Managing the Financial Needs of Autism

**Managing the Financial Needs of Autism**

**By Bernard A. Krooks, Esq and Sheeryl 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 their 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 thresholds 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.
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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 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 cross-over 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 and other types of autism spectrum disorder, the researchers say.

Study Finds That Autism Genes are Surprisingly Large

By Virginia Hughes

Enzymes called topoisomerases are crucial for the expression of extremely long genes in neurons, according to a study published 5 September in Nature. 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 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 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.
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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 intervention 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

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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-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...
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 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 provide 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-typical 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

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Elise Hahn Felix, LCSW

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- Parent

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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 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. BCBAs 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 (BCBAs) 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 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 decisions. 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 “inbeciles,” “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

YAI is thrilled to announce its school age program will be expanding thanks to a beautiful new facility at 180 Amsterdam Avenue on the Upper West Side.

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Photo courtesy of Theresa Genovese for Cetra/CRI Architectural PLLC.
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 understand 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 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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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 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 make 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

In the contentious world surrounding Autism Spectrum Disorders (ASD), one issue bridges the gap among researchers, parents, advocates, health and educational professionals and policymakers -- Early Intervention (Part C of the IDE) for infants and toddlers with ASD works and provides the best pathway to young children with ASD. A two-generation program provides a wide array of 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

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 any related to vision and hearing;
3. Severe intractable seizures;
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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Lynda Geller, PhD, Founder and Psychologist
Rahimne Andalibian, PsyD, Psychologist
Ronni Aronow, MA, MS, College Transition Consultant
Jaime Black, PsyD, Psychologist
Karen Chin, PhD, Psychologist
Katherine Cody, PsyD, Individual and Family Therapy
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Ilene Solomon, PhD, Neuropsychologist
Nancy Waring Weiss, MS, CCC-SLP, Speech and Language Pathologist
Beth Yurman, PsyD, Psychologist

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.theelijafoundation.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.

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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 regiments, 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. 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

Eric London, MD
Psychiatry Practice Specializing in Autism Spectrum Disorders

Director, Autism Treatment Research Lab, Institute for Basic Research
Scientific Advisory Board, Autism Science Foundation
Co-founder, National Alliance for Autism Research
Parent of son with autism

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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 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.

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.

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Accessing Government Benefits and the “Golden Ticket”

Mary Anne Ehler, 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 perspective 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, SSI and the others 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.

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 27

Protected Tomorrows, Inc.

Federal law allows early intervention programs to access public and private insurance as long as it does not disadvantage children. 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.

Mary Anne Ehler, CFP

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 Benefits on page 27

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see Benefits on page 27
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 little 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 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
- 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 profession

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.icahn.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.

Shirley Cohen, PhD
Dorothy Siegel, MPH
Lauren Hough, MSEd
there will be a waiting period imposed bySSI 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 no way will 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 government 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 that 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 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 if you do not plan. 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!

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 “Evangelina 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.
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 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.

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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Rebecca Sachs, PhD

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Evidence-Based Care for Your Child

Parents often seek EBPs 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 EBPs 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-Frazee, Baker-Er-
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 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 practices 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

see Literacy on page 25
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 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

Epic Scenes
From a Barbershop

see Barbershop on page 34

Do you need support for a child, teen or adult on the autism spectrum?

Asperger Syndrome and High Functioning Autism Association

- Monthly support meetings for families, teens, adults and spouse/partners
- Bi-annual conferences for professionals, family members and individuals on the spectrum
- Email listserv and member news publication, On The Spectrum
- Referral to resources and professionals through our phone and email support
- Recreational activities for families

www.ahany.org 888-918-9198 info@ahany.org

AHA Association, a Not-for-Profit Corporation

What Color is Monday?
carriecariello.com
facebook.com/WhatColorisMonday.com
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. Adults with autism may need more time when needed reports indicate, more and more college graduates are unemployed and need to move back home with their parents. 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 adult—those who 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 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 behavior—emotional, and educational supports to which they have become accustomed.

As a vocational training professional for adults with autism providing vocational training at a community-based autism training facility, I see firsthand the steep dropout-off from vocational experiences offered 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. It is instruction that is 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 guaran-
teed. It is instruction that 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 individ-
uals I train are supported by direct-support professionals who are experts in Autism Education training—as they build new voca-
tional skills and navigate the extremely complex world of employment. My job is to develop and maintain a library of instruc-
tional 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 individuals. 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 ability funding. While a part-time workday may not seem that difficult to attain for the average person, it is surprisingly complicat-
ed to achieve this for adults with autism, for a variety of reasons. The art and science of job development—distinct from job search-
ing—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 opportuni-
ties—is to discover areas of strength and interest of the individual. When designing a training activity for an individual, I ask first (or reflect on) a series of questions to determine the individual’s level of interest and ability. If the individual is able to verbal- ly answer these questions, it becomes

A strong support system and by demonstrating self-regulation and self-control under times of stress. Optimism, humor, self-effi-
cacy, kindness and resilience are traits of positive psychology. Individuals with an au-
				

tism spectrum disorder can be taught to in-
ternalize 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 individ-
uals 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.

