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SUMMER 2010

FROM THE LOCAL, STATE, AND NATIONAL NEWS SCENE

VOL. 3 NO. 1

Helping Families and Individuals Cope With Stress

By B. Madeleine Goldfarb, MA
Director of Outreach and Education
The Autism Center of NJMS UMDNJ

I have the unusual, gratifying, and yes, at times paradoxical role of both professional working in the autism field as well as parent of a child on the spectrum. This gives me some unique insights into the subject of autism and coping with stress. First, let's define stress.

Our friends at Wikipedia.org tell us that stress is: A term in psychology and biology, first coined in the biological context in the 1930s, which has in more recent decades become a commonplace term of popular parlance. It refers to the consequence of the failure of an organism – human or animal – to respond appropriately to emotional or physical threats, whether actual or imagined.

Symptoms of Stress

Stress symptoms commonly include a state of alarm and adrenaline production, short-term resistance as a coping mecha-



nism, and exhaustion, as well as irritability, muscular tension, inability to concentrate and a variety of physiological reactions such as headache and elevated heart rate.

Alarm is the first stage. When the threat or stressor is identified or realized,

the body's stress response is a state of alarm. During this stage adrenaline will be produced in order to bring about the fight-or-flight response. There is also some activation of the HPA axis, producing cortisol.

Resistance is the second stage. If the stressor persists, it becomes necessary to attempt some means of coping with the stress. Although the body begins to try to adapt to the strains or demands of the environment, the body cannot keep this up indefinitely, so its resources are gradually depleted.

Exhaustion is the third and final stage. At this point, all of the body's resources are eventually depleted and the body is unable to maintain normal function. The initial autonomic nervous system symptoms may reappear (sweating, raised heart rate etc.). If stage three is extended, long term damage may result as the capacity of glands, especially the adrenal gland, and the immune system is exhausted and function is impaired resulting in decompensation.

The result can manifest itself in obvious illnesses such as ulcers, depression, and diabetes trouble with the digestive system or even cardiovascular problems, along with other mental illnesses ([wikipedia.org/wiki/Stress_\(biology\)](http://wikipedia.org/wiki/Stress_(biology))).

Let's first tackle the *alarm* stage. This

see Cope With Stress on page 34

An Autism Spectrum News Interview with Robert H. Ring, PhD Senior Director of the New Pfizer Autism Research Unit

By David H. Minot, BA
Associate Director
Autism Spectrum News

Currently, there are no drugs on the market indicated for use in individuals with autism spectrum disorders. Many individuals use off-label drugs for symptoms such as anxiety, hyperactivity, and depression that are not FDA approved for use in individuals with autism and carry no scientific evidence for the efficacy and safety of use in this population.

Dr. Robert H. Ring, PhD, Senior Director and Head of the new Pfizer Autism Research Unit and his team are devoting their lives to addressing the unmet needs of the autism community. The Pfizer Autism Research Unit is entering into a new frontier by developing new medicines targeting symptoms in individuals with autism spectrum disorders. This is no easy task and there are many challenges and difficulties his research unit faces to turn

this vision into a reality. The hope for a new drug isn't to replace the many effective treatment and therapies in use today, but to augment the success of these vital interventions by reducing the negative symptoms that disrupt and reduce the daily quality of life for individuals on the spectrum and their families.

Q: Tell me about the Pfizer Autism Research Unit.

A: The Autism Research Unit at Pfizer was formed early last year and represents the first research effort in large Pharma dedicated to the discovery and development of medicines that address the unmet needs of patients with autism disorders. The scope of our research investment spans from very basic biology all the way through to phase 2 proof of concept trials in the clinic with patients. My role as Head of Pfizer's Autism Research Unit, quite simply, is to ensure we develop and execute a strategy that translates the best available science into medicines for patients with Autism.

Q: Is Pfizer looking to bring a completely new medication to the market or take an existing medication and have it approved for use for individuals with autism spectrum disorders?

A: Although other companies have worked to reposition drugs already approved originally for other disorders into the autism space, our primary research goal at Pfizer is to develop innovative new medicines that target and treat both the core impairments of Autism as well as the many associated symptoms. We also have been looking closely at drugs in our development pipeline, past and present, for opportunities that might make sense to consider when the biology makes sense. This is an approach that other companies have been considering, but nowhere else have I seen the type of investment into basic discovery research for autism we have at Pfizer. This commitment to discovery will be required to build a sustainable portfolio of new medicines into the future, and is what distinguishes our effort from those of other

major pharmaceutical companies today.

Prior to joining Pfizer in 2009, I was leading preclinical mood disorders research at Wyeth. Although I worked in the area of depression, I have been keenly aware of the huge unmet need in Autism for some time and saw enormous opportunity for us to make an impact by leveraging the years of experience working in the areas of psychiatry and neurology towards autism. Also, one of my primary areas of research involved investigating the therapeutic potential of oxytocin, which remains a system of high interest to the autism field. I actually proposed a research effort in autism at Wyeth a number of years ago, but the timing just wasn't right for Wyeth. So, in many ways I feel like I have my dream job now at Pfizer.

Q: Would you say the recent surge of new autism science and genetic discoveries has helped in the development of the Pfizer Autism Research Unit?

see Interview on page 33

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Fall 2010 Issue:

"Addressing the Growing Needs of Adults"

Deadline: September 15, 2010

Winter 2011 Issue:

"Understanding and Treating the Comorbidities of Autism"

Deadline: December 15, 2010

Spring 2011 Issue:

"Autism and the Law Throughout the Lifespan"

Deadline: March 15, 2011

Summer 2011 Issue:

"Advancing the Science-Based Agenda for People with ASD"

Deadline: June 15, 2011

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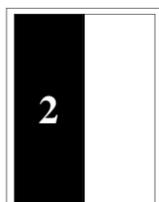
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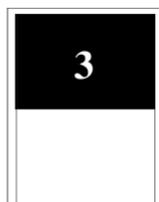
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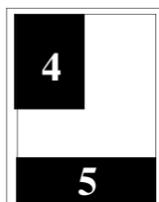
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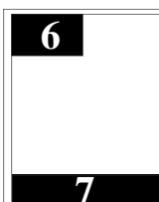
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From The Publisher

The Importance of Stress Management to You and Your Child

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

This issue of *Autism Spectrum News* is dedicated to helping families and individuals with autism spectrum disorders cope with and manage stress. Autism is inherently stressful for both the individual with the diagnosis and everyone involved in that person's life. It is crucial to recognize this and understand that, while so much of the associated stress may seem out of one's control and unavoidable, being proactive and developing stress management coping techniques will allow for a happier and more fulfilling life for everyone.

