 2012; service providers, insurance companies, behavioral health organizations, parents and medical providers are challenged to accurately identify which families had autism coverage, who was considered a qualified

see *Insurance Law* on [page 32](#)

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Legal Guardianship: The Pros and Cons for Your Adult Disabled Child

By **Beth Polner Abrahams, Esq**
Managing Partner and Owner
The Law Office of Beth Polner Abrahams

What happens when your special needs child turns age 18? It's a crucial question faced by every affected parent and family. The answer to the question, and special needs planning, means different things depending upon your state's laws. How can you make certain you've done all you legally can to protect your special needs adult child?

The first step, in general, is for special needs planning to begin with preparation of your own will (or trust) which includes what is called an inherited special needs trust to benefit and protect your disabled family member's eligibility for government benefits like SSI and Medicaid, provide for future management of the inheritance, and specifically to carry out your wishes for the future care and security of your loved one.

Most states have some type of legal proceeding to appoint a family guardian of an adult who cannot manage health care decisions and/or their financial assets. Some states have more than one type of guardianship proceeding. In New York, for example, one guardian proceeding is based upon your adult child's medically certified diagnosis of either mental retardation or



Beth Polner Abrahams, Esq

developmental disability, called the "17A" proceeding. Another guardian proceeding requires proof, without specific diagnosis, for a judge to declare your adult child as incapacitated, called an "Article 81" proceeding. "Incapacity" means proof that your adult child is unable to arrange for his or her basic needs, such as food, clothing and shelter, cannot make health care decisions or manage their finances, and that personal or financial harm will result if no

guardian is appointed. A few states still use the term "incompetent" rather than "incapacity" for civil proceedings when a guardian is appointed.

The decision to be appointed your adult child's legal guardian can be as difficult as it is essential. What significance will a guardian appointment have on your adult disabled child?

In most states, including New York, the law presumes every adult age 18 and older is competent to make their own health care decisions. While a medical professional may allow you to participate in or make health care decisions for your adult child, it is not the law. Privacy laws, such as the Health Insurance Portability and Accountability Act (HIPAA), often bar parents from communicating with health care professionals. If surgery or emergency care is needed, you may not be permitted to make decisions nor have input if you have not been appointed as the legal guardian. However, some states, including New York, have adopted laws which permit family members who are not legal guardians to make health care decisions in hospitals as "surrogates." In New York, this is called the Family Health Care Decisions Act.

Still, for health care decisions outside of a hospital setting, it's a good idea to speak to a qualified attorney and to your adult disabled child's medical team to determine if your adult child can understand and sign an advance directive for health care deci-

sions. In New York, this is called a Health Care Proxy; in other states, it may be called a Health Care Power of Attorney. If your adult disabled child has the legal capacity to sign this advance directive, a legal guardianship proceeding may not be needed for health care decisions and management.

If you become the legal guardian for your adult disabled child, will this impact his or her civil rights? Can your child vote, marry, or obtain a license to drive? Can he or she get a credit card?

There are generally no laws which prevent persons with guardians (or disabled adults without a guardian) from entering into a marriage. In many states, the right to marry depends upon the individual's ability to understand the nature, effect, and responsibilities of marriage and its ceremony. The real question for parents and their adult disabled child is whether he or she is capable of consenting to marriage. Usually, the marrying couple does not have to provide proof of their legal capacity to obtain a marriage license. Sadly, some states still refer to "imbeciles," "lunatics," "weak minded," and "insane" in laws about marriage. But these terms are usually associated with dissolving a marriage and whether a marriage contract can be annulled or voided when one person (or their guardian) wants to end the marriage. In most situations, however, the guardian's role will

see *Guardianship on page 28*

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The Power of Dialogue: Small Business and Career Mentoring

By Valerie Paradiz, PhD
Director
Center for Integrated Self Advocacy

As a small business owner and non-profit administrator, I have had exposure to a variety of work experiences. The most difficult experiences ultimately taught me new strategies I didn't know I needed to learn. For example, in a job interview several years ago, I disclosed my diagnosis of autism. I was told at the time that I would be an asset to the non-profit who was hiring me because of my diagnosis and that I would provide insights to co-workers that would enrich the workplace. But then, just days before my start date, the employer informed me that the organization wasn't going to hire me after all, with the explanation that my perspectives on supporting people with disabilities would influence my co-workers too much. I had moved to a new home in a new town in order to take the job, and subsequently suffered significant financial loss because of it.

When I look back on this unfortunate experience, I know that, had I had a mentor, I would have fared much better during the job interview, hiring and disclosure process. For those of us with autism, even if we speak or have functional communication, it isn't always a given that we know how to ask for help. We also might not un-



Valerie Paradiz, PhD

derstand the positive reasons for developing a relationship with a mentor. During my recovery financially and emotionally, I turned to my sisters, both of whom are successful businesswomen. At first, I was afraid to reach out to them, thinking they would point out my blunders and bad choices. I felt my autism would be viewed as the problem. I was struggling so much

see *Dialogue* on [page 28](#)

By Brigid Rankowski
Writer/Autism Consultant

I've never been the type of person who has had their life planned out. This is one of those instances where it is appropriate to blame my mother for making me a free thinking person who does not put limits on my potential. The problem with viewing the world as limitless is figuring out the "how." My "what" is to live my life to its fullest potential and create the most positive change. Knowing how to go about a lofty goal such as mine is not easy. The path my life has taken is very unique to me, and that can be very overwhelming.

Luckily, I have found other people in my life who have had similar, unique paths and are more than willing to help guide me in the right directions. I have mentors, people who have been through similar situations and can help me figure out what to do. I learn through observing so trying to figure out new things all by myself can be frustrating. Asking questions and researching is how I learn new things so luckily people like Val don't get upset when I ask lots of questions.

I've been a mentor before when I was a Resident Assistant in college. The ability to have someone you look up to and respect help you by taking an interest in



Brigid Rankowski

your life is a wonderful thing. The beneficial relationship and the desire to help others succeed stay with a person for a long time. Both the mentor who enjoys passing on their knowledge and the mentee who learns from the knowledge grow from the relationship. One day the mentee will become the mentor and the cycle of growth will continue. Just as we will

see *Mentoring* on [page 28](#)



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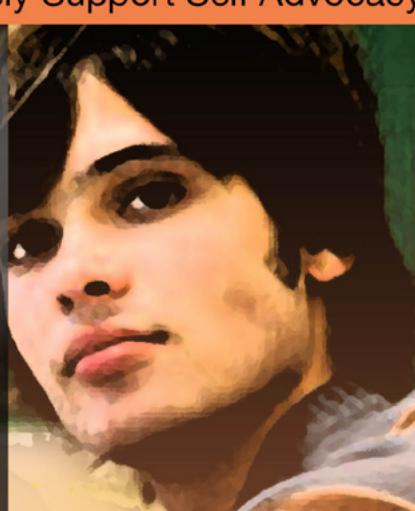
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Financing Post-Secondary Education and Training

By Ernst O. VanBergeijk, PhD, MSW
Associate Dean and Executive Director
New York Institute of Technology
Vocational Independence Program

According to the National Center for Education Statistics (NCES), “the average total cost of attendance in 2011-12 for first-time, full-time students living on campus and paying in-state tuition was \$21,000 at public 4-year institutions, \$41,420 at private nonprofit 4-year institutions, and \$30,840 at private for-profit 4-year institutions.” (NCES, 2013). College tuition and associated costs are rising faster than the rate of inflation. How can families afford to send their children to college? Are there any differences between sending a neurotypical child to college and sending a child on the autism spectrum or a child with some other neurological disability to post-secondary education? The short answers are: With planning and forethought families can send their children to college and yes, there are major differences including different funding streams and grants for children with disabilities who want to pursue post-secondary education.

When a child is first born, college seems like a distant goal- far off and beyond the horizon. However, given the substantial cost of college, parents must begin a rigorous savings plan in order to



Ernst O. VanBergeijk, PhD, MSW

be able to pay the hefty price tag these days. Depending upon where a family resides, some states offer college savings plans that are tax free. Certain restrictions apply so find out the details of these plans (e.g. they may only be used for in state colleges or in-state public colleges). Families should also check with a financial advisor who is not only familiar with the

local tax implications, but also the implications for future financial aid.

Some families with children that are blessed with athletic gifts hope to pay for college through an athletic scholarship. These are extremely rare. In fact, only about 2% of students going to college are on athletic scholarships. Academic merit scholarships and need based scholarships are far more common. A search through the internet can assist families to find foundations that provide scholarships for student who are interested in pursuing a certain profession. Other foundations made offer grants for children who are the sons and daughters of immigrants from a certain ethnic group and are interested in supporting students who will study the language, literature, and culture of the group. Start early in searching for this kind of scholarship. Start searching for these foundations a year or two before the student will enroll as a freshman. There may be cut off dates. These grants are often very competitive.

The main source of financing of college comes from the federal government in the form of Federal Student Aid. For students enrolling in a degree bearing program full time, the process begins with the completion of the Free Application for Federal Student Aid otherwise known as the FAFSA. Federal Student Aid comes in two forms: grants and loans. Grants are sums of money given to the student which are not expected to be re-paid as long as

the student makes Satisfactory Academic Progress (SAP). (Check with the institution in which the student is enrolling for its definition of SAP). When the federal legislation was initially introduced the majority of student aid was in the form of grants. Specifically, a student is eligible for Pell Grants, Federal Supplemental Education Opportunity Grants (FSEOG), and federal student work study monies. Now, the bulk of federal student aid comes in the form of loans. Loans come in the form of subsidized and unsubsidized loans. Readers are probably familiar with the names of some of the loan programs such as Stafford and Perkins loans. These are low interest loans that must be re-paid once the student either stops attending college or graduates. The amount of grants and loans are determined by the completion of the FAFSA and the calculation of the Expected Family Contribution (EFC).

For the children of military personnel there may be another option in helping pay for college:

Congress passed the Post 9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252), known as the “New G.I. Bill” on June 30, 2008. It provides the most comprehensive educational benefits package to service men and women since the original passage of the G.I.

see *Post-Secondary* on [page 32](#)

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The Challenge of Early Intervention Law for Children with Autism Spectrum Disorders and Their Families

By Sheryl Dicker, JD
Adjunct Professor of Disability Studies
City University of New York (CUNY)
Graduate Center



Sheryl Dicker, JD

In the contentious world surrounding Autism Spectrum Disorders (ASD), one issue bridges the gap among researchers, parents, advocates, health and educational professionals and policy-makers -- Early Intervention (Part C of the IDEA) for infants and toddlers with ASD works and provides the best pathway to address or ameliorate ASD (Warren et al., 2011, p. 1303). This article will explore the legal issues raised for infants and toddlers with ASD and their families struggling to receive appropriate Early Intervention (EI) services including: eligibility for EI services and the potential impact of the proposed changes to the Diagnostic and Statistical Manual (DSM); the intensity of EI services; and the payment of those services.

A. Eligibility

EI is the richest entitlement available to young children with ASD. A two-generational program provides a wide array of services to eligible children and their families. Unlike Part B of the IDEA, (the special education program for children ages

3-21), Part C does not base eligibility on the fulfillment of specific criteria for categories of disability. Instead, EI contains three possible eligibility categories: at risk (used by only four states); functional eligibility; and established conditions (Rosenberg et al., 2012). Most children are found eligible under the functional category—looking at

the young child's strengths, weaknesses and needs in five domains that include cognition, social-emotional, speech and language, adaptive and physical (Federal Register, 2011). Individual states set their own requirements for delay in these domains.

Rather than identifying significant delays in one or more domains, eight states, Alaska, Illinois, New Jersey, New Mexico, North Carolina, Pennsylvania, Vermont, and Wisconsin, have changed their regulations to make clear that children with ASD could fulfill the "established conditions" provision. Under this provision, a child must have an established medical or physical impairment with a high probability of resulting in a developmental delay. While this category has traditionally been used for children with various syndromes or genetic challenges, it may be the best course for any child suspected of having ASD during the infant and toddler years, because it will ensure that the child receives needed EI services quickly.

Perhaps the best model of a state regulation adding ASD to the list of "established conditions" is New Jersey which states: "d) The categories of physical and mental conditions that have a high probability of resulting in developmental delay are:

1. Chromosomal abnormalities, or genetic or congenital disorders;

2. Severe sensory impairments, including those relating to vision and hearing;
3. Untreated inborn errors of metabolism;
4. Disorders reflecting disturbance of the development of the nervous system;
5. Congenital infections;
6. Disorders secondary to exposure to toxic substances, including fetal alcohol syndrome;
7. Severe attachment disorders; and
8. *Autism spectrum disorders* (emphasis added)" (NJ ADC 8:17-7.1)

Eligibility also may be affected by changes in the new DSM V. First, it will create a single diagnosis—ASD. Second, it reduces the required categories to two—social-communication impairment and repetitive behaviors—rather than three, thereby removing requirements for delayed language alone, an important red flag for early identification.

Creating a single diagnosis of ASD eliminates categories used for the highest functioning children—Asperger syndrome and

see *Challenge on page 29*

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

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

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

The Elija Foundation provides advocacy support, educational outreach and comprehensive workshops in Applied Behavior Analysis for educators and family members. www.theelijahfoundation.org

Contact us through www.spectrumservicesnyc.com for clinical services.

Please visit www.aspergercenter.com for articles of interest for families and adults with Asperger Syndrome.

Evidence-Based Practices for Autism Spectrum Disorder: Making the Best Treatment Decisions for Your Child

By Alyson H. Sheehan, PhD
and Samara P. Tetenbaum, PhD
ASPIRE Center for
Learning and Development

The rise of wide-ranging treatment approaches for Autism Spectrum Disorder (ASD) has provided parents with the ability to construct an individualized approach to best suit each child's unique needs. However, sorting through all of these options can become overwhelming for many of the families that we see at our center. Between all of the therapeutic interventions, dietary regimens, and alternative techniques that float in and out of popular regard, devising a formula to address ASD symptoms can be a frustrating process of trial-and-error for both parents and children.

Consistent with the medical field's standards for best practices, mental health professionals have moved towards employing evidence-based practice (EBP) to ensure that clients receive the highest quality of care. However, deceiving terms such as "research-based," "scientifically-based," "proven," and "effective" are used to describe a slew of traditional and modern therapies, often leaving caregivers at a loss when it comes to differentiating between them. To top it all off, insurance compa-



Alyson H. Sheehan, PhD

nies, school districts, and other sources of financial support have become increasingly stringent in determining and enforcing specific criteria for service coverage. Gaining a clear grasp and understanding of what constitutes EBP is essential for parents and other caregivers who are charged with navigating this complex system.



Samara P. Tetenbaum, PhD

What is Evidence-Based Practice?

Evidence-based practice involves the implementation of practices that have demonstrated effectiveness through multiple trials of rigorous research design. Rather than anecdotal accounts from advocates of certain interventions, EBP's must have

measurable outcomes, a clear cause-and-effect reduction in symptoms, and show consistent effectiveness across studies conducted by multiple researchers who adhere to high standards of experimental design (Odom, Brantinger, Gersten, Horner, Thompson, & Harris, 2005).