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The Costs of Raising a Teenage Son With Autism

By Jeff Stimpson
Journalist

R esearchers at the Children’s Insti-
tute, a not-for-profit organization affiliated with the University of
Yale, in New Haven, CT, have studied the con-
nection between autism and the hemor-
rhage 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 accompa-
nying the study they conducted. “Parents
say their child’s condition has made it dif-
ficult to keep spending without the constraint
of accumulating credit card debt. A possible
reason parents offer is that they find
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 onto the floor. He said “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?”
I press two more buttons, resuscitating
the thing all over again, and send 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 go (and must).

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 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 begin-
ning 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 + un-
covered 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 “Paja-
mas! 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 expens-
es...) looking down when he’s bored and
setting his fingers to work. Then from
where he sits comes a sound like skin peel-
ing from the wall. I use a rope of leg-
ging dangling from his hand.

Why does he do this? “Must be some-
thing to do with sensation through his fin-
gertips,” his teacher said once.

I try to offer to look for one and I her
a rope of legging dangling from his hand.

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Why does he do this? “Must be some-
thing to do with sensation through his fin-
gertips,” his teacher said once.

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Managing Picky Eating in Children with Autism Spectrum Disorders

Diana A. Wolf, MA, BCBA
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 something different; or regular chicken 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.

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!

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 has 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 distractions (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

Resources from page 18

in their state at http://mchb.hrsa.gov/programs/titleivgrants/

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-usssi.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-development-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 consumer-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-children-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.ncll.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 their 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

determine 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 mental health 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 development disability. It’s important to note, however, that as of 2013, there is no legal test for determining legal age to vote.

Dialogue from page 13

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 technical freelance writing, understanding 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.

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, some- thing 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 Autism Global Initiative (www.autismglobalinitiative.com). To contact Valerie, please visit www.autismselfadvocacy.com for more information.

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 typical curriculum, and curricular supports. PASS worked persistently with the Deans of the college to develop a plan for slowly introducing curriculum changes throughout the university.

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Dialogue from page 13

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Challenge from page 15

PDD-NOS—which appear to have little scientific validity or reliability since those diagnosis 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 the 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 is also applicable 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 constructed 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 program does not provide 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 preschoolers 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 make the 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 Viewpoint,” 2012). 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 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” of autism. The states must now decide whether to have an 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 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 states follow the direct evidence 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.

Service System from page 17

Some recommendations require state programs to increase the number of individuals they serve. The Children’s Autism Medicaid Waiver was created 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 diagnosed as Asperger’s syndrome. However, their transition to their early childhood education system to receive services. Unfortunately, the type of services the child receives post EI depends on her or his 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 the child’s parents 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 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/committees-and-initiatives/autism/the-massachusetts-autism-commission-final-report.html.
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Autism Genes from page 4
to their role in untangling DNA, topoisomerase II are involved in transcribing DNA into RNA sequences. Following that, 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 downregulated 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 the genes.”

The results suggest that topoisomerase II 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 topoisomerase II 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 topoisomerase II — 27 percent — were previously linked to autism. (SFARI Gene is funded by the Simons Foundation, SFARI.org’s parent organization.)

“While this work was underway, two other studies appeared showing that a few individuals with autism carry mutations in topoisomerase II genes,” Abrahams notes. “The research from the Zylka lab, and others, is really quite exciting.”

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.

Integrative from page 21

A 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 psychotherapist at the Lindner Center. Joshua’s psychiatrist was able to collaborate and share 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 and a champion of any of Joshua’s needs and behavioral changes. This invaluable communication helps inform Joshua’s care team of how treatment is progressing and it needs to 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 individual’s 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

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 be creative and understand that they really enjoy 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, Zylka and 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 behaviors, 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.
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 challenges 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.

In keep in mind the goal of the autism insurance law was to improve access of essential treatments. While we have made headway, we’ve only gone 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 new law will 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 2008 is 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 the Army (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 administered by the Department of Education Education for approval of their CTP. The concept of Comprehensive Transition and Post-secondary (CTP) 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_gilbill 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 Program (CTP) program. Please visit www.nyuvt.edu/vip for more information. The authors also administer Introduction to Independence (1 to 1) 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.

References


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


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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 requirements are actually established by each state. In addition to paying for some medical services and prescriptions, Medicare may also pay for residential facilities, workshops and other programs. You can have both health insurance and Medicare. Medicare 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 Medicare 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 SSI programs, such as residential, recreation and learning opportunities, that are directly tied to the Medicare application. If you have not applied, and thus put yourself into the government system, your child will not be eligible for these programs. The means test and peace of mind that 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.

The truth is, ours is a life of a thousand tears and chocolate chip cookies warm from the oven. Life bursting with joy and frustration, of family karate. But that would not be real. Games and the trips to Cancun and the wind is quiet, there seas feel calm and the wind is quiet, there are big sunny squalls, and Joe and I are in awe of you. I heart you. But, 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 hurt his head. That’s why he kept telling me a haircut would give him a headache.

I was never 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 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 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 play.

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. We will 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.

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