The unknown is stressful, and one great way to address this is by staying informed and educated. There are many community supports and services available to both individuals on the spectrum and their families. By reading each issue of *Autism Spectrum News*, you are already ahead of the game by taking the initiative to educate and inform yourself with a trusted resource of evidence-based information and community resources.

As B. Madeleine Goldfarb, MA, Director of Outreach and Education at the Autism Center of the New Jersey Medical School at the University of Medicine and Dentistry of New Jersey states in her lead cover article, "Making healthy choices for ourselves is so important to how we feel and cope with the stress of raising a child with autism, in all its manifold incarnations. Being proactive in the creation and implementation of [stress management] strategies will put the power and control back into your life, when so much of what is autism may seem so out of your control. Autism may be the new normal, but how we cope with the stress will be the difference in how we perceive what can be a wondrous journey of discovery about our children and ourselves."

A recurring theme in many of the articles in this issue of *Autism Spectrum News* identify parent involvement and training as an important step in reducing stress associated with parenting a child with an autism spectrum disorder. It is crucial for parents to know what interventions and supports are being provided to their child during the school day and to also receive appropriate training to allow for the continuation of these interventions in the home.



Ira H. Minot, LMSW

On page 14, Tracey Spencer Walsh, Esq, Senior Counsel at Mayerson and Associates describes what she calls "The Best Kept Secret" that school districts are federally required to offer parent counseling and training as a related service to the child's IEP. "The federal law makes it clear that parents are entitled to counseling and training in how they can help implement their child's IEP goals and objectives. Parents can and should ask that parent counseling and training be listed as a related service on their child's IEP. The frequency and duration of the parent counseling and training depends on what your child's needs are. A student with autism with many severe behaviors should have intensive parent counseling - a half hour once a month is not enough. Parents should present an expert report at the IEP meeting or have an expert participate at the meeting who can recommend the level of parent counseling and training that is appropriate for the disability you are supporting at home."

The McCarton Foundation details on page 15 the importance of translating what we have learned about stress and coping into clinical services guidelines. "Having a child with an ASD in a family is intrinsically stressful. Families must immediately and permanently adapt to a formidable challenge that will present ongoing challenges. How can we ensure that the clinical supports provided are

those that make the most significant difference? In terms of concrete and meaningful support services, we should provide parent training that increases skills and improves self-efficacy. In terms of individual characteristics, we should nurture the qualities associated with more successful adaptation. Our interventions need to have a family focus. We must assess and treat both the family context and the individual learner. Our commitments to effectiveness and efficiency should also influence our interactions with and services provided to families."

On page 20, Nomi Kaim, Member of the Asperger's Association of New England and an individual with Asperger Syndrome gives an insightful first person perspective of her daily battle with sensory, emotional, intellectual, and social overstimulation. "No one knows exactly why Aspies are so often overstimulated by experiences neurotypical individuals find quite manageable. It may involve some combination of over-responsiveness and inefficiency at the brain level. The psychological consequence of this neurological vulnerability is *near-constant stress*. A person prone to overstimulation moves through life in a continuous state of hyperarousal, waiting for the next unpredictable event to overpower him. Most people are familiar with sensory overstimulation, but there are other kinds: I have identified three more. Together, they make up what I refer to as the four faces of overstimulation."

On page 25, Mary Jo Hebert, Regional Coordinator of the Capital District Office of Parent to Parent of NYS writes of the importance for parents to address their own needs so that they can be both physically and mentally healthy to ensure they can devote their energy as best they can to their child's needs. "Parenting a child with special needs requires the discipline and dedication of a world class athlete, one whose event is played out not on the field or in the gym, but in the halls of schools and doctor waiting rooms. Children with special needs require exceptional amounts of energy. Getting rest, eating well, and carving out time for exercise is critical to preserve the stamina and energy needed to keep all the balls in the air. The quest to make our lives more manageable is ongoing. Adding our own needs as parents to our family's never ending to-do list does not come naturally; it's something we have to work at. The payoff is that the

better off we are emotionally, physically, and spiritually, the better off our families will be. To keep from cheating our families, we must take care of ourselves. We owe it to our children."

In addition to the articles mentioned, there are many more that address other vital areas of interest including the latest advances in autism science, legal issues, transitioning into adulthood, helpful information for parents of a newly diagnosed child etc., by experts in the field of autism that we hope will inform and inspire you.

Let me conclude by telling you about our exciting roundup of themes in the upcoming quarterly calendar of *Autism Spectrum News*. Our fall issue's theme will be "Addressing the Growing Needs of Adults." The deadline for articles and advertising for this important issue is September 15th.

Our calendar continues with our winter issue which will focus on "Understanding and Treating the Comorbidities of Autism." Next spring we will take an in-depth look at "Autism and the Law Throughout the Lifespan" and next summer our theme will be "The Vital Need for Autism Advocacy."