To pave the way, the National Autism Center conducted the National Standards Project in 2009. This research endeavor constituted the largest-scale empirical review of treatment to date. Rather than deeming treatment approaches as simply effective or ineffective, descriptive categories were created to allow room for growth and change within various areas of clinical practice. The amount and quality of research to support each type treatment was carefully examined, based on which the treatment was labeled as *established*, *emerging*, *unestablished*, or *ineffective/harmful*. The results from this study are extensive in scope, and the full report can be viewed on the National Autism Center's website (www.nationalautismcenter.org).

Outcomes from EBP classification have influenced the treatment process by lending strong support to some approaches, such as behavioral-based interventions, while highlighting a lack of substantiation for others. Furthermore, the potential for growth

see *Treatment on page 21*

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The Massachusetts Autism Commission's Report: Recommendations to Create a Comprehensive Autism Service System

By Faith Behum, MPP
Disability Policy Specialist
Massachusetts Developmental
Disabilities Council

The bill creating the Massachusetts Autism Commission was signed into law by Governor Deval Patrick in April 2010. Membership was required by law to consist of four members of the Massachusetts state legislature, fourteen representatives from state agencies, and fourteen citizen members including but not exclusive to parents, local non-profit managers, medical doctors and individuals with autism. Four subcommittees were also created to analyze the needs of individuals within certain age groups.

The legislative resolve establishing the Massachusetts Autism Commission directed its members to study a wide range of lifespan issues facing individuals with classic Autism, Asperger's Syndrome, High Functioning Autism, and Pervasive Developmental Disorder-Not Otherwise Specified. These issues included but were not exclusive to: coordination of state human service agencies, provision of adult human services, mental health services, public education, and independent living.

The Commission studied these issues as well as others and drafted 13 priorities that



Faith Behum, MPP

reflected what the members believed to be the most pressing issues facing individuals with autism in Massachusetts. The recommendations were drafted and agreed upon by the citizen Commission members; the state agency representatives provided content expertise during the drafting process.

The recommendations do not imply the endorsement of the Patrick Administration or any state agency.

A total of 79 recommendations appear in the final report released in March 2013. Next to every recommendation, it was indicated who or what agency would be responsible for implementing each as well as what resources would be needed to do so. Each recommendation was labeled with a start date to indicate when work would begin; an end date displaying when the recommendation should be fully implemented was also provided. The combination of the priorities, recommendations, and timeline created a 10 year roadmap designed to achieve the goal of creating and maintaining comprehensive supports and services for children and adults with autism in Massachusetts. The following is a sampling of the recommendations that appear in the report.

Summary of Recommendations

The number one and two priorities of the Autism Commission recommend changes to eligibility statutes and regulations at the Department of Developmental Services (DDS) and the Department of Mental Health (DMH) respectively. Currently, DDS requires adult applicants to have an IQ of 70 or lower to be eligible for adult services. Despite their possible adaptive functioning

limitations, adults with autism with IQs over 70 are ineligible for services from DDS. The Commission recommends that DDS no longer use IQ as a means to determine eligibility for its adult services. At the DMH, both children and adults with a primary diagnosis of an autism spectrum disorder are often found ineligible for services despite having a co-occurring serious mental illness. In these cases, an individual's functional limitations are considered a result of the individual's autism diagnosis. To counter this, the Commission recommended that DMH's statutes be changed to reflect a primary diagnosis of autism not be grounds for finding a person ineligible for DMH services.

Lack of accurate data on the state's autism population was found to be one of the biggest obstacles hindering policymakers attempting to address the need of the growing autism population. Many state agencies collect data on individuals they serve. Due to different, incompatible systems it is impossible to keep track of the numbers of individuals with autism and their needs. The Commission recommended that the Executive Office of Health and Human Services (EOHHS) inventory current data collection systems in and out of state and use this information to design a comprehensive data collection mechanism in Massachusetts.

see *Service System* on [page 29](#)

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Helpful Financial Resources for Parents of Children with Autism

By Lauren Agoratus, MA
Parent
Family Voices NJ

According to Autism Speaks, “The costs of providing care for each person with autism affected by intellectual disability through his or her lifespan are \$2.3 million in the U.S.” According to Families USA, 60% of bankruptcies are due to medical debt. The Catalyst Center report “Breaking the Link” shows that 2 million families of children with special needs experience financial hardship, regardless of previous financial status (see http://hdwg.org/sites/default/files/resources/Catalyst_Center_Breaking_The_Link.pdf.) So families of children on the spectrum are struggling - not just to get their children the services they need, but to stay afloat financially.

In the Beginning

Early intervention from birth to age three has the best chance at improving outcomes. Families can request an evaluation for eligibility for services. Contacts for early intervention in each state can be found at the National Early Childhood Technical Assistance Center (NECTAC) website at www.nectac.org, which also gives a description of early intervention services. Unfortunately, some states have



Lauren Agoratus, MA

a “cost share” for families on a sliding fee scale and some families have had to cut back on services. However, the Individuals with Disabilities Education Act (IDEA) that governs early intervention (and special education) requires that families be provided with services at no cost if they have an inability to pay for services.

Insurance

Federal law allows early intervention programs to access public and private insurance as long as it does not disadvantage families. Children may have traditional indemnity plans through their parents’ employers, Medicaid, or both. Families should remember to appeal denied claims as only 1/3 of claims are appealed and 50% of the time they are turned around in favor of the family on their first appeal. If children have Medicaid, their secondary insurance will pick up what the primary insurance doesn’t cover. More services may actually be available under Medicaid due to Early Periodic Screening Diagnostic and Treatment (EPSDT) - see <http://mchb.hrsa.gov/epsdt/overview.html>. Unfortunately, many children aren’t eligible for Medicaid and/or Supplemental Security Income until age 18 when parental income is no longer deemed to be the income of their child.

Many states also have autism insurance mandates (one state, New Jersey, has a mandate that covers children with autism and other developmental disabilities). However, these mandates are usually not comprehensive. In NJ, the law only covers approximately 25% of health insurance plans because it does not apply to “ERISA” or self-insured plans, which are a majority of plans in NJ. So although a good first step, insurance mandate laws may not be enough. For information on autism coverage in each

state, see www.autismspeaks.org/advocacy/states. Other mandates that may help are mental health parity, both nationally and in states. This means that coverage for mental health disabilities must be on par with that of physical health. “Biologically-based” is often used to determine coverage.

Lastly, health insurance reform, which went into effect for children 9/23/10, is helping families of children on the spectrum. The Affordable Care Act (ACA) eliminated lifetime limits and limited annual caps of coverage. Policies could no longer be rescinded due to illness and children with pre-existing conditions could not be denied coverage. There is some confusion over the ACA provision of Essential Health Benefits, which include “Mental health and substance use disorder services, including behavioral health treatment” (www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/ehb-2-20-2013.html). Advocates are seeking clarification on what is meant by “behavioral health” as it relates to autism. Another good resource on maximizing insurance coverage for children with autism is found at www.autismnj.org/document.doc?id=26. Some states even have funding for families for “catastrophic illness” which could cover medical bills, mileage/tolls/parking, phone calls, and hotels (for long hospitalizations). For more information, families can contact the Title V program

see Resources on [page 27](#)

Accessing Government Benefits and the “Golden Ticket”

Mary Anne Ehlert, CFP
Founder & President
Protected Tomorrows, Inc.

If you are a parent of a special needs child, government benefits and legal options are often confusing - even to those who have worked with them before. You know that there are programs out there for your child, but you are not sure where to start. You may wonder what the government provides, what it will cost you and how you are going to sort through all the information. You may have heard of legal decisions you need to make, but you have no idea how to begin, let alone find an attorney who is qualified and who has the compassion to work side by side with you.

Your biggest resource for funding your child’s future may come from government assistance programs. Knowing what assistance your child qualifies for will make a difference in the type of care your child will receive now and in his/her adult years. It is also critical you understand the connection between all the programs and how they can help your child in ways you might not have imagined. We sometimes hear that a family feels they “have enough money” to not worry about the government assistance, so we will also talk about the “golden ticket.”

A special needs planner will serve as a guide, someone with an experienced per-



Mary Anne Ehlert, CFP

spective who can bring clarity to an area that can seem very cloudy to the uninitiated. He/she can also refer you to a benefits department, who will act as your liaison, utilizing their experience to effectively navigate these often choppy waters.

As a general rule, you will want to apply for these programs even if you do not think you will qualify or need them - I will explain why this is the case.

First, let’s break down the types of assistance into four general categories of government benefits that you may want to investigate:

Entitlements - Taxpayers are entitled to Supplemental Security Disability (SSDI) and Social Security Administration (SSA) and Medicare because we bought these benefits by having money taken out of our paychecks throughout our working years.

Needs-Based - Supplemental Security Income (SSI) and Medicaid are available regardless of whether or not you paid into the system. Because these benefits are not purchased, the eligibility requirements are based on your income level and your assets.

Cash - SSDI, SSA and SSI are all programs that provide cash to meet daily living expenses and to supplement any other needs. Each of these programs has its own eligibility requirements.

Goods and Services - These benefits come in the form of medical and residential assistance. These services are vital to your child’s future as an adult. The programs include Medicare and Medicaid.

Now, let’s take a look at each program individually:

Social Security Disability and Social Security Administration

SSDI is a federal cash benefit that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual’s family if you are “insured” meaning that you worked long enough and paid Social Security taxes. SSDI cash payments are based on how much has been paid into the system and if the individual is substantially and gainfully employed. This is called the “income rule.” SSA pay is your retirement income, which can be taken as early as age 62. It is important that you always save your social security statements for review. You can now obtain a statement on SSA’s website, www.ssa.gov.

Medicare

Medicare is a federal health insurance program for, among others, certain younger people with disabilities. Medicare begins two years after Social Security payments begin. Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered. Medicare also does not pay for prescriptions. If you do not also have Medicaid, you might need to purchase a supplemental Medicare plan as well as a Medicare Part D plan for prescriptions.

see Benefits on [page 34](#)

The ASD Nest: A Successful Inclusion Model in the NYC Public School System

By Shirley Cohen, PhD,
Dorothy Siegel, MPH,
and Lauren Hough, MSED
ASD Nest Support Project
NYU Steinhardt

Ten years ago Dorothy Siegel and Shirley Cohen, working closely with administrators of a Brooklyn school district, initiated a pilot for the ASD Nest program. Now, ten years later, that pilot has evolved into a robust model based in 20 public elementary schools in New York City, with continuing replication to additional schools each year. With the recent publication of two books detailing how to establish and support this program model, the ASD Nest is ready to move beyond New York City.

Why Was the ASD Nest Program Created?

In recent years, the population of children being identified as having an autism spectrum disorder has been increasing dramatically, and a large proportion of that increase is associated with the diagnosis of children at the higher end of the spectrum. Those children often struggled in mainstream classes without the supports they needed to function well, while others found themselves in programs designed for students with severe disabilities that did lit-



Shirley Cohen, PhD

tle to advance their learning. There was no model for serving these children appropriately and thus no “home” for them within the NYC public school system.

What Is the ASD Nest Model: A Brief Overview

The ASD Nest program provides a much-needed home for these higher functioning children with ASD. The Nest is a full-time inclusion program that starts



Dorothy Siegel, MPH

at kindergarten in neighborhood schools and expands up one grade each year. The goal of the program is to help these children function comfortably and successfully in mainstream settings in their school and community. The core features of the model are:

- Co-taught classes with two teachers, one certified in special education and the other in general education, or both with dual certification



Lauren Hough, MSED

- Reduced class size and a low ratio of students with ASD to typically developing students: 12 students in kindergarten classes, 4 of them with ASD; 16 students per class in grades 1-3, 4 of them with ASD; and 20 students per class in grades 4-5, up to 5 with ASD

- A multidisciplinary team that meets weekly to discuss students, with each

see *Inclusion* on [page 33](#)

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The Early Intervention program is funded by NYS and county governments for children birth-3 suspected of having a developmental disability or delay. Services are authorized by the county. The CPSE program is funded and regulated by the NYS Education Department, county and your local school district for children 3-5. Services for both programs are provided at no direct cost to families for children who meet eligibility guidelines.

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NIH Grant From [page 4](#)

and Icahn School of Medicine at Mount Sinai. Established in 1968, the Icahn School of Medicine is one of the leading medical schools in the United States, with more than 3,400 faculty in 32 departments and 14 research institutes. It

ranks among the top 20 medical schools both in National Institutes of Health (NIH) funding and by U.S. News & World Report. The Mount Sinai Hospital, founded in 1852, is a 1,171-bed tertiary- and quaternary-care teaching facility and one of the nation's oldest, largest and most-respected voluntary hospitals.

In 2012, U.S. News & World Report ranked The Mount Sinai Hospital 14th on its elite Honor Roll of the nation's top hospitals based on reputation, safety, and other patient-care factors. To learn more about the Seaver Autism Center, visit www.icaahn.mssm.edu/research/centers/seaver-autism-center.

This article has been reprinted with permission from the Mt. Sinai Seaver Autism Center. To view the original article, please visit <http://www.mountsinai.org/patient-care/service-areas/children/news/mount-sinai-researchers-receive-nih-grant-to-study-promising-treatment-for-autism-subtype>.

Independence from [page 8](#)

living program options: POINT in White Plains, Westchester; and QILP in Forest Hills, Queens. These programs offer young adults the opportunity to continue to cultivate their independence and live in their own apartments, with support from

Compass staff. This support may include help with work, cooking, bill paying, and grocery shopping. Developing these skill sets helps participants be part of their community and the larger community. Daniel Braun now sees new opportunities: “What I like best is the chance to live in the city, in an apartment-style pro-

gram made for high functioning people, with plenty of access to things to do. It is exciting, and Forest Hills is ideal because we don't need to rely on others; everything is close.”

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teens, and young adults understand and access benefits, get internships and competitive employment, socialize enjoy dinners and weekend trips, and forge their own path toward independence.

For more information, please contact 516-729-0066 or visit www.jccany/compass.

Financial Future from [page 1](#)

there will be a waiting period imposed by SSI and Medicaid before the child will be eligible for those benefits. Thus, they will have to do without certain benefits for an extended period of time if proper planning is not done.

While obtaining eligibility for government benefits is necessary to receive services as an adult, these government benefits alone will not provide all that a child with autism will require in the future; and in no way will provide the “extras” that a parent would want their special child to have. Further, most parents are not pleased with the fact that they have to disinherit their special needs child in order for their child to access government benefits.

Supplemental Needs Trusts

Fortunately, there is a very important tool that parents can use to allow a child with autism to remain eligible for government benefits, but also have all of the “extras” that parents would want them to have. This important tool is the Supplemental Needs Trust (hereinafter referred to as SNT), which is sometimes referred to as a Special Needs Trust. An SNT holds assets for the benefit of the special needs child without those assets being included in determining eligibility for government benefits. Generally speaking, monies in the trust can be used to pay for items that are not provided by the governmental benefit systems. Thus, the assets in the SNT are used to “supplement” and not “supplant” or replace governmental benefits.

SNTs can provide a number of items and luxuries. They can be used to provide for education, vacations, electronics, companions, insurance and many other life-enhancing services not provided by government benefits. In addition, an SNT has the ability to hold everything from cash and investments, to real property.