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

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

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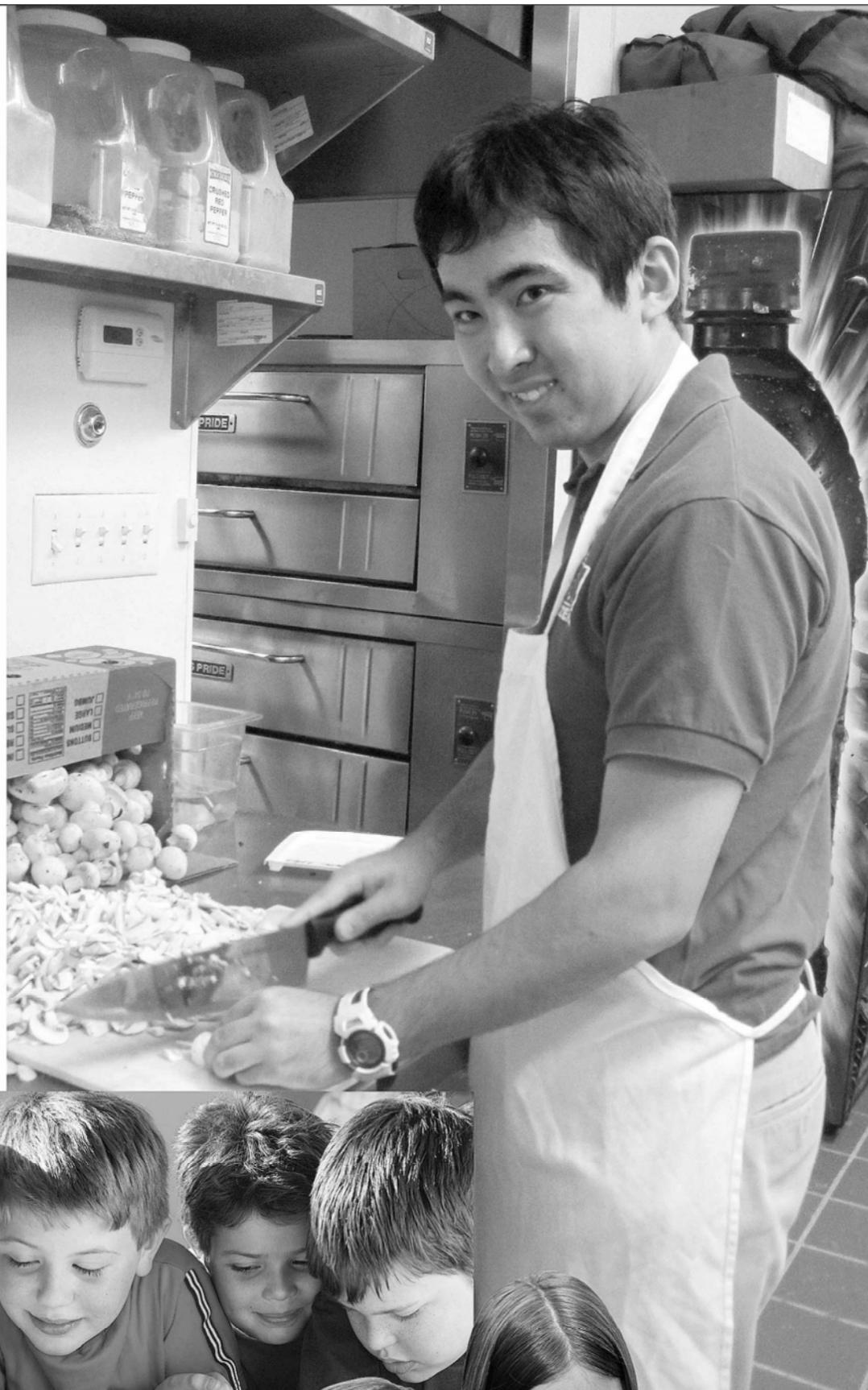
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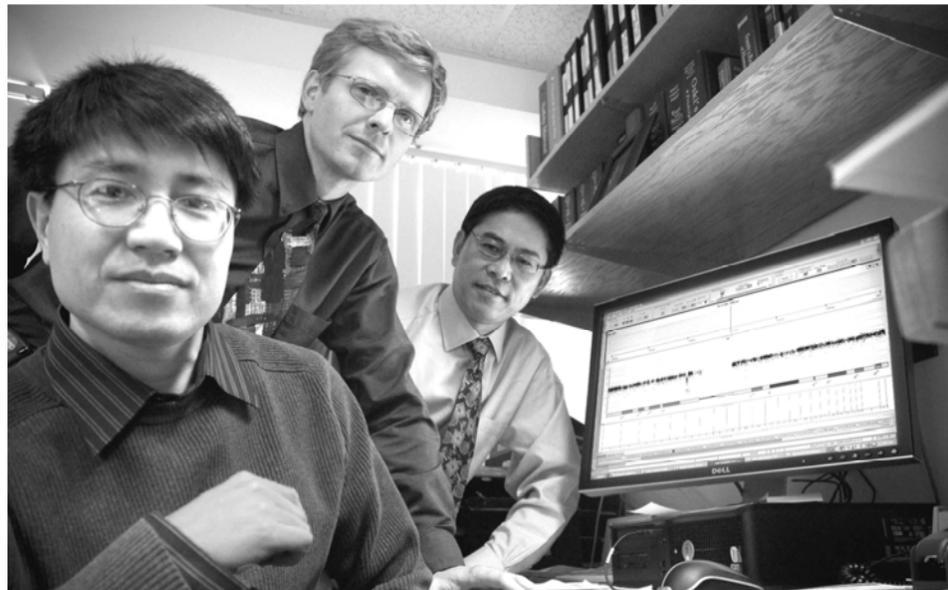
A Better Genetic Test for Autism

Chromosomal Microarray Analysis Picks up More Abnormalities Than Current Tests

By Children's Hospital Boston and
The Autism Consortium

A large study from Children's Hospital Boston and the Boston-based Autism Consortium finds that a genetic test that samples the entire genome, known as chromosomal microarray analysis (CMA), has about three times the detection rate for genetic changes related to autism spectrum disorders (ASDs) than standard tests. Published in the April issue of *Pediatrics* (and online as of March 15), the authors urge that CMA become part of the first-line genetic work-up for ASDs.

Expectant parents who have family members with ASDs, as well as families who already have an affected child, often request genetic testing. However, there is still only limited knowledge about actual causative genes. The currently recommended tests (karyotyping to look for chromosomal abnormalities and testing for Fragile X, the single largest known genetic



Yiping Shen, PhD, David Miller, MD, PhD, and Bai-Lin Wu, PhD

cause of ASDs) often come up negative. Chromosomal microarray analysis is a genome-wide assay that examines the

chromosomes for tiny, sub-microscopic deletions or duplications of DNA sequences, known as copy-number variants.

CMA offers about 100-fold greater resolution than standard karyotyping. However, since it is new, it is often considered a second-tier test. Depending on where a person lives, or what insurance they have, CMA may not be covered by health insurance. "Based on our findings, CMA should be considered as part of the initial clinical diagnostic evaluation of patients with ASDs," says Bai-Lin Wu, PhD, Director of Children's DNA Diagnostic Lab in the Department of Laboratory Medicine, which has offered CMA to families since 2006.

The research team, led by co-senior authors Wu (heading the Children's team), and David Miller, MD, PhD, of Children's Division of Genetics and Department of Laboratory Medicine (heading the Autism Consortium team), assessed the diagnostic value of CMA in the largest cohort to date - 933 patients with a clinical diagnosis of ASD (by DSM-IV-TR criteria) who received clinical

see *Genetic Test* on page 33

80 Percent Autism Divorce Rate Debunked in First-Of-Its Kind Scientific Study

Kennedy Krieger Researchers Find Autism Does Not Affect Family Structure

By Brian Freedman, PhD
Clinical Director
Center for Autism and Related Disorders
Kennedy Krieger Institute

Having a child with autism can put stress on the parents' marriage, and a frequently cited statistic leads to a common perception that the divorce rate among these families is as high as 80 percent. But a recent study by researchers from Kennedy Krieger Institute in Baltimore found that a child's autism has no effect on the family structure.

Brian Freedman, PhD, lead author of the study and clinical director of the Center for Autism and Related Disorders at Kennedy Krieger Institute, said the findings seem to debunk a lot of the general understanding about high divorce rates among parents of children with autism. Dr. Freedman and his research team found that 64 percent of children with an autism spectrum disorder (ASD) belong to a family with two married biological or adoptive parents, compared with 65 percent of children who do not have an ASD.

Dr. Freedman presented results of the study in Philadelphia at the International Meeting for Autism Research (IMFAR), an annual scientific meeting convened to exchange new scientific progress among autism researchers from around the world.



Brian Freedman, PhD

Receiving the news of a child's autism diagnosis can be devastating, and Dr. Freedman said the pain is compounded as parents ponder what will happen to them as a couple. "In the work I've done with children with autism, I've come across many couples who quote this 80 percent

divorce rate to me. They don't know what the future holds for their child, and feel a sense of hopelessness about the future of their marriage as well - almost like getting a diagnosis of autism and a diagnosis of divorce at the same time," he said.

With very little empirical and no epidemiological research addressing the issue of separation and divorce among parents of children with autism, researchers sought to more scientifically examine the incidence. Using data from the 2007 National Survey of Children's Health, they examined a nationally representative sample of 77,911 children, ages 3 to 17.

Previous research speaks to the fact that parenting a child with autism is stressful, and it puts pressure on the marriage. Dr. Freedman noted that past studies have found couples with a child with autism experience more stress in their marriage than couples with typically developing children or couples with children with other types of developmental disabilities, such as Down syndrome. Mothers of children with autism report more depression than those with typically developing children, while fathers report they deal with the stress by distancing themselves and becoming less involved with the family.

"While there are indeed stressors in parenting a child with autism, it doesn't necessarily result in the family breaking up more often than would occur in an-

other family," said Dr. Freedman. "And as someone who works with a team of health care professionals to treat and provide support for families of children with autism, it's important for us to make sure our patients' parents know that, and for our fellow clinicians to provide reliable, evidence-based information about the divorce rate among this population as well."

This analysis of the National Survey of Children's Health data showed there are certain factors in a family that can contribute to divorce, such as having a child with particularly challenging behaviors, with or without autism. For some families, the challenges of parenting a child with special needs may indeed result in straining the marriage to the breaking point. Further research is needed to understand the relationships among in-tact families with children with autism to identify how they work through the challenges.

"I would hope this research drives home the importance of providing support to these families, and letting them know that their relationships can survive these stressors," he said. "We should continue to provide training for parents so that they can work through the stressors in their relationship to keep their family together and have a successful marriage."

see *Divorce Rate* on page 20

AUTISM SPECTRUM NEWS DESK

Autism Spectrum News Attends United Nations International Autism Event *Autism Ambassadors Stress the Need for Increased Awareness, Education, and Support*

By David H. Minot, BA
Associate Director
Autism Spectrum News

On April 22, *Autism Spectrum News* had the fortunate opportunity to attend an autism panel discussion at the United Nations, sponsored by the Permanent Mission of Qatar to the United Nations to commemorate World Autism Awareness Day. The event, moderated by Al Jazeera's Riz Khan, featured parents, therapists, practitioners and special guests from different countries discussing issues of common concern under the theme, "The Impact of Autism on the Family: Families responding to the Challenges."

Speakers representing the autism community from various countries voiced their concerns about the rising prevalence of autism spectrum disorders, many of which mirror the same issues communities tackle right here in the United States: a lack of quality evidence-based services,



United Nations Secretary-General Ban Ki-moon Speaks at the Mission of Qatar World Autism Awareness Day Reception

inadequate community education, a need for reduced stigma against individuals and

their families, a lack of funding for vital programs and services, etc.

Autism has no borders, and this event made it clear that the international community of individuals and families of children with autism spectrum disorders share the same special needs. As Kiyoko Akasaka, Under-Secretary-General for Communications and Public Information stated, this event was "an opportunity to come together to build on our efforts for more awareness, more understanding, more research, and more support for all people living with autism – for a more inclusive society."

After the panel discussion, the Permanent Mission of Qatar to the United Nations and the Al Shafallah Center for Children with Special Needs hosted a reception honoring the United Nations Secretary-General for his continuous support towards a better understanding of Autism. At the reception, UN Secretary-General Ban Ki-moon attended and addressed the attendees:

"Ambassador Al Nasser, Ms. Al Qasimi, (Director, Al Shafallah Center for

see United Nations on page 38

New York State Senate Passes Landmark Autism Legislation *Requires Insurance Coverage for Evidence-Based and Clinically Proven Treatments*

By the New York State Senate
Majority Press

The Senate Democratic Majority passed groundbreaking legislation to protect children with autism, setting the bar for a new national standard for treatment and services. The legislation (S7000B/Breslin) requires early intervention screening, diagnosis and treatment for autism spectrum disorders, saving families facing autism thousands of dollars a year.

Despite research demonstrating that early intervention and intensive behavioral therapies can yield significant improvement in the quality of life for those with autism, diagnosis and treatment have been excluded from coverage by health insurance carriers in New York.

The prior insurance law did not provide clarity to consumers or insurers as to the scope of the required coverage. This bill includes an updated definition of autism spectrum disorder, and tells insurers what must be covered. The Commissioner of Health would be responsible for publicizing regulations identifying treatment and therapy options for autism coverage.

Twenty states previously spoke up for those affected by autism by passing legislation to provide them with insurance coverage. The passage of this much needed legislation would make New York the



21st state to require such coverage. This bill is one of the strongest in the nation, not only requiring policies to cover autism, but does so without a financial cap. Furthermore, the coverage is extended for the entire life span of the individual.

The bill would only allow evidence-based and clinically proven treatments to be covered.

Senator Neil D. Breslin (D-Albany), Chair of the Insurance Committee and sponsor of the bill said, "This law would restore the voice of those indirectly affected by autism. Many families paying out-of-pocket for autism treatments risk

their homes and the educations of their unaffected children, mortgaging their entire futures for something that should be covered by basic health insurance."

Senator Shirley L. Huntley (D-Queens) said, "Autism is a developmental disorder that affects many children and families across New York State and the nation. The rates of children with Autism have been increasing over the decades, and more and more parents are having to find ways to pay for varied types of treatment and therapy for their autistic children. This bill gives parents and families increased options and access to treatments and de-

creases out of pocket costs. The availability of extra resources will enable parents to be more proactive and involved with understanding the disorder and how to effectively take action. A bill like this is long overdue, and will benefit the lives of many New Yorkers."