The beauty of a properly drafted SNT is that there is no “pay-back” of funds to Medicaid after the beneficiary (the child with autism) passes away. This means that after your child’s death you can direct where the remaining funds in the SNT go.

How to Fund a Lifetime of Need

As friends worry about how they will pay for college, parents of children with autism have financial worries that extend for their



Bernard A. Krooks, Esq

child’s lifetime. This is daunting and fear of the future can stop parents in their tracks. As discussed, creating an SNT will enable a child with autism to remain on public benefits and still have the “extras” parents want them to have. However, ample funds must be available to take care of the child for life.

How much money needs to be saved for the child? While that is not an easy question to answer, a parent can begin to think about what kind of care their child may need and estimate what it may cost on a monthly basis. Then, think about how much this could cost over your child’s lifetime. It is also important to consider the effects of inflation on the purchasing power of the assets in the trust. While not an exact science, going through this process will give you a good ballpark estimate of how much money will be necessary to fund the trust.

The dollar amount you come up with may seem staggering. How will parents ever be able to save enough money to provide the care the child is going to need for the rest of their life while trying to fund one’s own goals?

The most common method to funding this type of long-term care is through life insurance. As discussed above, the SNT is a legal entity that can hold assets in which a person with autism is the beneficiary and not disturb their important and necessary government benefits. The SNT created can be the recipient of life insurance proceeds. Life insurance can often be structured so



Sheryl R. Frishman, Esq

that funds can be used to provide for a child while keeping the rest of the parent’s estate intact.

There are a number of different types of life insurance, and your specific situation will ultimately determine what is best for you. It is extremely important that you work with your attorney that creates your SNT to ensure that the beneficiary forms are properly filled out. Your special needs attorney can also recommend good insurance brokers who work specifically and well with families with special needs.

While there are other ways to create wealth, life insurance (if you are able to qualify) used together with an SNT is typically the easiest and least expensive way to generate funds for an SNT in the event of an untimely death of the parents.

Where to Find Help

People are always concerned about having to use an attorney and the costs involved. The possibility of your child with autism losing their public benefits, not having enough money to live on, and the possibility of leaving your child’s future caregivers with no direction will be a much higher cost that your vulnerable child will have to bear after your demise if you do not plan. This planning needs to be done correctly and by a highly qualified special needs planning attorney. Please visit the Special Needs Alliance www.specialneedsalliance.org to find

a qualified special needs planning attorney in your area. This is not something every attorney or even a general estate-planning attorney can do. You need to find a professional in your state that specializes in special needs planning so you can assure your child is protected. This is not something you want to bargain hunt for! Not doing the planning correctly can end up costing so much more than using the right qualified attorney. Your qualified attorney can recommend life insurance brokers and investment personnel who can work on your team to get a solid financial plan in place for your child.

While planning for your child with autism’s financial future cannot give you complete peace of mind (as nothing can), a proper plan can be put in place, and there are fabulous tools available to ensure that your child will have adequate funds after you are gone. Not planning will put the child you want to protect more than anything in the world in jeopardy and in a vulnerable position. Many people feel they are young and healthy and that nothing is going to happen to them any time soon. Do not wait until it is too late to do the planning. If you are reading this article you are ready to do the planning. Mahatma Gandhi said, “Learn as if you were going to live forever. Live as if you were going to die tomorrow.” We cannot be sure what tomorrow will bring. The time to plan is now!

Nothing in this article should be construed as legal advice. Please consult with your own attorney before relying on the information contained herein.

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Awards Reception from [page 1](#)

brought to fruition a wide range of initiatives that enhance the lives of people on the spectrum and foster awareness.

The vision of the DJF Foundation is for all adults on the spectrum to have opportunities that honor their individuality. This is the goal Linda had for her own son Danny who passed away at age 9 and in whose memory The Daniel Jordan Fiddle Foundation is named.

Linda has received numerous honors for her accomplishments on behalf of the Autism community that have recently included a Russ Berrie Award for Making a Difference, the Jefferson Award for Public Service, and honors from the New Jersey Coalition of Inclusive Ministries and ASAH, New Jersey’s association of special education private schools and agencies. Linda also received Redbook magazine’s “Strength & Spirit” Award and was featured, as one of the five most inspirational women in the United

States. She has been recognized before the New Jersey legislature for her humanitarian efforts that “exemplify a standard of excellence towards which others should strive.” In September 2011, Linda received the “Seeds of Hope” award for her leadership in the field of Autism and was featured in NJ Monthly Magazine’s September, 2011 issue. In March 2012, United States Senator Robert Menendez honored Linda with the “Evangeline Menendez Trailblazer Award,” for her pioneering work on behalf of the Autism community.

Linda is currently a member of the national Board of Directors of the Autism Society and is a founder of Advancing Futures for Adults with Autism, a national consortium of Autism organizations focusing on adult issues. She was recently appointed by New Jersey Governor Chris Christie to the Commission on National and Community Service. Linda is also dedicated to humanitarian efforts around the world from New Orleans to Cambodia.

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The Importance of Integrative Care: Collaboration Among Therapists, Doctors & Family

By Rebecca Sachs, PhD
Staff Psychologist
Fay J. Lindner Center for Autism
and Development Disabilities

Climbing on the playground tower at the Fay J. Lindner Center was a bundle of energy and joy named Joshua. Dressed in swim trunks from his camp day, hair cut short and handsome and a T-shirt covered with Angry Birds stickers, Joshua slid down the pole, gave his mom a quick hug and kiss, and plopped down on the ground by his therapist. Despite knowing that he was going to be asked to do something quite challenging, Joshua looked up at his mom with an expression suggesting he knew he could rise to the occasion.

Joshua is a 12-year old boy diagnosed with ODD, Anxiety-NOS, and an ASD. Even with the “alphabet-soup” with which he is labeled, Joshua is happy and flourishing. He has been coming to the Lindner Center for a little over a year and a half and with hard work and collaborative planning Joshua has been developing the skills to deal with his oppositional behaviors, anxiety, and Autism diagnoses.

Joshua’s case is the perfect example to illustrate the efficacy of integrated care. Collaborative treatment not only marries



Rebecca Sachs, PhD

psychological and medical treatment in a patient-centered way, but also incorporates the patient, family members and friends, and other professionals (such as teachers or camp counselors) to address a patient’s needs. Growing research examining integrated care shows that a coordinated, team-based approach allows a patient to benefit

from a full range of expertise and is associated with better treatment outcomes and reduced health-care related costs.

With an integrated care approach to mental illness, the patient is never alone. All team members work with the patient to help control symptoms and build skills. Integrative care balances supporting the patient throughout treatment with maintaining the patient’s personal autonomy and individuality. When done properly, collaborative care recognizes that the patient plays a key role in his or her treatment. Depending on the age and strengths and limitations of the patient this can mean many things. Patients are encouraged to pay attention to their feelings about the treatment process, express and advocate to team members what is important, and potentially gain a full understanding of diagnoses and treatment. Furthermore, patients, family members, and professionals often have different “goals.” When goals are created collectively and include the patient’s input, they are more likely to be achieved and have long standing results. Not only is the patient encouraged to be honest and express his or her feelings and needs, but also the professional team is more likely to “check-in” and understand each patient’s experience and personal goals. Additionally, a patient can contribute to his or her own care by seeking infor-

mation, attending skills-based and support groups, and following through on plans made with the therapist to practice skills outside of session. For Joshua, this means expressing with the encouragement of his team when he feels high anxiety or the urge to aggress. With practice and praise, Joshua is now better able push himself to engage in more challenging social situations and grow therapeutically, as well as express when he has reached his limits and needs a break.

Also important to integrated care is the role of medical doctors in a patient’s life. Often it is the family doctor who first sees a patient when he or she is experiencing mental health symptoms. Many mental health issues often manifest in somatic or bodily ways and the patient and family do not know where else to go. A family doctor may refer the patient to mental health professionals and other services in the community. In an integrated care approach even after a diagnosis is made and treatment begins, the family doctor is still included in care. Given the doctor’s long standing relationship in a patient’s life, the family doctor is often one of the individuals who knows the patient best. In addition to being a valuable resource of information, a family doctor can work with members of a

see *Integrative on page 31*

Treatment from [page 16](#)

among emerging treatments has led to substantial efforts in devising techniques for measuring and dispersing promising empirical evidence of effectiveness (Reichow, Doehring, Cicchetti, & Volkmar, 2011). In other words, therapists, teachers, parents, and clients have been called to engage in a collective movement towards gathering data for facilitation of the much-needed advancements in ASD treatment.

Evidence-Based Care for Your Child

Parents often seek EBP to address their children’s symptoms, yet they may struggle to choose which EBP best applies to their own child’s profile of strengths and weaknesses. Additionally, it may be difficult to discern a provider’s commitment to the implementation of EBP to best treat an individual child. Referencing unbiased and reliable resources, including national and local ASD associations, peer-reviewed research journals, and the organizations cited in this article, is often a helpful starting point in assessing the efficacy of a given approach. Consulting with multiple professionals, seeking guidance from educational and medical providers, and networking with parents who face similar challenges may also be helpful tactics (Tetenbaum & ANichols, 2012). Most importantly, it is essential that caregivers remain active and apprised throughout the duration of any intervention. Research has identified parents’ involvement in the treatment process to be a key factor in children’s successful outcomes (Brookman-Fraze, Baker-Er-

iczen, Stadnick, & Taylor, 2011).

It is also important to note that the dynamic and ever-changing nature of the ASD treatment pool produces promising treatments that parents may be interested in pursuing before the evidence base has been fully established. For example, clinicians at our center have modified Cognitive Behavioral Therapy (CBT), an evidence-based treatment for numerous mental health concerns, to specifically fit treatment needs of children and adults on the autism spectrum. This treatment is considered *emerging* since supportive research is still in progress (National Autism Center, 2009), but we have consistently achieved strong positive responses among clients. On top of parents at our practice noting significant improvement in their children’s symptoms, many other clinicians have begun to implement CBT for mental health concerns in their work with ASD clients. As more research emerges, more clinicians have adapted this approach. A book summarizing current research in CBT for youth with ASDs has recently been published (Scarpa, White, & Atwood, 2013) and shows promising results from utilizing for this population.

Parents considering an emerging therapy approach are advised to make a number of preliminary considerations (Prizant, 2011). First, existing evidence that has been collected for treating similar concerns should be taken into account. For example, several years of research has substantiated CBT as a highly effective treatment for depression and anxiety in children

see *Treatment on page 34*

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Seeing beyond disability.

Financial Literacy for ASD College Students

By Mary Riggs Cohen, PhD
Director, The Center for Teaching
and Research in Autism
Pace University

I was having lunch with my daughter, a recent college graduate, and she remarked that in her opinion the main thing today's college students are unprepared for is managing their finances. She said "No one really teaches us everything we need to know. What we really need are courses on financial management. It is true that the complexities of today's finances are often confusing even for those of us who have been dealing with these issues for years. College students are often flooded with credit card offers upon turning eighteen and many also encounter rental leases and loans for the first time. A majority of college students are unfamiliar with the concept of monthly budgets, monthly payments, late fees and interest. This combined with a barrage of online advertisements, internet scams and marketing that targets the millennial generation makes it difficult for them to manage their money. It is a sobering statistic that the average college student has approximately \$2,500 in credit card debt. These issues are compounded in ASD college students who generally have even less experience with monetary matters.



Mary Riggs Cohen, PhD

Money Issues and ASD

In my role as director of the OASIS College Support Program at Pace University, I have on occasion received phone calls from alarmed parents such as "How did my daughter spend \$400 in two weeks?!" It is not just a lack of experience that contributes to the money issues of ASD students. Many have executive functioning deficits that make planning (budgeting) difficult

and their social naiveté causes them to fall prey to internet scams or "too good to be true" deals. As a result, many individuals on the spectrum overpay for items or purchase items they don't even need or want. The deceptive nature of some advertising is not easily discernible to ASD students and their literal interpretations of ads cause many to lose money because they "can't read between the lines". ASD college students are often easy marks because they don't know the true value of items. One student paid a large sum of money for tickets to an event that was free. It is always challenging when a socially naive person encounters a financial predator. This is why it is critical that ASD individuals have a sense of financial scams and what kinds of situations to avoid. The following are a few examples:

- If a deal sounds too good to be true, it probably is.
- If you get an e-mail that looks like it's from your bank and asks for your account info, don't answer it.
- If someone offers you a great bargain if you pay right away in cash, don't be pressured to buy quickly.
- If you get an e-mail from another country offering you money if you help them transfer money from that country, don't answer it.

- If someone asks you to cash a check for them, don't, because it could be counterfeit.

These are common scams but I'm aware of ASD individuals who have been drawn into them unwittingly.

An additional area of concern is internet shopping and impulsive/compulsive behavior. Walter Mischel's research in the 60's and 80's showed that the ability to delay gratification (i.e. save money) is predictive of an individual's future success, however we do not actively teach the importance of learning to delay gratification for long-term goals. At present we inhabit a world of marketing geared to instant gratification online. It is estimated that we are exposed to between 4,000 to 5,000 advertisements daily and much of it is on the internet. Spectrum individuals are often impulsive and many are avid collectors and that spend hours shopping online for specific items. Immersion in specific interests can contribute to compulsive buying of collectibles, video games, or movie downloads. Sites such as eBay can become addictive because of the bidding aspect. One individual spent over \$1,000 on eBay in one night buying art supplies. The use of debit and credit cards also makes such spending sprees possible. Our society's use of "plastic money" makes it all too easy

see *Literacy* on [page 25](#)

An Affordable, High-Quality University Option for Students on the Spectrum

By Lisa Pollich, PhD,
Charles Eli Carr,
and John A. Schiavone II
CUNY Project REACH

The City University of New York (CUNY), a stalwart champion for equal access to higher education, formed Project REACH (Resources and Education on Autism as CUNY's Hallmark) in December of 2011. The Project's goals include educating the student body, staff and faculty about students with autism spectrum disorders (ASD), as well as ensuring that students on the spectrum are given a fair chance to succeed in the college arena.

We are seeing a sharp rise in students diagnosed with autism spectrum disorders seeking college degrees, and campuses all across the country are struggling to keep up with the demand for support. Services for this population have been seen most often in kindergarten through 12th grade, but until recently the supports seemed to end there. Many colleges and universities lack any formal support or accommodations to help students on the spectrum perform the most difficult transition for any student: starting college. CUNY saw that it needed to expand the types of supports to serve this population of students. Project REACH was created in order to investigate, research, and put into action the best



Lisa Pollich, PhD

practices that can be used to provide this growing population of students the reasonable accommodations, both academically and socially, that they need to graduate school and pursue their careers.

To develop a clear picture of the needs of students on the spectrum, REACH sought out the opinions and feedback of professionals by gathering them into a strategic advisory meeting to speak about the inadequacies of current higher education prac-

tices and what could be done to improve them. The project also solicited feedback from the CUNY student population to make sure it accurately addressed their concerns. So REACH and its family of programs are not only a direct extension of the Central Office of Student Affairs, but an arm of its student populations.