Senator Brian X. Foley (D-Blue Point) said, "Families of children with autism spectrum disorders are constantly looking for ways to help their children to better experience the world and to receive the treatment necessary to improve their quality of life. Too often, these families have difficulty accessing these services and treatment programs because they cannot afford to pay for it out of their own pockets. Requiring insurance companies to cover the cost of these treatments will help to ease the burden on many of the families who are living with this disease."

Senator Andrea Stewart-Cousins (D-Westchester) said, "For years, due to vague State requirements, the people across State of New York have not been able to receive full or even partial coverage for autism spectrum disorder. I am pleased to stand with my colleagues in support of legislation that both clarifies the required scope of coverage to consumers and insurers, and will allow individuals with autism to receive coverage they deserve for the screening, diagnosis and treatment of this disorder."

see Autism Insurance on page 30

Making Family Rituals and Traditions Work for You

By Richard Cohen, PhD
Chief of Mental Health Services
YAI/National Institute for People with
Disabilities' Center for Specialty Therapy

For the last 10 years, Jann Tobias's family has celebrated New Year's Eve with a family dinner. With careful attention to detail, she uses her aunt's tablecloth and her grandmother's china, making a beautiful presentation of her family's favorite foods. Jann's husband, Bob, carves the roast beef with his father's knife. Over dinner, they tell stories about the relatives whose recipes comprise the meal. Dinner is followed by the year's home movies that her daughters had hurriedly helped their father splice together earlier that day. The night's festivities conclude with Jann's son, who has autism, conducting an appropriately embarrassing and humorous "Ode To The Last Year" sing-along that the family makes up.

Learning about Jann's family rituals, I was struck by how the celebration featured the best of each member of her family. When I shared this with Jann, she laughed but remarked that those crazy customs are the true glue of her family.

For families with a child on the autism spectrum, traditions and family rituals are frequently dropped because of the uncertainty of their child's behavior. Many families have told me that they would rather play it safe than risk the disruption.

However, developing and finessing family rituals can be a wonderful way to recognize transitions and milestones – the birth of a child, transition between schools, and other events – while



Richard Cohen, PhD

providing a sense of security during times of change and uncertainty.

Through stability, familiarity, and repetition – techniques professionals use to engage children on the spectrum – these rituals become safe and predictable. Whether a graduation ceremony or the hushed recital of a funeral mass, rituals can ease celebratory or challenging transitions.

While rituals and family traditions can have significant positive impact on the health and well-being of families of children with autism and other developmental disabilities, the key is to adapt them to your family's needs and be flexible, without losing the meaning.

In Jann's family, flexibility is crucial in integrating important traditions as a positive and meaningful part of her family's life. "Our son would sometimes get over-stimulated at the table and break some dishes," she said. "We decided that if family heirlooms got broken, we'd just glue them back together and put them out again next year."

Family rituals can be times to not only celebrate as an entire family, but also to pause as a couple and recognize each other's accomplishments, large and small. They can also be traditions to pass down to children and future generations.

When a couple marries they are joined in union, and their families come together as well. For the couple, the task at hand is finding a satisfactory balance between maintaining their own identity and negotiating a communal lifestyle (Rubinstein, 1971). Previous generations exert strong influences on a newlywed couple, influences which must be negotiated into their identity. The couple must choose which family rituals to maintain, modify, or integrate, and which rituals to discard.

Karen recalls struggling early in her marriage to get her husband on board with her family's traditions. "We all loved listening to music together and it seemed like all that my husband and his family wanted to do was watch baseball," she said.

It took years, but eventually she was able to let go of the resentment and embrace her husband's love of baseball - while introducing him to her love of music. Now, both baseball and music have enriched the family fabric.

see *Rituals* on page 31

Ritual Strengthening to Help Rebuild Important Family Rituals That Eroded Over Time

- What family activities from your childhood years had meaning to you?
- What did they say about your family?
- What keeps you from making them part of your family today?
- Be flexible and modify your ritual to make it meaningful to your family.
- Decide when and where the ritual will be performed. The timing and location are up to you.
- Remember Rome wasn't built in a day – don't expect immediate change.

Ritual Rebuilding to Help a Family Recapture Its Identity Based on Family Traditions

- Can the ritual's impact be enhanced by inviting others to participate?
- Can the ritual be repeated or does it need to be modified and made more fun for your family now?
- What activities can you engage in with your family, so you can share the joy they experience?

Part II - An Autism Spectrum News Interview with Charles N. Cartwright, MD Director of the Autism Center at the YAI Network

By David H. Minot, BA
Associate Director
Autism Spectrum News

When a young or adult child receives a diagnosis of an autism spectrum disorder (ASD), stress frequently accompanies that diagnosis and can affect parents, siblings and other extended family member in different ways. This is the second part of an interview with Dr. Charles N. Cartwright, Director of the YAI Autism Center at the YAI Network in New York City, who shares his insights on this and other topics.

Q: This issue of *Autism Spectrum News* is devoted to "Helping Families and Individuals Cope with Stress." What are some of the emotional and financial strains that you have seen on families?

A: Until a child receives the diagnosis, there may be a great deal of worry and concern: "What's wrong with my child? Why does he or she seem different than other children? "What could this be?"



Charles Cartwright, MD

Then once parents receive the diagnosis, they are even more overwhelmed: "What does this mean for the future? How are we going to cope? What do we need to do to find the best treatment?" and, the inevitable, "How are we going to afford this?"

The financial resources that it takes to provide optimal care for children with ASD are astronomical. Families are sometimes forced to mortgage their homes to provide necessary services for their children. Or they may have to work several jobs to afford the cost of treatment.

Quite often, one parent often takes primary responsibility for caring for the child's needs because the other parent is focused on working. Worry and exhaustion take its toll, and place a great deal of strain on families. Siblings of children with autism also experience significant stress and tension. It's often confusing and frustrating, and can be scary if the child has significant emotional/behavioral issues, such as aggressiveness toward family members.

At the same time, I want to emphasize the remarkable resilience that so many families show. On a daily basis, I meet families who are inspirational in the way they care for their loved ones. It is a humbling experience to see the sacrifices that these families make and the obstacles they overcome, to give the best to their children.

Q: Why is it important for parents to network with other parents who have found successful treatment for their children?

A: This networking can be done on the Internet or through a local support group in your community. Parents also should take advantage of ad hoc opportunities. For example, while sitting in waiting areas at physician offices they may share information about resources and treatments, what works and what doesn't work.

However, parents should remember that each family's experience is different -- the person they speak to may have a strong opinion that doesn't necessarily reflect the quality of care of a particular center or the effectiveness of a particular treatment.

When looking for residential services for an adult with an autism spectrum disorder, parents need to start planning early, when their children are teenagers or younger. There are agencies that can help with this process, for example, registering with the State office of developmental disabilities.

As the number of children diagnosed with ASD has grown and these children

see *YAI Interview* on page 38



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Seaver Autism Center Scientific Research Leads to a Better Understanding of Genetic Mechanisms in the Etiology of Autism Spectrum Disorders

By Joseph D. Buxbaum, PhD
Director
Seaver Autism Center for
Research and Treatment

Seaver Center researchers announced exciting results from two recent studies examining genetic mechanisms in the etiology of autism spectrum disorders.

Treatment in a Mouse
Model of Phelan-McDermid
Syndrome Restores Nerve Cell
Communication to Normal Levels

At the recent meeting of the International Society for Autism Research, Dr. Joseph Buxbaum presented exciting developments in future treatments for Phelan-McDermid Syndrome (PMS), a syndrome that has behavioral characteristics that fall under the autism spectrum disorder (ASD) category. Previous research has shown that a loss or gene mutation in a gene called SHANK3 can cause absent or severely delayed language abilities, intellectual disability, and autism. Seaver Center researchers developed mice with a mutant SHANK3 gene and observed a lapse in communication between nerve cells in the brain, which can lead to learning problems.



Joseph D. Buxbaum, PhD

The researchers then injected the mice with a derivative of a compound called insulin-like growth factor-1 (IGF1), which is FDA-approved to treat growth failure in children. After two weeks of treatment, nerve cell communication was normal and adaptation of nerve cells to stimulation, a key part of learning and memory, was restored.

“The result of IGF1 treatment of these mice is an exciting development on the road to ultimate therapies for individuals with PMS and similar autism syndromes,” said Dr. Buxbaum, Director of the Seaver Autism Center. “If these data are further verified in additional preclinical studies, individuals with a SHANK3 mutation may benefit from treatments with compounds like this one.”

International Autism Genetics
Consortium Identifies New
Autism Susceptibility Genes

As members of the Autism Genome Project or AGP, Seaver Center investigators analyzed copy number variants (CNVs; rare submicroscopic insertions and deletions in genes) in high-density genotyping data collected from 1,000 individuals with ASD and 1,300 without ASD. The AGP consists of 120 scientists from more than 50 institutions representing 11 countries who formed a first-of-its-kind autism genetics consortium with a goal of identifying autism susceptibility genes.

The results of the study provide further support for an emerging consensus within the scientific community that autism is caused in part by many “rare variants,” or genetic changes found in one percent or less of the affected population. While each of these variants may only account

for a small fraction of the cases, collectively they are starting to account for a greater percentage of individuals with autism. More importantly, they are also providing insights into possible common pathological mechanisms of ASD.

Additionally, the findings show that CNVs disrupting genes are more common in ASD than in controls. Some of the more compelling findings include CNVs in SHANK2, SYNGAP1, DLGAP2 and the X-linked DDX53-PTCHD1 locus.

The AGP explicitly tested whether genes previously implicated in intellectual disabilities but not in autism represented autism genes. The evidence was quite clear that such genes are also autism genes. The overlap between autism susceptibility genes and genes previously implicated in intellectual disabilities further supports the hypothesis that at least some genetic risk factors are shared by different psychiatric developmental disabilities.

Therapies specifically targeted to identified genetic causes (“personalized medicine”) are now being tested in several neurodevelopmental syndromes associated with autism, including Fragile X syndrome, tuberous sclerosis, and Rett syndrome. The identification of additional autism genes will expand such approaches and lead to new therapies.

see Genetic Mechanisms on page 34

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The Best Kept Secret

School Districts are Obligated Under Federal Law to Offer Parent Counseling and Training

By Tracey Spencer Walsh, Esq.
Senior Counsel
Mayerson and Associates

When you have a child with autism, there are so many things to “stress about” but parents should not have to do it all alone. School districts are obligated under federal law to offer, as a related service on the Individualized Education Plan (IEP), parent counseling and training. It is the best kept secret.

It is perhaps the most overlooked legal right parents with an ASD child have. Many school districts around the country ignore this provision, and some, like the New York City Department of Education, claim it is embedded in its District 75 (Special Education) program and therefore routinely fails to put parent counseling and training on the children’s IEPs.

Imagine that you are at your child Josh’s IEP meeting either for the first time or the “umpteenth” time. Your child’s teacher paints a picture that, no matter what she tries, she can’t get Josh’s behaviors under control – she’s “at a loss.” You think to yourself, “Me too!” The Committee on Special Education (CSE) chairperson sighs and says, “That’s very typical with autism,” and moves on to discuss the class size your child should



Tracey Spencer Walsh, Esq.

be in next year. Wait. Stop. Typical of autism? Hmm ... you were told by Josh’s pediatrician that autism is a spectrum disorder and that Josh will present with unique needs and, while there are commonalities among ASD children, there is nothing typical about autism; behaviors

vary from child to child and there can be a multitude of reasons for the behaviors. But you are not sure and you are in a room filled with educators – don’t they know best? You think so, but that is not how you feel. You are not even sure what questions you should ask, but you try and blurt out, “Are Josh’s behaviors normal?” The teacher is about to answer, but the CSE chairperson cuts her off and answers you with a curt, “Yes, it’s normal for children with autism,” and continues with the conversation about class size. You are just not sure. During the meeting, the team decides on the related services Josh will get: speech and language therapy and occupational therapy. It occurs to you more strongly than ever that you really need help with managing these “normal behaviors” and you ask, “Is there any help I can get to help Josh with his behaviors?” The CSE chair gives you a sympathetic smile and tells you that she is sure there are parent groups you can join, but offers you nothing beyond that. You think to yourself, “I need help supporting Josh’s needs at home – I don’t know how they teach him skills at school.”

Know Your Federal Rights

Your instinct is right, and Congress has recognized that parents do need help in the form of parent counseling and training.

The federal regulations define parent counseling and training as:

- (i) ... assisting parents in understanding the special needs of their child;
- (ii) providing parents with information about child development; and
- (iii) helping parents to acquire the necessary skills that will allow them to support the implementation of their child’s IEP or Individualized Family Service Plan (IFSP) (34 C.F.R. 300.34(c)(8)).