Working with a grant from the FAR Fund totaling \$100,000, CUNY Project REACH was able to fund four separate CUNY campus' endeavors to build programs for individuals on the spectrum. Additionally, each campus project was connected with CUNY LEADS (Linking Employment, Academic and Disability Services) counselors. As their name suggests, CUNY LEADS are CUNY's in-house employment counselors for the disabilities community throughout the CUNY system. The consistent theme of the REACH projects includes peer-mentoring, counseling services and the education of campus faculty and staff. The individual programs are similar in many ways. Each program operates using a maximum annual budget of \$20,000, and all services are offered free of charge to any identified student.

Students in Brooklyn College's Collaborative Autism Spectrum Program (CASP) were offered a full range of services including tutoring, social-skills training, career-readiness training, courses on navigating communication and more. On another front, CASP created strong links with the

Asperger Syndrome and High Functioning Autism Association NY chapter, an outside support network.

Transitioning to College Support (TCS), the project formed within Kingsborough Community College (KBCC), saw a gradual rise in their identified population combined with an 80% retention rate for individuals enrolled in the program. TCS also made sure that ASD resources were made available to the entire KBCC faculty by holding webinars and hosting resources online. Their successful series of workshops have assured them future opportunities to expand and deploy these services in the future.

The College of Staten Island used their grant money to start the Building Bridges Initiative (BBI). This program is one of the most comprehensive programs for students on the spectrum in the city of New York, receiving rave reviews from professionals, parents, and students alike. BBI provides a wide range of services including academic coaching and peer mentoring. They also have a website that serves as a resource to educate the public and college community about autism spectrum disorders and a rapid screening tool to help people see if they should seek a diagnosis from a mental health professional, all from the comfort of their own home.

The Borough of Manhattan Community College started Project PASS (Progressing

see *Affordable* on [page 28](#)



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

By Carrie Cariello

Epic Scenes From a Barbershop

Yesterday afternoon I poked my head into the family room where Jack, Charlie, and Henry were sprawled watching Scooby Doo, and announced we were going for haircuts. "No!" they shouted in unison. "No haircuts!"

I told them we'd stop at the school book fair first, and jollied them out the door with promises of new joke books and Batman stories. About forty-five minutes later, we pulled into the barbershop parking lot, and Jack began to whimper and whine. As I opened the van door his agitation accelerated and he refused to get out of the car. Wow, I thought to myself. He's really off today. I scanned my mental list of things that typically contribute to Jack's offness—bad night of sleep, hunger, dog-sighting—but couldn't come up with a reason. "A haircut will give me a headache!" he repeated over and over.

Once I finally got him out of the car, he wouldn't come inside. He stood outside kicking the door with a blue sneaker while the patrons waiting inside exchanged glances. I told him brightly that his favorite stylist, Terri, was here, she was going to



Joe and Carrie, fifteen years ago

cut his hair like she always does, and then I gritted my teeth, bent close to his ear, and hissed that I would take every one of his books back if he didn't come in the door this minute.

"It will hurt!" he raged. "I will have a HEADACHE from this haircut!"

We waited for a little bit, and just as it

was Jack's turn to climb into the chair, Joe walked in to drop Joey off on the way to bring the taxes to our accountant. Jack started to throw an epic tantrum, jumping and crying and twirling like a tornado.

I looked over my shoulder as Joe started out the door, asking for help with my eyes. He walked back in and took Jack by the

shoulders, directing him towards the large black barber chair as Jack screamed and flailed. I backed away, letting Joe handle the moment, and made nervous conversation with a mom who was waiting with her two sons.

In the midst of the chaos, Joe and Terri discovered a giant spot of dried gel behind Jack's left ear. I remembered the day before how he'd disappeared into the bathroom and came out with his hair slicked and sticky; he must not have washed it all out during his nightly shower. And he was terrified it would hurt.

Slowly, they maneuvered him towards the sink, promising they could wash it out. But Jack was lost to any reason—agitated and deregulated and just plain out of his mind, he kept sitting up and getting water everywhere. I heard an edge in Joe's voice and decided to step in, to declare game over.

This did not go over well with my husband, and when we got home we launched into an epic argument.

And our epic argument made Jack's epic tantrum seem like child's play, as we waged our war of how could you not see that giant gob of gel in his hair and why don't you try taking him for haircuts and doing homework with him every night. A war of the

see *Barbershop* on [page 34](#)

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The Alien World of Work for Adults with Autism

By Matthew J. Ratz, MEd
Vocational Trainer for
Adults with Autism

After college, one is confronted with the confounding world of job searching. Unlike anything one has experienced before, a job search is filled with resumes, cover letters, and interviews, salary negotiations, networking, and writing that looks nothing like the work just finished to earn a degree. As recent media reports indicate, more and more college graduates are underemployed and need to move back home with their parents. And while these “boomerang” anecdotes are frustrating for recent grads, these experiences may be worlds away from the experience of their same-aged peer with autism.

Adults with autism, when they reach age 21, face an entirely different world whose challenges are equally confounding. As students transition out of special education, they move from their teachers being guided by the multifaceted Individuals with Disabilities Education Act (IDEA) into the world of adulthood where their employers are guided by the narrower Adults with Disabilities Act (ADA). A number of important supports are suddenly stripped away, either a result of a lack of funding (such as speech therapy) or as a result of a lack of legal requirement (such as regular measurement



Matthew J. Ratz, MEd

and assessment of skills). Adults with autism at age 21 move suddenly from a world of educators concerned primarily with students' continued learning and growth to a world of employers concerned instead with adults' shedding the costly behavioral, emotional, and educational supports to which they have become accustomed.

As a vocational training professional for adults with autism providing vocation-

al training at a community-based autism training facility, I see firsthand the steep drop-off from a learning experience guided by academics and by anticipated and consistent growth to an experience guided by the need for employment based on ill-fitting concepts of adulthood and independence. Instruction that was academically-driven and educationally-necessary at the age of 19 and 20 becomes quixotic in the world of individual finances and self-advocacy at the age of 21 when continued state funding is not guaranteed. Adults with autism, whose disability makes sameness, routine, and environmental control reassuring, are rocketed into environments without clear routines or clear expectations.

All of this serves as a backdrop to where I stand when an adult arrives at my facility. Though I may be clued in to this individual's behavioral triggers as well as his interests, I do not have the clear, objective-aligned goals of an Individualized Education Plan (IEP) to guide my work; nor do I have the support of a certified special educator to facilitate instruction. Instead, the individuals I train are supported by direct-support staff—who may have *no* formal Special Education training—as they build new vocational skills and navigate the extremely complex world of employment. My job is to develop and maintain a library of instructional activities and materials; additionally, as a trained special educator, I aid staff in

their presentation and facilitation of these activities to diagnosed individuals.

These vocational training activities in areas of clerical skills, mechanical skills, order fulfillment, and hospitality, among others, run alongside job development which is motivated by the goal of part-time or full-time paid employment for every individual. Regulations vary by state, but adults with disabilities are often required to maintain a minimum number of hours of paid employment or equivalent hours of relevant, hands-on training in order to receive funding under Social Security disability funding. While a part-time workday may not seem that difficult to attain for the average person, it is surprisingly complicated to achieve this for adults with autism, for a variety of reasons. The art and science of job development—distinct from job searching—for adults with autism is remarkably multifaceted, and quite different from the typical job search one might encounter.

One of the keys for supporting adults with autism—and it is a key that unlocks both training and employment opportunities—is to discover areas of strength and interest of the individual. When designing a training activity for an individual, I ask (or reflect on) a series of questions to determine the individual's level of interest and ability. If the individual is able to verbally answer these questions, it becomes

see *Work on page 33*

Psychology from page 7

autism spectrum disorder could increase successful problem solving skills, decrease a sense of helplessness and promote a sense of autonomy that could be beneficial. Individuals with an autism spectrum disorder typically have difficulty with social interactions, communication, anxiety and rigidity. At times people on the spectrum experience extreme sensitivity to environmental and sensory stimuli, difficulty coping with change and transitions, stress and problems negotiating the social world. Their difficulties are reflected in higher levels of depression, anxiety, paranoia and phobias, compared to the general population (Bellini, 2004). Fostering an optimistic perspective and alternatives to past behavioral patterns may provide increased capacity to cope with challenging situations and circumstances.

Humor is a fundamental aspect of social interaction. Most of us experience humor without being aware of its many benefits. Research on humor highlights cognitive development, cognition and emotional development. Humor facilitates social connections and interactions that can be both enjoyable and stressful. In such circumstances, most people will turn to humor to relieve both anticipated and actual stress. Individuals with autism are frequently challenged by anxiety and stress responses when confronted with social demands. Cultivating a capacity for understanding and using humor in social situations has the potential to promote participation and reduce stress associated with social demands.

Incorporating humor into the lives of individuals with autism can benefit their well-being. Teaching humor as a source

of joy and as a coping strategy are important given studies showing higher levels of anxiety and depression among individuals on the spectrum (Bellini, 2004). Humorous and positive reframing strategies may enable them to cope better and manage challenging life experiences and confront circumstances. Humor comes less naturally to the person with autism but it can be taught. Continued exposure and modeling of humor, for persons on the spectrum will help them learn that the unexpected can be safe as well as funny.

Self-efficacy is the beliefs that people have about their ability and readiness to perform a task. Overall, self-efficacy is required in order to cope effectively with life demands and improve quality of life. Self-efficacy is developed by cumulative successful learning experiences. Individuals with autism struggle with learning new skills and are exposed to frequent failure. Teaching skills, nurturing controllable positive behaviors and habits that lead to productivity and increasing the learners' awareness of other capabilities can benefit their self-efficacy. Reviewing expectations and behaviors of caregivers and peers, choosing effective teaching methods, increasing self-management and coping skills and helping individuals to own their success can all increase self-efficacy in individuals with autism.

Philosophers have described kindness as helpfulness toward someone in need, not in return for anything. Kind people are described as making thoughtful choices and doing benevolent things for others. Researching kindness and autism often focuses on treating individuals with autism with kindness. If people with autism are taught to administer kind acts, they will

more likely be accepted as contributors in the communities and to step out of their more familiar, dependant roles as consumers of service. It is possible to teach kind deeds and other pro-social behavior related to kindness. For example, drama, role-playing, pet and animal therapy and volunteering in the community are all examples that are important building blocks for individuals on the spectrum to foster a higher quality of life.

The last characteristic that positive psychology focuses on is resilience. Resilience is described as an emotional or psychological shield that protects one from the damaging effects of life's more negative elements. We speak of resilient individuals as those who persevere, carry on, and triumph over challenges and adversity. People with autism spectrum disorders have unique challenges that make them vulnerable in the face of adversity. Their ability to cope and adjust is dependent upon their cognitive capabilities, communication skills, flexibility and social problem-solving capacities. Deficits in coping skills constitute significant contributing factors to increased vulnerability, which can lead to anxiety and depression. Resilience is a key component in reaching effective adaptation and successful coping with life challenges. Resilience can be taught to individuals with autism at all levels of functioning by nurturing self-regulation, increasing opportunities to experience success, autonomy and independence and by increasing problem-solving skills and general knowledge. The way resilience can be measured in people with autism is their ability to express and execute positive preferences and choices, showing a willingness to learn and experience novelties, maintaining

a strong support system and by demonstrating self-regulation and self-control under times of stress. Optimism, humor, self-efficacy, kindness and resilience are traits of positive psychology. Individuals with an autism spectrum disorder can be taught to internalize these traits, to help maximize their quality of life. We as parents, professionals and educators, have a responsibility to help support and enhance these traits in individuals with an autism spectrum disorder in order to help empower them to play a more active role in creating their own happiness and enhance their quality of life.

Jill Krata, PhD, is Manager of Clinical Services of the YAI Autism Center. For more information, please visit yai.org/autism or contact YAI LINK for information and referral for services at 1-866-2-YAI-LINK.

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The Costs of Raising a Teenage Son With Autism

By Jeff Stimpson
Journalist

Researchers at the Children's Institute, a not-for-profit organization affiliated with the University of Rochester, NY, studied the connection between autism and the hemorrhage of cash a family endures when one of their own has the condition. "It's a disorder that seems to have an impact on the entire family," reads the press release accompanying the study, from 2008. "A new study finds the average household with children with autism not only spends thousands of dollars more in expenses, but also makes less money overall."

My 15-year-old son Alex has done his part to make sure the situation has grown only worse in the past five years. First he wanted an iPad. My wife Jill bought his first-generation beater (\$190 on eBay) for him months ago, and was smart enough to also spring for a thick black plastic shield (a "Defender," \$30 then and still about that on eBay). It keeps the iPad screen off our hardwood when Alex drops the iPad screen-down with a *smack*.

"Alex, don't drop that!"

Finally the iPad meets our hardwood enough to put a mountain range of hair-line cracks across the screen. He brings it to me. "iPad!" he proclaims. The screen is black. "Alex, what do you want me to do?"

Slide to Power Off the thing reads. Jill taught me to press the Power button and the button on the side of the iPad simultaneously until the screen goes black in these moments of parenthood and the apple appears in the center of the black screen.

I press two more buttons, resuscitating the thing yet again, and hand it back to Alex. He goes away to punch buttons.

I don't feel great about shelving my son to technology in tough moments – no one who works with children with autism should ever believe that parents feel good about that – but you must understand that I got a job six weeks ago.

I'm 51 and I got a job! I was laid off four years ago and I got a job at a cool Times Square startup suddenly making more than



Jeff Stimpson

less overall. I look out my office window and not 50 yards away sits the ball they drop on New Year's Eve. *The ball. Cool.*

I work on the first day Alex is home from camp, the first of some 14 days he'll have home between the end of his 10 days of summer camp and the faraway beginning of school. We arrange for a neighbor to watch Alex during this period that Jill said over and over would "work out."

Jill emails on the first day. "Alex + uncharged iPad + our neighbor sort of MIA. Please. DO NOT be in a bad mood this evening. This is really shaping out to be a sucky day."

I warned Jill about this weeks ago after my first interview. Our neighbor doesn't feel well. And I'm supposed to do ... what? On lunch hour I weave my way through the tourists up Broadway to Forever 21 to buy leggings for Alex. Alex calls them "Pajamas! Pajamas!" They're girls' tights for dance class, really, and normally they're two for \$10. They are two for \$7.50 this week. Wow.

Alex rips both pair in less than a week (...thousands of dollars more in expenses...) looking down when he's bored and

setting his fingers to work. Then from where he sits comes a sound like skin peeling after a sunburn and I see a rope of legging dangling from his hand.

Why does he do this? "Must be something to do with sensation through his fingertips," his teacher said once.

Because both Jill and I work now, we're running low on paper towels, which we run through when Alex misses the toilet and makes a mess on the bathroom floor in the morning. They're at Costco, \$18 for a bundle of 12 rolls. When I was unemployed (...thousands of dollars...) I used to wheel the rolls home by foot with our cart. Now I snap to Jill about delivery or having someone deliver paper towels.

Eating costs a lot. "Many children on the spectrum have difficulties with eating a limited diet," reads the Eating Problems primer of National Autism Resources (www.nationalautismresources.com/autism-eating-problems.html). "Reasons for children's eating problems may range from a need for food to look a certain way, to avoiding certain textures of foods."