Parent counseling and training is mandated as a related service to be offered as part of your child’s IEP.

The Official Comments to the Federal Regulations under the Individuals with Disabilities Education Act (IDEA) help us to understand what is meant by parent counseling and training (Under the Related Services heading in the Official Comments published March 12, 1999 in the Federal Register (Vol. 64, No. 48, at page 12423, et seq.), Parent Counseling and Training is included and defined).

The federal law makes it clear that parents are entitled to counseling and training in how they can help implement their child’s IEP goals and objectives.

see Secret on page 30

Teaching Social Literacy: The Social Skills Seminar

By Mary Riggs Cohen, PhD
Licensed Psychologist
The Asperger Center for
Education and Training

For many individuals with Asperger’s Syndrome (AS) the social world remains a “black box” that is incomprehensible, confusing and a source of frustration in their daily lives. While some retreat from social gatherings and avoid social contact, there are a great number of individuals who seek to understand social behavior and long for interpersonal connections. Although individuals with AS are often portrayed as aloof and uncaring, those who know them are aware that this is an inaccurate (and unfair) characterization. There are many who desire social contact but do not know how to initiate or maintain relationships. Tired of their solitary existence and isolation, they try to gain insight into the mystifying social behaviors of neurotypical individuals.

In 2003, I was asked by colleagues at the University of Pennsylvania to develop a program to teach young adults with Asperger’s Syndrome how to increase their social awareness and gain a better understanding of the social world around them. The result was the Social Skills Seminar, a twelve week course that meets weekly for three hours. With few models to draw upon, the curriculum was created, to a great extent, through trial and error. Some



Mary Riggs Cohen, PhD

training methods were research based while others were developed from knowledge of the learning styles of AS individuals. Over the last seven years, more than 300 men and women with Asperger’s Syndrome, nonverbal learning disability, and social anxiety have participated in this program in Philadelphia and New York City. As the course has developed, there have been many opportunities to learn what “works” and “doesn’t work” with our participants. The instructors and

social coaches who have contributed to the development of the course have helped me to evaluate the successful components of the program and we have reached the following conclusions.

Social skills training programs have often been found to be ineffective because only basic instrumental skills (eye contact, greeting) are taught. Individuals must “understand social norms and develop more sophisticated social cognition skills” which are essential to the development of interpersonal relationships and achieving social success (Geller, 2009).

Asperger adults are often told to smile and make eye contact but no one has explained to them the rationale for these behaviors. Moreover the approach to adults has been to modify existing programs used for children and adolescents rather than address the unique demands of adult social development. As a result, many AS adults view social skills training as juvenile, a repeat of what they already know, and inappropriate for their current social needs. There is a critical need for social skills training that is geared to adults who have acquired some basic skills but need to progress to the complexities of dealing with co-workers, establishing romantic relationships and discovering the social norms of college life as well as the workplace. It is also essential that social skills be taught in an intellectually stimulating fashion drawing from current research in the various scientific disciplines that study social behavior.

Tager-Flusberg (2001), argued that social perception is the main deficit seen in Asperger Syndrome. Social phobias also exhibit perceptual differences by their “negative bias” to social situations (i.e. only noticing faces with unfriendly rather than friendly expressions). Although AS adults can often make appropriate responses in a laboratory setting, they have difficulty in real-life situations, which are more complex and require quick responses to often ambiguous situations (Frith, 2004). Students in the social skills seminars can often arrive at a correct response, given enough time, by using logic. However, this does not translate to the social world where cues must be processed quickly.

The Social Skills Seminar program incorporates these critical elements in an interesting and interactive format over twelve weeks of three hour sessions. Although the program was initially designed for participants with Asperger’s Syndrome, it has been used successfully with participants with diagnoses of high-functioning autism, nonverbal learning disability and social phobia. The program focuses on communication skills, recognition of nonverbal communication, job interview skills, and interpersonal skills (friendship, dating, sexuality). An experiential approach is employed in which participants are observed, and sometimes videotaped, while role-playing common

see Social Literacy on page 30

Translating What We Know About Stress and Coping into Clinical Services Guidelines: *Helping Families of Children with Autism in Ways that Make a Difference*

By Mary Jane Weiss, PhD,
Cece McCarton, MD, and
Ivy Feldman, PhD
The McCarton Foundation

In every aspect of intervention, there is often a gap between research and clinical practice. What we know from an empirical perspective is often not immediately translated into how we provide services. For example, within discrete trial training, there has been an evolution in our understanding of how to teach. Historically, discrete trial instruction (DTI) was done in blocks of trials of the same instruction given repeatedly. Instructions were delivered in a tone of voice that was dissimilar to natural speech. The wording of instructions was exactly the same on each trial. Those practices limited the generalization of skills taught through DTI. We now know from an empirical perspective that there are more efficient ways to teach. For example, we know that interspersing mastered skills with new material increases performance. We also know that teaching more naturalistically aids generalization. Still, we still see antiquated DTI in many settings. Why is that? Part of the reason may be our tendency to continue to intervene as we were initially trained. It is difficult to alter our practices. Another explanation is that it



Cece McCarton, MD

simply often takes time for empirical evidence to strongly effect clinical practices. There is a lag time between our discovery of how to best teach skills and the translation into clinical practice.

In the area of family support, this is also true. Much of what we do as service providers is guided by a global desire to

provide comprehensive services to families of individuals with autism. We know that having a child with autism in the family is inherently stressful, and that negative stress effects are common. We know that social support can help individuals cope, and we know that some individual characteristics seem to serve a buffering role.

Social support seems to be important, as we have reviewed in a previous article. The perception of social support as available seems to be critically important (e.g., Weiss, 2002; Wolf, Noh, Fisman, & Speechly, 1989). Individuals who feel that they have people in their lives with whom they can share their feelings and experiences cope much better than those who do not report the availability of such support. Formal support services such as parent training and respite services are also important, and help to teach specific skills (e.g., parent training). It has also been shown to be helpful to know others in a similar situation (e.g., Farran & Sparling, 1988; Honig & Winger, 1997).

Support Services

What would this mean in translation to clinical practice? Families of individuals with autism should be provided with parent training to increase their skills in successfully interacting with their children. Socially significant changes in parent-

child interaction are not likely to result in the absence of parent training. Parents need instruction in effective ways to teach skills and in effective ways to reduce challenging behaviors.