I guess Alex read that, because he used to like McDonald's nuggets, about \$8 in Manhattan when you get them with the meal. Now he likes Popeye's 3-Piece Tender Combo, \$6.39. For years it was hot dogs at dinner, Hebrew Nationals, \$4.50 for a pack of seven. *Think of all the sodium*, we used to think before he stopped eating anything at all except Chee-tos, Chips Ahoy and Utz Dark Specials.

"One especially helpful feeding therapy is food chaining," Eating Problems continues. "Food chaining has been developed as a systematic method for the treatment of children with extreme food selectivity. Food chaining is an individualized, non-threatening, home-based feeding program designed to expand food repertoire by emphasizing similar features between accepted and targeted food items."

These days Alex's food chaining involves drinking a glass or two of chocolate milk a day (Ovaltine: \$4.99 for a 12-ounce tub) and munching Chips Ahoy (Original, about \$5, but \$3 on sale). His Special pretzels run \$3.50, but almost every store sells for them for \$2.99 though the corner of the

bag still says \$3.50. Isn't that strange?

"Pretzels!" he says. "Cook-EEs!" He's nibbled blueberries, watermelon and, most recently, fried breaded eggplant. He used to like but has kicked chocolate, bacon and yogurt. Food for him is cheaper, overall, than a steak dinner. I'll give \$500 to the first person who gets him to eat a steak dinner.

"Cheos," Alex says. "Char-oos."

"Chee-" I say slowly.

"Cheah-"

"Chee-TOs!" \$2.78 to \$3.18, depending on the sales. "Cheer-AHs!" Alex says. "Alex," I reply, "we don't have any right now. We'll buy you some tomorrow."

What kid, neurotypical or otherwise, doesn't want Chee-tos or an iPad? Alex doesn't ask for expensive, trendy jeans or the hottest and latest sneakers. He doesn't care if people care about how he looks. On the books, he should be cheaper than a typically developing kid. Even the four-digit lawyers' fees we've forked over to get Alex into a "residential program," round-the-clock education we believe is his last best shot at any kind of productive adulthood, might also hit parents trying to get their typically developing child into a private school or college.

A study in the *Archives of Pediatric Medicine* estimates the lifetime cost of an individual's autism at \$3.2 million, taking into account what Jill and I shell out plus the costs "to society in general." The latter includes, among other things, that Alex will likely never support himself as an adult. A society that chooses to call itself compassionate will have to keep him alive and reasonably happy for a long time.

The extra cost of autism involves neither dollar signs nor decimal points. It involves the anxiety that my wife Jill and I live with – the unknown future for Alex when we are no longer around to provide the intensive care and love that he so desperately needs.

Jeff Stimpson's books are "Alex the Boy: Episodes From a Family's Life With Autism" and "Alex: The Fathering of a Premie." Visit his blog is at www.jeffslife.tripod.com/alextheboy.

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to keep spending without the constraint of exchanging money. For individuals with ASD this can have very negative results. Many don't know how much items or services really cost because they don't need to be aware. While teaching a recent financial literacy seminar to ASD students, it was surprising to learn that they knew nothing about credit card interest. Most of these students said their parents manage the credit card bill so they were not aware of the consequences of accumulating credit card debt. A possible solution to this lack of awareness is for parents to create a PayPal student account, or get a Bill My Parents Later Prepaid Teen Credit Card from MasterCard or a PASS card from American Express. These options allow par-

ents to set limits and monitor spending.

Money Can't Buy You Love (or Friends)

Trusting ASD individuals are often used by others. A most unfortunate aspect of their lack of social awareness is that they end up paying for meals, giving away prized items, and loaning money to unscrupulous types that pretend to be their "friends." Many on the spectrum are generous people who desperately want relationships and may even allow themselves to be taken advantage of in exchange for a friend. ASD individuals often don't have much relationship experiences to draw upon so it is essential that they understand what constitutes a healthy and balanced relationship in terms of money. Romantic relationships can be even

more precarious in this regard. Purchasing gifts for the object of one's affection is risky particularly if you don't know them well or met online. Lavish expenditures can cause people to feel uncomfortable as well as bring out the predatory nature of some. There are numerous examples of ASD individuals who have turned over their credit cards to devious types who exploited them. As such, ASD individuals should be very reticent to offer to pay for anything until they know the person well. The best course is to share expenses most of the time.

Educational Solutions

Parents of ASD individuals can teach financial literacy in a variety of ways. The website www.moneysavvygeneration.com

has information on teaching young children, curriculums, and financial game software such as My Mathematical Life Game (how to create budgets, calculate interest, and understand credit), Financial Football, or Financial Soccer (financial management). Other games that were created by Staples to teach saving principles are Bite Nightclub (with vampires!), Celebrity Calamity and Refund Rush. Most ASD students will benefit from visual budgets displays created on an Excel spreadsheet. Monthly college expenses such as transportation, supplies and entertainment are budgeted so the student can be aware of money available for each.

This article is based on a presentation at the 2013 AHA spring conference and an article in the fall 2013 edition of AHA's *On The Spectrum*.

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CEO and Behavior Analyst
Verbal Beginnings, LLC

Chicken nuggets, french fries, chips, cookies, and juice. Chicken nuggets, french fries, chips, cookies, and juice. The cycle repeats over and over again; breakfast, lunch, and dinner. Day after day after day. Sometimes, you'll try to switch out the regular chocolate chip cookies with reduced sugar or regular potato chips with veggie chips to try to get some nutritional value in him. But you don't succeed. He'd rather not eat anything for days, than even taste anything new. And going out to eat... Forget it! There has to be some solution to this problem, but all my pediatrician says is give it some time, he'll grow out of it.

Feeding Myths

Myth #1: If you withhold food from your child, he/she will eventually come around and eat anything you offer him/her.

Truth: Children with autism that experience feeding problems are not motivated by food and sometimes don't feel hunger. Withholding food from a child is a very dangerous, inappropriate, and ineffective strategy to fixing feeding problems.



Diana A. Wolf, MA, BCBA

Myth #2: If he/she tries something and doesn't like it, he/she will never like it.

Truth: Research shows that it takes 10-20 tastes of a food to determine preference. Tasting a food means chewing it fully and swallowing it (Birch & Marlin, 1982).

Myth #3: Feeding problems are all about oral motor skill deficits and sensory sensitivity.

Truth: Although some children exhibit oral motor skill delays or oral sensitivity, which may have led to a reduction in food variety, often times there's a behavioral component which needs to be addressed prior to working on desensitization and skill acquisition.

Statistic: 90% of children diagnosed with Autism have feeding problems (Kodak & Piazza, 2008).

Why Do Children Have Feeding Problems?

Parents often can't figure out why their child who was eating all sorts of different foods at 1, all of a sudden began narrowing down his diet to only a handle of foods at his current age. The direct cause of feeding problems is something unknown, although multiple variables play a role in food selectivity. Below is a list of a few.

Variable 1: Experiencing pain or discomfort during mealtime. This can occur from a medical condition (e.g., reflux), deficits in oral motor functioning which result in gagging (e.g., inability to properly chew food), or accidental choking.

Variable 2: Watching someone else have a bad reaction to a food. Examples: Mom

or dad express dislike for certain foods. Or if the child witnessed someone choke or vomit from eating.

Variable 3: Children with Autism strive from routine and rituals. There is an insistence on routines and a resistance to change in the Autism community. Possibly attributed to language delays or deficits, children with Autism find it comforting to know the expected and seem to develop what could be equivalent to a phobia of trying new foods.

How to Fix Picky Eating

Tip #1: Set a schedule for meals and snacks (**NO SNACKING IN BETWEEN**). This will increase the motivation of eating foods presented during meal and snack times because the child will have time to build up his appetite. On the same note, if the child is thirsty, offer water, not juice or milk. Anything other than water could become too filling and ruin his/her appetite.

Tip #2: Minimize distractions. Present meals and snacks in a location that is away from any distraction (e.g., toys, TV, etc.). If the child is not concentrating on the food and is constantly running around or engaged in another activity, he/she is less likely to eat everything presented to

see Picky Eating on [page 31](#)

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the area where you live. School districts may challenge the service providers' rates so that your providers' rates should be defensible as within the market rate range. Factors include the provider's level of experience, reputation, and education and sometimes "certification" in the field (e.g. an ABA provider who is Board Certified as a Behavior Analyst – BCBA).

To ensure that you have a "winnable" case for reimbursement, you must first provide the school district with notice about the services you intend to implement and that you intend to look to the school district

for reimbursement. Parents are advised to give this notice in writing, and it must be given 10 business days *prior* to implementing the services.

If you decide to file a demand for due process for reimbursement/funding for your child's program, you will have to prove that the program or private school for which you seek funding is appropriate to meet your child's needs, and you should anticipate that your providers will have to testify and give evidence that their services are helping your child make meaningful progress.

You can also include in your demand for due process a claim for "compensatory education." Compensatory education is a

remedy available to students who have not received the services that they were mandated to receive in a previous IEP, or were never mandated to receive the services, but should have been. This remedy is intended to "compensate" the child with services.

The field of special education law is a complex field that requires advocacy and expertise. A helpful source of information for families is the Council of Parent Attorneys and Advocates (COPAA) (www.copaa.org). If you want to find an attorney or advocate, COPAA maintains a list of special education attorneys around the country. You do not have to go it alone!

Tracey Spencer Walsh, JD (Fordham University School of Law, '94) is a Partner at Mayerson & Associates, a New York law firm dedicated to representing children and adolescents with autism and other disabilities, and assisting families in accessing the education and related services necessary and appropriate for students. Tracey is also an Adjunct Law Professor at Fordham University School of Law and teaches a Special Education Advocacy course. Tracey has also been a featured speaker at many national conferences on special education topics. Please visit www.mayerslaw.com for more information.

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in their state at <http://mchb.hrsa.gov/programs/titlevgrants/>.

Other Help for Families: Supplemental Security Income

Besides insurance, as mentioned above, children may be eligible for Supplemental Security Income. For information on SSI, see www.socialsecurity.gov/ssi/text-child-ussi.htm. Even if a child isn't eligible due to family income, they can reapply at age 18.

Education-Related Services

Once children reach age 3, they may be eligible for preschool disability services until they graduate or age out of the special education system (usually at age 21). Related services can include speech, occupational, physical therapies, sensory integration, social

skills, etc. Although districts may ask for parental consent to access insurance, they still must provide related services in the child's Individualized Education Program even if families deny consent. If families have questions about school related services, they can contact the Parent Training and Information Center in their state at www.parentcenternetwork.org.

Developmental Disabilities Services

States may also have services for children and adults with Developmental Disabilities. In the past, for example, NJ's services included respite, camp funds, cash stipends, home modifications, behaviorists, etc. Families can get information from their Governor's Council on Developmental Disabilities found at www.nacdd.org/about-nacdd/councils-on-developmental-disabilities.aspx. Families in some states may also be eligible for Personal Care Assistance to help their child with ADLs (activities of daily living). To find a consum-

er-directed care program, visit <http://web.bc.edu/libtools/insights-publications.php>.

Special Needs Trusts

Lastly, families may need to develop a special needs trust to prevent the possible loss of eligibility for programs like Medicaid and SSI. This will also help protect the child's future. For more information, please visit www.pacer.org/publications/possibilities/saving-for-your-childs-future-needs-part1.html.

Centers for Independent Living

The last step is to maximize the child's independence. Centers for independent living help with independent living skills such as life skills, vocational assessment, housing, transportation, etc. They can also help consumers access resources for independent living, such as filling out

applications for services or employment, and can be found at www.ncil.org.

Families of children with autism spectrum disorders need to utilize resources to ensure that their child gets the services they need. By planning financially, they can help their child reach their best potential, without sacrificing their family's financial stability.

Lauren Agoratus is the parent of a child with autism/kidney disease. She is the NJ Coordinator of Family Voices, the national network that works to keep families at the center of children's health care for children with special healthcare needs; in NJ, Family Voices is housed at the Statewide Parent Advocacy Network (SPAN), www.spanadvocacy.org. SPAN is also the home of the state's Family-to-Family Health Information Center. Lauren can be reached at (800) 654-SPAN or by email at familyvoices@spannj.org. Families can find free help in their state at www.familyvoices.org/states.php.

Guardianship from [page 12](#)

include determining what services will need to be in place, if any, for the couple to live together safely and happily after the marriage.

The opportunity to have a driver's license and operate a vehicle will also depend upon passing a written test and driving test as required by state law. Whether it is appropriate for your adult disabled child to have a driver's license should be discussed with your adult child and his or her medical, psychological, or other treatment professionals.

The right to vote also depends upon local (and Federal) laws. In New York, a person determined by a court to be "incompetent" is not permitted to vote. All the same, in many states, including New York, the standard for appointing a guardian is not incompetence but rather a determination of incapacity or certification of a diagnosis of mental retardation or developmental disability. It's important to note, however, that as of 2013, there is no legal test for

registering and voting but your adult disabled child individual must understand the nature of voting and decisions to be made. For an excellent state by state chart of voting rights for persons with disabilities, go to www.bazonline.org and click "Self-Determination > Voting > Voting Policy Documents > Vote 2012 It's Your Right."

And credit cards or credit? There is no legal barrier to obtaining a credit card or other credit, such as a car loan or mortgage, whether a person is disabled due to mental illness, developmental disability, or other incapacity. If credit can be used responsibly, there is no legal reason why your adult disabled child, including one with a court appointed guardian, might not obtain credit. Many parents worry and wonder if their adult child (disabled or not) has the legal capacity to enter into a contract for credit and even understand credit terms. It's important to keep in mind that access to credit and protection from creditors is complex, and consumer legal rights are layered between state and federal fair lending laws and credit standards. If your

adult disabled child is drowning in credit difficulties, you may need to be appointed as guardian to dispute, negotiate, or compromise creditors' claims with a court's assistance or supervision. Still, even without a guardian, many state laws protect certain income (including Social Security) and limited resources of your adult disabled child from creditor claims. And, no guardian is needed to enroll a disabled adult on a state's do-not-call registry.

Finally, take time to review your own estate planning if your adult disabled child is receiving, or may need government benefits, such as Medicaid or SSI. In the past, many families believed that the federal and state governments would always be there for their disabled adult child's needs. Gone are those days when the government will fund each and every program for persons with disabilities. Cuts are expected in housing services and supports for persons with disabilities. A Special Needs Trust (SNT), written in consultation with a qualified attorney, is an important source of supplemental support for your adult disabled child

throughout their life after you are gone. The decision to become your adult disabled child's legal guardian is a significant step. It offers protections for your adult disabled child, and, it is a decision which should be made together with your adult disabled child, if he or she is capable, and his or her medical, social, and psychological treatment team. All the ramifications – both positive and negative – for your adult disabled child should be considered, including his or her personal goals and ambitions. The goal is to protect your child, now and for the rest of his or her life.

Beth Polner Abrahams is admitted to practice law in New York State, with an office on Long Island. For more information about her law practice go to www.bpanstlaw.com. To receive updates in special needs and elder law, at no charge, her law blog may be found at www.bpalegalupdateblog.wordpress.com or register to receive the updates at the website. Law Office of Beth Polner Abrahams, (516) 741-9175 and Info@BPAbrahamsLaw.com.

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as it was with self-doubt that I didn't want to feel criticized even more. I was wrong, and I'm glad that I asked for help. My sisters were good listeners, and they also pointed out that, autistic or not, I had been given a raw deal and that the lost opportunity wasn't my fault.

This had never occurred to me: that external forces beyond my control had played a role in my misfortune. That's when I began to understand the power of dialogue when it comes to finding solutions and charting a path in one's business, career and personal life. No one can do this alone, and a mentor is someone we can trust and speak to about all aspects of our lives. For some of us on the spectrum, access to a mentor, or realizing how important they can be, might come late in life, especially if we don't have opportunities to experience having mentors when we are young.

I love the work that I do. In addition to the tough times, I have had the benefit of experiencing tremendous happiness and feelings of success in many collaborative projects and programs with others. There

is a special magic to feeling that kind of shared commitment and responsibility. I have felt this in a number of settings, such as at the ASPIE school, a middle and high school for students on the spectrum that I co-founded in Upstate New York and more recently, the Autistic Global Initiative (AGI), a program I direct for the Autism Research Institute that is devoted to building capacity in adult services. In such situations, I learn as much from supporting others with my assistance as I do receiving their support. I also have a mentor whom I speak with regularly. Our dialogue keeps me on track and is an anchor when I'm faced with change or big decisions.

"To have faith in the power of dialogue is to believe in the promise of humanity." These words come from the Buddhist scholar, Daisaku Ikeda. I turn to them as a kind of guiding principle in my interactions at work, as well as with those whom I mentor. Dialogue involves listening as much as it does communicating. Recently, I became involved in a mentor and mentee relationship with a young woman with Asperger's syndrome whom I have known for many years. She recently completed her under-

graduate degree and has been living independently for the first time, going to work, paying the bills, making a life. Brigid has many talents that have steadily grown and emerged as she moved into adult life, placing her in a position to start her own small business as a writer and disability consultant. During this emergence, we began dialoguing about her goals and dreams, and about practical things, too. We talk about the book she will write, the conference presentations she will do, and the differences between a 1099 and a W-2 tax form. We discuss how to plan for and pay taxes when you're self-employed. We cover industry topics, too, such as negotiating contracts as a technical freelance writer, understanding why it's important to research an organization to determine one's fees, as well as how to balance pro bono with paid work.

Most recently, Brigid was recruited by the Houlton Institute, an online education provider, to serve as a teaching assistant to professors who lead online trainings and certifications for professionals, educators, and families of people with autism and other disabilities. In fact, she has become my TA for two courses I teach: the

Integrated Self Advocacy ProSeries and Certification and the AGI Residential/Daily Living Course for Direct Support Providers (www.houltoninstitute.com). In addition, Brigid has become a consultant to the Houlton Institute as they develop a training program to hire more young adults with autism and other disabilities to work as TAs for their courses.

Mentoring a fellow autistic is a wonderful experience. I learn a lot from Brigid, and in the process, I find myself revisiting my past—with all its ups and downs. In our dialogue, that past becomes malleable and flowing. It morphs itself into something new and refreshing and promising, something embodied by Brigid and her generation of young adults on the spectrum. Therein lies the promise of our humanity.

Valerie Paradiz, PhD, is Director of the Center for Integrated Self Advocacy (www.houltoninstitute.com/programs/isa_landing) and Director of the Autistic Global Initiative of the Autism Research Institute (www.autism.com). To contact Valerie, please visit www.autismselfadvocacy.com for more information.

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always be our parents' children, we will also always have mentors to go and seek

advice from.

Recently, I've decided to make a big change to go back to school and work on my career instead of just having a job. Al-

though this is a great step forward, it is one that requires a leap of faith on my part. It feels very good to know I am supported and guided by my friends to help me figure

things out. Having the support of my mentors allows me to not let the anxiety hold me back and instead I can feel like things will be all right.

Affordable from [page 22](#)

Autism Spectrum Services) and focused heavily on curriculum redevelopment as a means to make classes more accessible to students on the spectrum. They studied various classroom components such as teaching style, syllabi, and curricula. PASS worked persistently with the Deans of the college to develop a plan for slowly bringing about changes in the classroom that would help make classes more accessible to students on the spectrum, while not changing the high academic standards of the City University of New York.

Compared to other ASD higher education programs throughout the United States, Project REACH is inspiring. When we compared our project to one of the larger and well-regarded programs in our region, we found our services to be almost equal. Both programs

present students with peer mentoring, social-skill workshops, and career counseling. The services offered by this program cost the student's family \$2,600 per semester, in addition to the cost of private school's tuition.

Another program located in the South-Atlantic region charges a \$4,000 per semester fee (in addition to tuition) and offers comparable services to Project REACH as well as including a large focus on civic engagement. There is a university that offers graduate-student led study sessions 5 days a week as well as many of the academic services listed above and live-in residence hall support for \$6,500 a semester. Finally, for \$8,000 a semester, a student could receive very similar accommodations to all previously mentioned, as well as take part in "Psycho-Educational" support groups and focused vocational support including career placement. All of these fees are in addition

to the tuition for the University in question.

CUNY has 24 campuses and an estimated number of 1,000 students on the spectrum that need services and reasonable accommodations. As this article clearly states, a fully functional program that provides top of the line quality services and supports is not cheap by any means. Many universities charge for their programs because they need some, if not most, of that money to fund the services and supports that they provide students. As Project REACH moves forward with assembling the best practices and putting them to work CUNY-wide, we are trying to bring our services to CUNY campuses without a financial burden tacked on to students' families. Additionally, REACH seeks to bring understanding and support to not only faculty and staff, but students as well. In that sense, CUNY Project REACH sets itself apart from the previously men-

tioned universities as it is not explicitly a program of accommodations, but a program of social change. We aspire to meet the needs of every student on the spectrum who attends any of our 24 campuses and nurture the understanding in their peers that will lead to a more accommodating society. REACH has received an additional \$100,000 grant awarded by the FAR Fund for the 2013-2014 academic year, and with it we will be able to "reach" out to more students on the spectrum and change even more lives for the better.

Lisa Pollich, PhD, is Project Director and Charles Eli Carr and John A. Schiavone II, are Project Staff at CUNY Project REACH. Questions and comments can be sent to Lisa Pollich at Lisa.Pollich@mail.cuny.edu. Visit our website at www.cuny.edu/projectREACH.

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PDD-NOS—which appear to have little scientific validity or reliability since those diagnoses cannot be adequately replicated (“What Changes May Mean,” 2012). However, the new proposal has stricter standards for communication and social deficits, further tightening the definition and making it more difficult for many higher functioning infants and toddlers (Lukasik, 2012). In addition to the hurdles created by eliminating categories for higher functioning children and the removing provisions for delayed language alone, the DSM V also looks to young children’s interactions with other children, not caregivers, to determine eligibility (“Proposed Revisions,” 2012). This criterion may not be achievable for infants and toddlers with early signs of ASD since many have few interactions other than with caregivers. Thus, the DSM V presents unknown barriers for eligibility for infants and toddlers.

B. Services Required Under IDEA

In the first case decided by the United States Supreme Court under the IDEA, *Board of Education v. Rowley*, the court determined that a child’s required Individualized Educational Plan (IEP) needs to be reasonably calculated to provide only *some educational benefits* to the child. This decision has been held to apply to EI. It has been used to reject parents’ proposals for their child with ASD to get the “best” program or the program that will “maximize their child’s potential.

Following this constricted view of the law, many courts have held that a child is not entitled to an Applied Behavioral Analysis (ABA) program (even when parents can prove the effectiveness of this program for their child) if the school or lead agency provides an alternative that gives the child

some *meaningful* benefit. Courts, however, have upheld a child’s right to receive ABA services based on the individual needs of that child.

C. Intensity of Services

As in Part B, there is not a set policy on the number of hours of ABA or other therapies a child should or can receive, nor is there research on this important point. The American Academy of Pediatrics, however, has recently recommended that infants and toddlers with ASD receive at least 25 hours of intensive EI services which could include ABA as well as speech, physical and occupational therapies (Warren, 2011).

D. Payment

Traditionally, EI services are reimbursed by a variety of sources, including Federal Part C funds, state, and local funds. In many states, Medicaid is used to pay for many EI services including ABA. Often, parents seek additional services outside of EI to obtain the “best” services possible for their children. Parents are entitled to reimbursement when services are reduced or changed for reasons not related to the child’s needs; parents are not entitled to reimbursement simply because they believe the child would benefit from additional or different services. Yet, cases seeking reimbursement, which seem to predominate in New York, provide an advantage to wealthy families who can afford to take the risk of paying for private programs without a guarantee of ever receiving reimbursement.

Many parents have sought to use insurance to pay for services not covered by the IDEA. For autism organizations, insurance reform has been a top priority resulting in insurance legislation passed by the majority of states (“Autism Votes,” 2010). Most of those state laws cover only children, some

with age limits; some with caps on available funding; and some with questionable long-term utility. In the EI context, they are not very useful since EI should be covering most needed services. The 2010 federal Affordable Care Act (Act) upheld by the United States Supreme Court requires insurance companies to cover all children with pre-existing conditions such as ASD and to cover adults by 2014 (“Patient Protection and Affordable Care Act,” 2010). The Act also could cover “behavioral health treatments” that are medically necessary and evidence-based, such as ABA, as part of the essential benefits package. Unfortunately, the new federal regulations implementing the Act have not specifically referred to ABA services under its definition of the essential benefit package. Thus, state-based advocacy to correct this omission will be critical.

E. Conclusion

There is a constant struggle for infants and toddlers with ASD to receive appropriate EI services in a timely manner. This struggle is a direct result of the many legal problems surrounding EI. It is imperative that more states follow the direction of the eight states that have specifically added ASD as an established condition to their regulations. It is important for advocates to watch the impact of the DSM V on future EI eligibility. It is also important for advocates to insure that ABA services are covered by the state’s definition of “essential services” under the Act. Ardent advocacy is necessary so that children with ASD will continue to be identified early and receive needed EI services expeditiously.

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Service System from page 17

Some recommendations require state programs to increase the number of individuals they serve. The Children’s Autism Medicaid Waiver is designed to serve children with autism between the ages of 0 and 9, who are at risk for institutional placement. Annually, upwards of 205 children benefit from this intensive in-home community based program. This is a fraction of the number of children the program could serve; 800 children applied for the Children’s Waiver during an open enrollment in 2012. The Commission recommended that the Children’s Autism Waiver increase both the yearly number of children served to 500 and the age of eligibility to be greater than nine.

The state’s seven community-based statewide Autism Support Centers were recognized by the Commission as excellent sources of support and information to families caring for a child with autism. Currently, the Support Centers are only funded by DDS to serve children with autism and their families. This prohibits the Centers from serving adults with autism. The Commission recommended increasing the ages of individuals served at the Centers as well as increase state funding for the centers to work with a larger population.

During the Commission’s discussions, it was noted that a few existing services needed to be improved to better meet the

needs of the diverse autism population. The state’s Adult Medicaid Waiver is a tremendous source of support for adults with a range of disabilities. The Commission recognized the needs of adults with autism in the Waiver program do not always mirror the needs of people with other disabilities. Enhanced behavioral support consultation was recommended for DDS eligible adults with autism as well as improved and increased availability of behavioral support for adults with autism living in group homes.

In recent years, laws in Massachusetts such as the Autism IEP Act and the Transition Specialist Endorsement were passed to improve the education students with autism and other disabilities receive in public schools. Due to lack of resources and capacity, Massachusetts struggles to ensure school districts are complying with these laws. The Commission recommended a coordinated system be created to review education complaints and a new data system developed to track the complaints people make and their progress. To further ensure students receive the education they are entitled to, the Commission also recommended an Autism Endorsement be created for teachers to expand their knowledge on how to effectively educate children and youth with autism.

The Commission heard many families and individuals voice their frustration with the lack of coordination between state

agencies. The Massachusetts Early Intervention program provides access to comprehensive services and treatment for all children prior to age three including specialty services for children diagnosed with autism. After age three, children transition to their early childhood education system to receive services. Unfortunately, the type of services the child receives post EI depends on his or her IEP, health insurance, and school district resources. This transition often causes a disruption in services for young children causing them to regress in the skills they acquired while in EI. The Commission recommended that EI train staff about the state’s autism insurance law and develop tools to help staff and families navigate insurance options for behavioral treatments after age 3 in order to maximize a family’s available resources as much as possible.

Access to accurate information on services and resources was found to be another way to improve coordination and alleviate stress for families and individuals. It was determined that since DDS’s Division of Autism is one of the main state agencies that interact with individuals with autism it should be designated as the state agency for information and referral for individuals with autism throughout their lives.

Progress

In January 2013, the Commission filed

14 pieces of legislation to address multiple recommendations. Hearings have been held on six of the bills while five more bills will be heard in September 2013. The Chair of the Autism Commission, Barbara L’Italien, as well as staff to the Commission Faith Behum, made multiple presentations across the state about the report’s findings and recommendations to the autism community. The purpose of these presentations is to educate people in the community about the report and discuss with them what they can do to make the recommendations a reality. The Commission is working on the prospect of becoming a permanent entity in the state that will monitor the progress of the recommendations as well as examine new issues facing the autism community. The Commission has a long road ahead towards full implementation of all 79 recommendations but is well prepared for the journey with its 10 year roadmap.

If you have any questions about the Autism Commission report, please contact Faith Behum, Disability Policy Specialist at the Massachusetts Developmental Disabilities Council at Faith.Behum@state.ma.us or (617)770-7676 ext.107. The entire Autism Commission report can be located at www.mass.gov/eohhs/gov/commissions-and-initiatives/autism/the-massachusetts-autism-commission-final-report.html.

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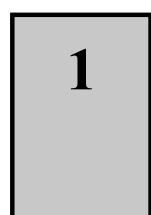
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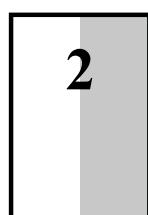
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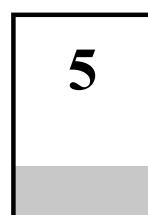
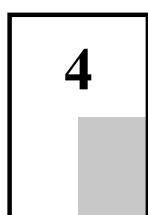
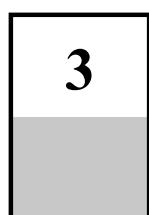
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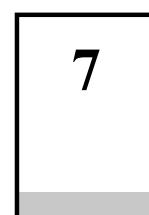
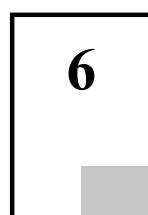
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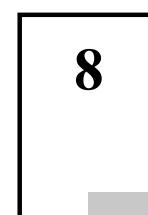
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Autism Genes from page 4

to their role in untangling DNA, topoisomerases are involved in transcribing DNA into RNA sequences².

Following that lead, the researchers exposed cultured mouse and human neurons to topotecan and then measured changes in expression across the genome.

Topoisomerase inhibitors turn up the expression of 28 genes and dial down the expression of 155 genes, the study found. All of the dampened genes are large, at least 67 kilobases (kb).

“As you get bigger and bigger, the odds are greater that the gene’s expression goes down,” Zylka says. “Around 200 kb or longer, the drugs inhibit like 90 percent of those genes.”

The results suggest that topoisomerases are important for the expression of extremely long genes.

The paper showcases “some really, really beautiful cell biology,” says Brett Abrahams, assistant professor of genetics at the Albert Einstein College of Medicine in New York, who was not involved in the study. “It’s less clear to me what to make of the potential autism link.”

Autism Lists

The researchers noticed that many of

the genes regulated by topoisomerases are involved in the function of synapses, the junctions between neurons, and also in autism. They cross-referenced their list with autism candidate genes catalogued by various sequencing studies and by SFARI Gene, a comprehensive database of genes linked to autism. (SFARI Gene is funded by the Simons Foundation, SFARI.org’s parent organization.)

They found that 49 of the 183 genes affected by topoisomerases — 27 percent — had previously been linked to autism, a proportion much higher than would be seen by chance.

While this work was underway, two other studies appeared showing that a few individuals with autism carry mutations in topoisomerase genes^{3,4}. This month, two studies in *Nature Neuroscience* linked TOP3B — a topoisomerase that influences RNA — with schizophrenia, cognitive impairment and fragile X syndrome^{5,6}.

The researchers also found that the autism candidate genes on their list are 217 kb on average, compared with 59 kb for a typical gene expressed in neurons of the cortex.

Abrahams notes, however, that a lot of the genes on the list have been only weakly linked to autism. What’s more, he says, it’s unclear whether the long-gene effect is specific to autism.

“What about cancer genes? What about diabetes genes? What about genes involved in sleep regulation?” Abrahams asks. “If you were to take any of these other lists, would they also show enrichment for long genes?”

Nobody knows why autism genes might be so long. Zylka speculates that it might be because of mechanisms involved in replicating DNA. In dividing cells, he says, there is a selective pressure against long genes because the enzymes involved in making RNA and copying DNA can crash into each other.

Neurons don’t divide, however. “We think that evolutionarily, neurons can express these really big genes because there aren’t as many detrimental effects,” he says.

In ongoing experiments, Zylka and Philpot are investigating drugs that, like topoisomerase inhibitors, have the ability to disrupt the enzymes and, in turn, upset a host of autism genes.

“That’s something we’re really, really interested in — environmental influences,” Philpot says. So far, he and Zylka have found at least one compound that has effects on long genes similar to those of topoisomerase inhibitors. “We have some exciting data.”

News and Opinion articles on SFARI.org are editorially independent of the Simons Foundation.

This article was originally published on SFARI.org and is reprinted with permission. You may view the original article, published 16 September 2013, at <http://sfari.org/news-and-opinion/news/2013/autism-genes-are-surprisingly-large-study-finds>.

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Integrative from page 21

patient’s team to prescribe and monitor the use of medication and communicate any non-mental health medical considerations that may impact the patient’s life and care. In addition to a family doctor, a medical doctor or nurse who has specialized in psychiatry may be part of a patient’s care, as medication may be used to control some symptoms. In the case with Joshua, he was able to receive psychiatric care in tandem with his psychotherapy at the Lindner Center. Joshua’s psychiatrist was able to consult and collaborate with his therapist and mother to best understand how effectively medications impacted his symptoms. This easy communication enabled Joshua’s doctor to prescribe a regimen that best fit his needs. However, as Joshua’s needs changed, especially with the onset puberty, the medical staff integrated into Joshua’s care also changed. Joshua will soon be seeing a developmental pediatrician who can apply specialized expertise to Joshua’s medical care, both meeting his general medical and psychiatric needs. The flexibility of

an integrated approach allows care to appropriately change throughout the patient’s lifespan.

Finally, and perhaps most important to integrated care, are the people who are involved in the patient’s day-to-day life. Family members, friends, teachers, and co-workers are in a good position to offer emotional and logistical support, to note both positive and negative changes in behavior that may be important to treatment, and to help implement real-life applications to the care the patient receives. In Joshua’s case, his mother is a good communicator of any of Joshua’s needs and behavioral changes. This invaluable communication helps inform Joshua’s care team of how treatment is progressing and if it needs be adjusted. Furthermore, Joshua’s therapist sees him only 45 minutes a week and his medical provider even less often. Skills building and symptom management cannot happen effectively if done in isolation and only at Joshua’s appointment times. With his care team, Joshua and his mom make careful plans on how skills can be practiced and how he can intentionally and therapeutically

be challenged to reinforce the work done in session. For example, prompting Joshua to communicate about his emotional experience in a specific way or doing a real life application of “exposure” therapy with a camp counselor to address an anxiety trigger while at camp have been two ways Joshua has been able to extend his work to out of session.

While some organizations, such as the Lindner Center, deliver comprehensive and coordinated primary and mental health care, individuals and families can also create integrated care among professionals from different organizations. Sometimes this may just mean communicating needs and starting a conversation with a family doctor, therapist or psychiatrist about the importance of integrated care. As an individual moves forward towards creating a more integrated care plan, here are some things to think about:

- Who should take the lead and who will most often communicate with the patient or patient’s family?
- What consent forms must be filled out

so that the different team members can collaborate to create an integrated care approach?

- Who will have access to the patient’s mental health and medical treatment records and who will have the primary responsibility for maintaining and managing these records?
- What are the legal requirements and rules related to sharing mental health and other physical health information across professionals and settings?
- What is the best way to share resources with the different professionals who are part of the patient’s integrated care?
- How does limited time or competing schedules affect effective integrated care and what can be done to overcome these barriers?

For more information about this article or the Fay J. Lindner Center for Autism and Development Disabilities, please visit www.fayjindnercenter.org.

Picky Eating from page 27

him/her or will not be receptive to any interventions you may want to try.

Tip #3: Model foods that you want your child to eat. If he/she sees you eating, he/she may be more willing to try it.

Tip #4: Eating is a demand! A lot of times, parents will ask the children if they want to eat or what they want to eat. It has become a vicious cycle of trying to avoid tantrums over foods. It’s easier to keep the peace and avoid the tantrum. But are you helping your child in the long run? Sometimes we must withstand a few tantrums to show that

eating is a demand and if they comply with the demand (or follow our directions) they will get something fun.

Tip #5: Tap into motivation. Children who have feeding problems often times will not feel hunger or find food motivating or rewarding. For that reason, we need to find something that they really enjoying doing or playing with and reserve that object or activity until after they had followed your direction to eat. Some examples of current powerful reinforcers (motivators) include iPads, TVs (mini-DVD players are great for meal times), stickers, coloring, DS systems, etc. Each child’s reinforcers will be different so it’s

important to pick out the right one. Just remember, they can’t have access to the fun toy any other time or else motivation will be lost.

Tip #6: Reward > Demand. Start out slow. Make it really easy for them to earn their reward. You want them to be successful! It could be as simple as eating 1 bite of a new food for 30 minutes of their favorite iPad game or a piece of their favorite dessert. Once you are getting successful bites, build on that success and increase the demand (e.g., 2 bites = 15 minutes of iPad time). Usually, the demand will need to be reduced when the next new food is introduced. It’s like starting all over again.

It’s hard when your child doesn’t have a healthy diet and you end up cooking two dinners every night (chicken parm for the family and hotdog for your son) or end up packing containers of food to take into a restaurant when going out (if you’re adventurous to do so). Applied Behavior Analysis is a scientifically proven approach that has shown to be effective in improving behavior problems, communication deficits, social skills deficits, and FEEDING problems in children with Autism. It is the only treatment recognized by the United States Surgeon General for children with Autism.

For more information, visit www.verbal-beginnings.com.

Insurance Law from [page 10](#)

provider of ABA services, how services needed to be provided and how to process documentation and billing.

Although many of these initial problems have been resolved, many remain and new obstacles have surfaced. Here are a few we are encountering:

- Many families are distraught by the copayments charged for each service session. Copayments range from \$20 to \$50 per session. Individuals may receive five service sessions each week, so a family could pay up to \$250 per week in co-payments. For

many families, this is too great a financial burden so they are reducing or foregoing services.

- The expansion of qualified ABA service providers by the new emergency regulations raises new concerns as to whether all providers have the knowledge and expertise to provide effective services to individuals with ASD and their families.
- Providers of services are faced with the challenge of limited service provision hours. Since most ABA services are scheduled for three to five sessions each week after the traditional school

day, it is difficult to employ full-time providers when the window of service provision is so limited.

- For families and providers of services who are navigating the different authorization procedures, documentation and billing requirements with numerous insurance companies and behavioral health organizations these systems can be perplexing.
- Finding qualified, experienced providers able to deliver high quality services can be difficult for families.

Keep in mind the goal of the autism in-

urance law was to improve access of essential treatments. While we have made headway, we still have a long way to go. Hopefully the issues I brought to light will be resolved through the innovation of all stakeholders and further modifications to the regulation. It is my belief that the strain we are all experiencing has to do with the complexity of this endeavor which is precisely why my subtitle to this article is, "No one said it would be easy."

For more information about the Anderson Center for Autism, please contact Patrick D. Paul at PatrickPaul@acenterforautism.org or visit www.andersoncenterforautism.org.

Post-Secondary from [page 14](#)

Bill in 1944. The Post 9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252), allows for the transfer of unused educational benefits from the veteran or active duty service member to his or her dependents (spouse or children). The educational benefits can be applied to traditional college degree programs as well as on-the-job training, apprenticeships, and non-college degree programs. The Post 9/11 Veterans Educational Assistance Improvements Act of 2010 (P.L. 111-377), more commonly referred to as the "New G.I. Bill 2.0," expanded the definition of eligible service personnel to include full time active guard and reserve members. Now, the military service member can be from any branch of the military (Army, Air Force, Marines, and Navy) as well as the National Guard and Coast Guard (VanBergeijk, Cavanagh, Borchers, 2012).

For a child of a service person to receive the transfer of benefits, the military person has to have served in the armed forces for at least 10 years. The college or vocational program needs to be an approved program by the Veterans Administration. The benefits are as follows: (1) four academic years (36 months) of tuition paid at a rate up to the equivalent cost of the most expensive public undergraduate college in the military person's home state; (2) a monthly living stipend (which varies depending upon the location of the college); (3) an extension of the Montgomery G.I. Bill in terms of eligibility – instead of the benefit only covering veterans who left the military within 10 years, the benefit has been extended to 15 years after the veteran has left the service; (4) approved overseas programs are now eligible for the first time; (5) an annual stipend of up to \$1,200 for educational expenses (e.g. books); and (6) a one-time licensing fee or certification test fee (up to \$2,000) that is not counted against the 36 months of tuition benefit. Private colleges tend to be more expensive than public colleges. The New G.I. and the New G.I. Bill 2.0 created a program to help offset the difference in the cost of private versus public colleges. The "Yellow Ribbon Program" is a federal program where the government will match up to 1/2 the cost differential between the most expensive public college in the veteran's home state and the cost of the private college. The private college must agree to match an equal amount that the federal government is providing. Therefore, up to 100% of the cost differential could be covered by this program.

Students using The Post 9/11 Veterans Educational Assistance Improvements Act benefit are still eligible for financial aid. Students must complete the Free Application for Federal Student Aid (FAFSA) in order to determine the Expected Family Contribution (EFC). The students, depending upon their family's income, may be eligible for Pell Grants, Federal Supplemental Educational Opportunity Grants (FSEOG), Work Study monies, and both federal subsidized and unsubsidized loans.

What About Students with Autism and Students with Intellectual Disabilities?

If a student on the autism spectrum is able to apply to college and matriculate full time in a degree bearing program, then he or she is entitled to apply for Federal Student Aid through the FAFSA just like any other college student. If that same student is the son or daughter is the dependent of an active duty serviceperson or veteran, then he or she may also be eligible for the transfer of G.I. Benefits discussed previously. However, many students on the autism spectrum are unable to be accepted directly into a college. Some have not yet finished high school. Others are unable to matriculate full time in a degree bearing program full time. Another group of students on the autism spectrum has a co-morbid intellectual disability and may never be able to pursue a degree bearing program as a full time student. Are the doors of higher education and job training then closed to these students? The answer is no.

When in 2008 Congress passed the Higher Education Opportunity Act (P.L. 110-315), it re-authorized Title IV which is the Title that governs Federal Student Aid. It also made some very distinct changes in the legislation to encourage students with intellectual disabilities to continue to pursue their education post-high school. It created the concept of Comprehensive Transition and Post-secondary (CTP) programs. Institutions of Higher Education with an already approved Title IV program are eligible to submit applications to the U.S. Department of Education for approval of their CTP. The colleges must demonstrate that the CTP has a curriculum and advising structure that is specific to students with intellectual disabilities (ID) including some students with autism. Further, the college must demonstrate to the DOE those students with ID are in educational and vocational training activities with the neurotypical population at least 51% of the time over the course of their program.

As a result of the change in legislation students with ID, including some who are on the autism spectrum, are now able to apply for Federal Student Aid through the Free Application for Federal Student Aid (FAFSA) just like any other college student even though they may not have graduated from high school and even if they are not enrolled in a degree bearing program. However, students with ID who apply to a U.S. DOE approved CTP are only eligible for certain forms of Federal Student Aid. Students are only eligible for grants - the Pell Grants, the Federal Supplemental Opportunity Grants (FSEOG), and Student Work Study monies. The grants are not expected to be re-paid as long as the student maintains Satisfactory Academic Progress. Depending on the cost of the CTP, these grants may not be sufficient to cover tuition, room, and board. Students with ID under this legislation ARE NOT eligible for federal subsidized and unsubsidized loans. Parents must turn to private lenders for "Continuing Education Loans" which are not readily available through all private lending institutions. Please note: the language is very specific for this type of loan-do not confuse this with the traditional student loans which require the student to be enrolled in a degree bearing program full time. Also note: the interest rates on the **Continuing Education Loans** are higher than the federal student loans.

Not only are students with Intellectual Disabilities not eligible for Federal Student Loan programs, but their enrollment in a U.S. DOE approved CTP is not covered by either the Post 9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252), or the Post 9/11 Veterans Educational Assistance Improvements Act of 2010 (P.L. 111-377). Hopefully, with advocacy efforts, students with ID including some students on the autism spectrum will have access to loans and the transfer of veterans' benefits upon future re-authorizations of these pieces of legislation. Future re-authorizations of the Individuals with Disabilities Education Act (IDEA) will also need to address the fact that a student covered under IDEA funding is not eligible for Federal Student Aid. In the future all of these pieces of legislation will need to be coordinated with the Higher Education Opportunity Act for the maximum benefit of students with disabilities.

Parents should not despair at these impediments. Creative families have contacted their state offices of Vocational Rehabilitative Services and Persons with Developmental Disabilities Services in order to obtain assistance with funding for their children's attendance at a Com-

prehensive Transition and Post-secondary (CTP) program. Given how relatively new the CTP concept is, parents and advocates will need to educate service providers on the merits of model in order to obtain additional funding. Finally, parents should look for grants specific to autism and other disabilities as a source of funding. Some will come from foundations or not for profit organizations. Others may come from state governments. For example, the State of Ohio has a scholarship program specifically for students on the autism spectrum who want to attend college in Ohio. Check with your home state's department of education to see if they have a similar program.

For more information about Federal Student Aid visit: www.fafsa.ed.gov.

For an up to date list on the U.S Department of Education approved Comprehensive Transition and Post-secondary programs visit: <http://studentaid.ed.gov/eligibility/intellectual-disabilities>.

To learn more about the New G.I. Bill Benefits and the application process visit the U.S. Department of Defense web site which features a page on the new benefits: http://www.defense.gov/home/features/2009/0409_gibill/ or visit the U.S. Department Veterans Affairs web site dedicated to the topic at: <http://www.gibill.va.gov/>.

Ernst VanBergeijk is the Associate Dean and Executive Director, at New York Institute of Technology Vocational Independence Program (VIP). The Vocational Independence Program is a U.S. Department of Education approved Comprehensive Transition and Postsecondary (CTP) program. Please visit www.nyit.edu/vip for more information. The authors also administer Introduction to Independence (I to I) a seven week summer college preview program for students ages 16 and up.

New York Institute of Technology proudly participates in the Post 9/11 Veterans Educational Assistance Improvements Act and the Yellow Ribbon benefit programs supporting our servicemen and women and their families.

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Inclusion from page 19

team made up of classroom teachers, a speech/language therapist, occupational therapist, social worker, and school administrator

- *Pre-service training* on ASD and intervention through graduate coursework at Hunter College the summer before a newly hired teacher or therapist starts work in the program
- *On-going professional development* through workshops and on-site support
- *Social therapeutic intervention based* on social cognitive theory, relationship development approaches, and the developmental social pragmatics model, along with the school's grade level academic curriculum.
- *A positive behavior approach* in the classroom and across all other settings
- *A home-school collaborative connection*, with two-way communication notebooks, workshops, meetings, and a parent newsletter

What Does It Take to Implement This Model Effectively?

Successful implementation relies on full utilization of all of the model's core elements right from the start. Our experiences

in replicating the program also taught us that the following conditions are also necessary.

At the district level - The district understands the model, is committed to its successful implementation, and provides adequate funding on a timely basis to support it; a student evaluation process is put into place to identify children appropriate for the program; and the district establishes a collaborative relationship with university-based autism experts to provide consistent training, professional development, and on-site support for teachers and therapists.

At the school level - The schools selected for participation should be caring places, with a welcoming attitude toward children with disabilities, a positive behavior support approach, and a collaborative culture. The principal should be a strong instructional leader who is knowledgeable about inclusion; and the teachers should be flexible, willing to co-teach with a partner, and willing to learn the ASD Nest approach.

How Do We Know It Is Effective?

There are now over 500 students in the ASD Nest program in New York City elementary schools. The overwhelming majority of children admitted to the program stay in the program, keep up academically with their typically developing peers, and are promoted from grade to grade. Teachers and parents tell us that the children become

much more socially aware and that their self-regulation improves substantially.

On the third grade New York State tests in English language arts and math, the students with ASD meet or slightly exceed the scores of the general education students in their schools: ASD students in the Nest program (n=70 across 10 schools) ELA 666, Math 697; general education students at the same schools (n=805) ELA 665, Math 689.

Two studies that examine other aspects of our students' functioning are currently underway. Both studies are being directed by researchers not connected with the program.

A Million Dollar Moment

Last June, Dorothy attended the fifth grade graduation ceremony at PS 186, the Castlewood School, in Queens, a veritable United Nations of children hailing from forty or more countries. Fifty-three children graduated this year, eight of them having benefited from six years in the ASD Nest program. This was a perfectly executed, typical American-style graduation – changing of the color guard, singing of God Bless America and the school song, a video montage of every child, a few children and adults giving polished speeches, a procession of children to the stage to receive their diplomas, and special awards for music, art, citizenship, etc.

Every one of the eight ASD Nest children in that graduating class appeared to

be just another fifth grader participating in a long ceremony in a hot auditorium. What are the odds that all these eight children would have been participating so "normally" in that grade school graduation ceremony had they not been in the ASD Nest program with its tailored interventions and supports along with wonderful ASD Nest teachers and therapists? Dorothy knew the answer: slim to none. To the parents of those eight ASD Nest children, it was a Million Dollar Moment.

For further information about the ASD Nest program please go to our website at <http://steinhardt.nyu.edu/asdnest/>, or contact us at asdnest.web@nyu.edu.

Shirley Cohen, PhD, is Professor Emerita at Hunter College, City University of New York. Dorothy Siegel, MPH, is Project Director and Lauren Hough, MEd, is a Coach/Consultant at the ASD Nest Support Project at the Steinhardt School of Culture, Education and Human Development at New York University.

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Work from page 22

easier to discern areas of strength and interest; if, however, the individual is only partially-verbal or totally non-verbal, then the only method of discovering strengths and interests is trial and error.

This same process of trying multiple things before achieving success can be applied to job development; however the approach must be one of *development*—actually building a job around the skills, strengths, and interests of the individual. I have observed people rise to the challenge of jobs some thought would be impossi-

ble for them; but for every individual with autism who outperforms expectations, several others are terminated for poor performance because the expectations were unrealistic. For the individuals with autism I have worked with, a poor match between the job duties and the individual's strengths results in several frustrating consequences that extend far beyond mere unemployment.

Job development truly is a science and an art, and it is a pathway that should be pursued well before an individual "ages out" of special education services. Because of the domains autism affects—specifically social

communication and a narrow field of interests—helping an adult with autism to find a preferred job vacancy, prepare a winning resume and cover letter, ace an interview, and effectively negotiate a salary is incredibly challenging, especially if the disability's impact is profound. Instead, an adult with autism's skills, interests, and personality need to be actively *marketed* to a potential employer; if an employer is able to "buy in" to an individual's skills and potential with a company, half the battle is won.

When planning for vocational experiences with adults with autism, it is vital that these areas be considered. By first un-

derstanding how services will change or disappear entirely after an individual's 21st birthday, a parent or provider can effectively fill the gaps. Then, by uncovering an individual's area of strength and interest, these skills can be better aligned with employers' needs, and jobs can be developed in a customized way. Throughout the transitional experience, a parent, teacher, or provider needs to remember that although autism is a profound disability, individuals with autism want the same things all people want: to make choices, to earn a living, and to make an impact in the community and the world.

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

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

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

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

For further information contact the facilitators:

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

Upcoming Meeting Dates: 2013 - 10/27, 11/24, 12/15 2014 - 1/26, 2/23, 3/23, 4/27, 5/18, 6/22

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

Benefits from [page 18](#)**Supplemental Security Income**

Supplemental Security Income (SSI) is a federal income supplement program funded by general tax revenues (*not* Social Security taxes). Its purpose is to help, again, among others, the disabled who have little or no income. This program is for those who are not entitled to the benefit but need it. This benefit is subject to both the income rule and the asset rule. The current accepted assets that you can have are your house, a car, a prepaid funeral and \$2,000. If the person receiving benefits exceeds this by any amount, they are disqualified from receiving benefits. A special needs planner will help you put strategies in place so that your child can qualify for these benefits. SSI currently provides a maximum of \$710 per month to be used for basic needs such as food, clothing and shelter. It is generally for people who have little or no work history.

Medicaid

Medicaid provides medical assistance for certain individuals and families with low incomes and resources so it is subject to income and asset rules. It typically goes with SSI. Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each state. In addition to paying for some

medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs. You can have both health insurance and Medicaid. Medicaid pays for deductibles and co-pays that your health insurance does not cover.

Many families who have high net worth do not think they need to apply for Medicaid benefits because they plan to self-fund any needs that their child may have or they just believe that their income is too high. This thinking is flawed. There are numerous valuable programs, such as residential, recreation and learning opportunities, that are directly tied to the Medicaid application. If you have not applied, and thus put yourself into the government system, your child will not be eligible for these programs. Thus, these government programs are your child's "golden ticket" to a happier, safer and more fulfilling future no matter what your financial standing may be.

It is important to evaluate your child's entire picture and take a few more things into consideration:

- Although you may be dealing with a child at this time, what do you see for him/her in the future? Supported employment? Workshop employment? Residential living?
- Does your existing health insurance remain in effect when your child turns 26 and is no longer a full time student? How does ObamaCare affect your child?

- What assets are presently in his/her name? Example: savings bonds, life insurance, stocks, mutual funds, homes, etc.
- Is there a possibility of inheriting any money or assets?

Once you have answered these questions, you can then look at what benefits may be eligible to receive and how to best position his/her assets and income.

Often parents ask, "Is there a way I can leave an inheritance to my child with disabilities without negatively impacting my child's benefits?" Yes. An individual may set up a Special Needs Trust that will permit this. There are several types of special needs trusts and these trusts require very particular expertise. Remember, when thinking about trusts, it is imperative that you speak with an attorney who has extensive experience and knowledge in the Special Needs Trusts arena.

These issues are often confusing. The important thing is to be patient and do your homework so that you are better prepared for the future.

Let's say that you think you have this all under control. You have educated yourself about government benefits and you have set up a stand-alone special needs trust. The next questions should be, "How do I fund the future? How much is going to be enough? Yes, government benefit programs are critical, but those pay for

basic support. Life is much more than that. What about recreation, extraordinary medical care, the use of a cell phone, transportation costs, vacations, and other items that make life as wonderful as it can be? How much is enough? How much is really needed?"

The task of identifying that number can be time-consuming and feel daunting at times. Parents and family members should think about this just like they think about their own "retirement." What do you want to see in the future? Build a cash flow that will fund that vision. That process will help you identify the financial need.

As we said in the beginning, it can sometimes feel daunting. But one step at a time is the key to success. Then the progress unfolds before you and peace of mind kind of creeps up on you. Starting with Step One is the most important. And that Step One is just deciding you want to plan for a safe and secure future for your loved one.

Mary Anne Ehlert is the founder and president of Protected Tomorrows, Inc., the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. For more information, visit www.protectedtomorrows.com, contact info@protectedtomorrows.com or call (847) 522-8086.

Treatment from [page 21](#)

(Friedburg & McClure, 2002). Work with providers and consultants to weigh the risks and benefits, and also consider practical information and experiences. Explore educational resources, clinical data, and other parents' perceptions of their children's

progress. The Association for Science in Autism (www.asatonline.org) is an excellent resource for families who are considering specific therapies. Research summaries on many of the current approaches to ASD treatment, as well as information on the strength of the research, are easily accessible through ASAT's website and quar-

terly newsletter. Finally, don't be afraid to ask treatment providers directly about empirical support for the treatments that they offer and research efforts that they may be involved in. Well-trained professionals will be up-to-date on empirical developments, and they will whole-heartedly welcome your collaboration in structuring the

optimal treatment for your child.

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Barbershop from [page 23](#)

always and the never; you always undermine me and you never hear him when he's screaming.

Like many men, Joe's first instinct in a stressful situation is to try and solve the problem, to create a solution. Boy needs haircut, gel in hair, wash gel out. (I didn't mean for this line to come out so cave-man-like! Honest!) I, on the other hand, am very sensitive to Jack's distress, to the screams of the water is running down my back and those scissors will hurt. In most cases, Joe's practical yin to my emotional yang works very well; he stays focused on the task at hand while I soothe and pacify. And the hair gets cut.

But not this time.

I believe kids can bring out the worst in a marriage. Like miniature construction workers with teeny-tiny pick axes, they chip away at your foundation until there are huge, gaping cracks. Five kids can do a lot of damage. And a kid with autism? Well, I probably don't need to go on and on about that.

So Joe and I went round and round with our verbal jabs and punches as if we were boxers in a ring, ducking and moving like Rocky and Apollo. But instead of Mick and Adrienne and that weird guy Rocky used to work for on the docks watching us, our spectators were four

boys and a girl. And their eyes were as round as saucers.

"You no SHOUT! You hurt ME EARS!" Henry refereed. We paused momentarily to tell them Mommy and Daddy are just having a disagreement, we are fine, it's no different from the way they fight with each other over Legos and matchbox cars and who got the last purple popsicle.

"We never fight like this," Charlie whispered conspiratorially to Joey.

"Why don't you get DIVORCED already", was Jack's contribution.

Maybe right now you're reading this post and shaking your head, thinking how you and your partner don't disagree or argue in front of your kids. And if that's true, I'm in awe of you. I heart you. But, you may want to find another blog to read because we probably don't have all that much in common.

(Also, allow me to lend you Jack for a week. Let's see how long you keep your cool with a seventy-five pound boy who lies on the kitchen floor for forty-five minutes screaming "I HATE THIS FREAKING PIECE OF SQUASH!")

The irony of the barbershop scene is not lost on me. I mean, I was interviewed by FOX News, spouting off things like their behavior always has purpose and try to understand what motivates them. Meanwhile, I missed the real reason Jack didn't want to get a haircut: he was afraid the

scissors would pull on all that flaky white gel and would hurt his head. That's why he kept telling me a haircut would give him a headache.

I wrote a book about autism, and how much it's made our family better. And it really has. But I'm nervous some people may interpret my message to mean we have a handle on autism, we manage it flawlessly and effortlessly. But this business of spectrum disorder is a tricky one; just when the seas feel calm and the wind is quiet, there is a sudden violent squall, and Joe and I are left reeling, wet and shivering in the cold. And then, like any good married couple, we turn on each other.

The truth is, ours is a life of a thousand frustrations. Sometimes we fight, sometimes we cry. We are always trying to find better ways to communicate when the storm of autism sweeps over us.

It would be much easier to only share the bright spots with you, the license plate games and the trips to Cancun and the family karate. But that would not be real. And so I offer you our imperfect life, a life bursting with joy and frustration, of tears and chocolate chip cookies warm from the oven.

I offer you our truth. Sometimes it is raw and fragile.

After a fitful night of sleep, this morning I woke to a cool, gray day. I wanted to curl under the covers and sleep until noon. I

wanted to pack up all of Joe's clothes - the ugly flannel shirts from college, his new dress pants from Banana Republic - and throw them down the stairs for dramatic flair. I wanted to cry.

But I didn't do any of these things. Instead, I went through the motions and the mechanics of our life. I toasted waffles and went to the gym and waved to the teacher in the preschool line. And slowly, like winter turning to spring, I started to thaw.

Will we get divorced? Probably not. We will do what we always do; we will return to one another. With a brush of our hands or a quick smile over something funny Henry says at dinner, we will move forward. Joe's dark brown eyes will twinkle and he'll share a small joke as a peace offering.

We will forgive.

Because it was Joe who was there to hear me say something is wrong with him as we sat on our old brown couch in Buffalo, talking and worrying about Jack late into the night. He was the one I called to shout he said mama just now, mama! In my darkest moments of frustration and fear, he is the one I need the most.

This is our own epic life.

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

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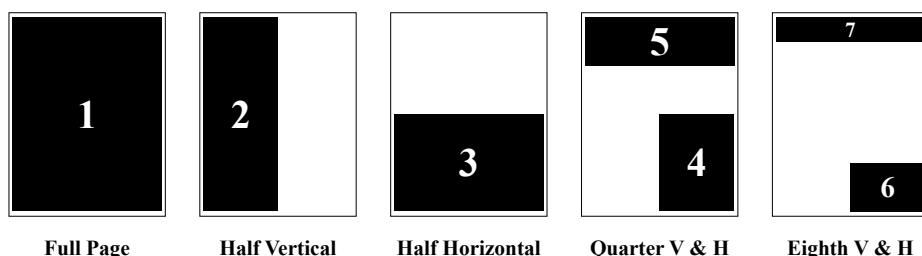
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