Most families report that a great source of stress and worry is the management of challenging behaviors. The unpredictability and intensity of challenging behaviors have a real world impact on family choices. Families may restrict their activities substantially to avoid and prevent such escalations. When such difficulties occur, there can be safety concerns, emotional reactions, and embarrassment. As families experience more of such escalations, they become more helpless and less confident in their ability to manage such behaviors.

How can such parent training be delivered in a way that is most likely to impart skills effectively? We know that didactic training alone is insufficient for skill development, and that Behavioral Skills Training (BST) is more effective. In BST, skills are taught directly, with role play, modeling, rehearsal, and feedback. Our parent training efforts need to reflect this; we need to teach parents in hands on ways. Because of the gap between environments, training is likely to be more efficient if done in the home. This creates logistical and service delivery challenges,

see Stress and Coping on page 22

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“Read the Hat”

How the Neurological Disorder of Autism Produces Social Disorder

By Eustacia Cutler, PhD
Mother of Temple Grandin

The best way to demonstrate the truth of this is to start with an account of a Families Together gathering in Idaho, a state known to me only from the old Bing Crosby song, “Away Beyond the Hills of Idaho.”

Families Together, I soon learn, is an organization addressing the social distress of young people on the autism spectrum—also the emotional distress that autism has stirred up in their parents and siblings. The Idaho gathering is a dinner with entertainment supplied by those on the spectrum. Above us on a platform, 12 year old James (who has Aspergers Syndrome) is finishing up his grand finale Karaoke, spinning first on his feet and then on his back - plump, blonde and in ecstasy.

“I like rhythm,” he tells us as he joins our table, snapping his fingers from the recollected joy. “It’s like alcohol. Once you do it you can’t stop it.”

Alcohol? Where did a twelve year old pick up that one? Has he had experience with alcohol or is it just his sing-song way of expressing his happiness? Aloud I agree with him and describe my own nights of driving home late at night after long band gigs, hollering lyrics at the top of my lungs, the music still ringing in my



Eustacia Cutler, PhD

ears. I quote him Carly Simons’ number, “Music is a Natural High.”

“Yes, alcohol that’s addictive, but it’s good for you. You do it, you just can’t stop it.” James sighs happily, but after a moment adds, “Music makes me lose control. I hear a really good song and I just dance, dance, dance... But still, it kind of makes me feel out of control.” He squirms in his chair, musical ecstasy beginning to churn indigestibly with the way he’s been told he ought to behave.

For James, the balance between exuberance and decorum is a constant and vaguely threatening hazard. Though he’s highly intelligent and articulate, at ease with a word like “addictive,” he has gaps in his neurological wiring that mean he can never quite get the knack of what’s going on between people that they don’t put into words.

For example, the other day when he raised his hand in class and the teacher nodded to him, he pointed to the clock and said, “I want you to know you have two minutes left and you better hurry up.” He was right, of course, but to the teacher he was way out of line. Why? How? It was late, first things first. But according to the mysteries of school room etiquette, something else comes first: something the teacher calls “suitability.” In her eyes, James with his constant lack of it is a non-stop unidentifiable flying object.

How do any of us know what’s suitable and what isn’t? The curious truth is, we don’t have to know. Somewhere in the lost eons of the past we acquired the neurology for it with the result that most children pick up social cues unaided, much as they know the difference between a dog and a cat. Nobody teaches them that either, they just know. They know, too, while still young and relatively helpless, how to endear themselves to their betters and just how far they can push them to get what they want. Negotiation is also built into our neurology - but not for James.

In the case of his encounter with his teacher, no doubt he was bored as many school children are, but bored or not, most children accept school room customs without any explanation. For James to accept any kind of custom, he has to understand it in the same conscious, intellectual way that he grasps the explanation of a new word. And then he must memorize it, as he would memorize the spelling of that word. Because this procedure is so much slower, James has to be allowed extra time. But even with extra time the very process makes him anxious, which then requires extra patience on the part of his teacher. Will the two of them ever achieve any kind of classroom rapport via such a roundabout, nerve wracking route? The answer is probably and sort of. At heart James is a sociable creature. He likes people, he wants friends, but it’s hard work for both of them.

I doubt if we’re going to “cure” James of his missing neurology, not unless we think we can actually cure the entire human race of its quirks and lacks. The point is to support and guide him so he can live a full life—as he sees it. James is enormously appealing; one wouldn’t want to change that, and part of his appeal lies with his wildly eccentric responses. When the subtleties of a new situation escape him—and they often do—he manages to

see *Read the Hat* on page 38

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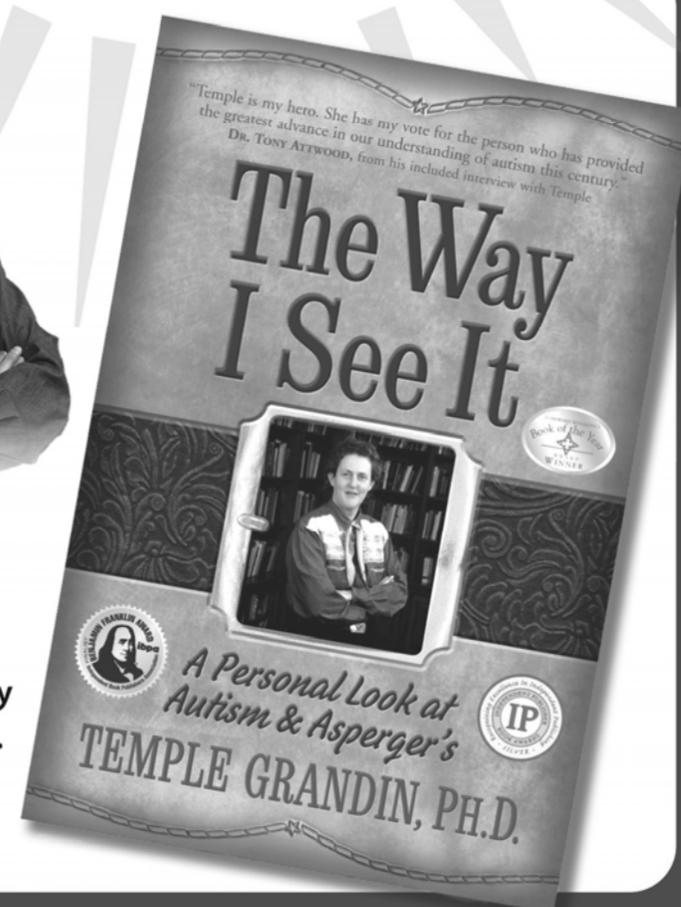
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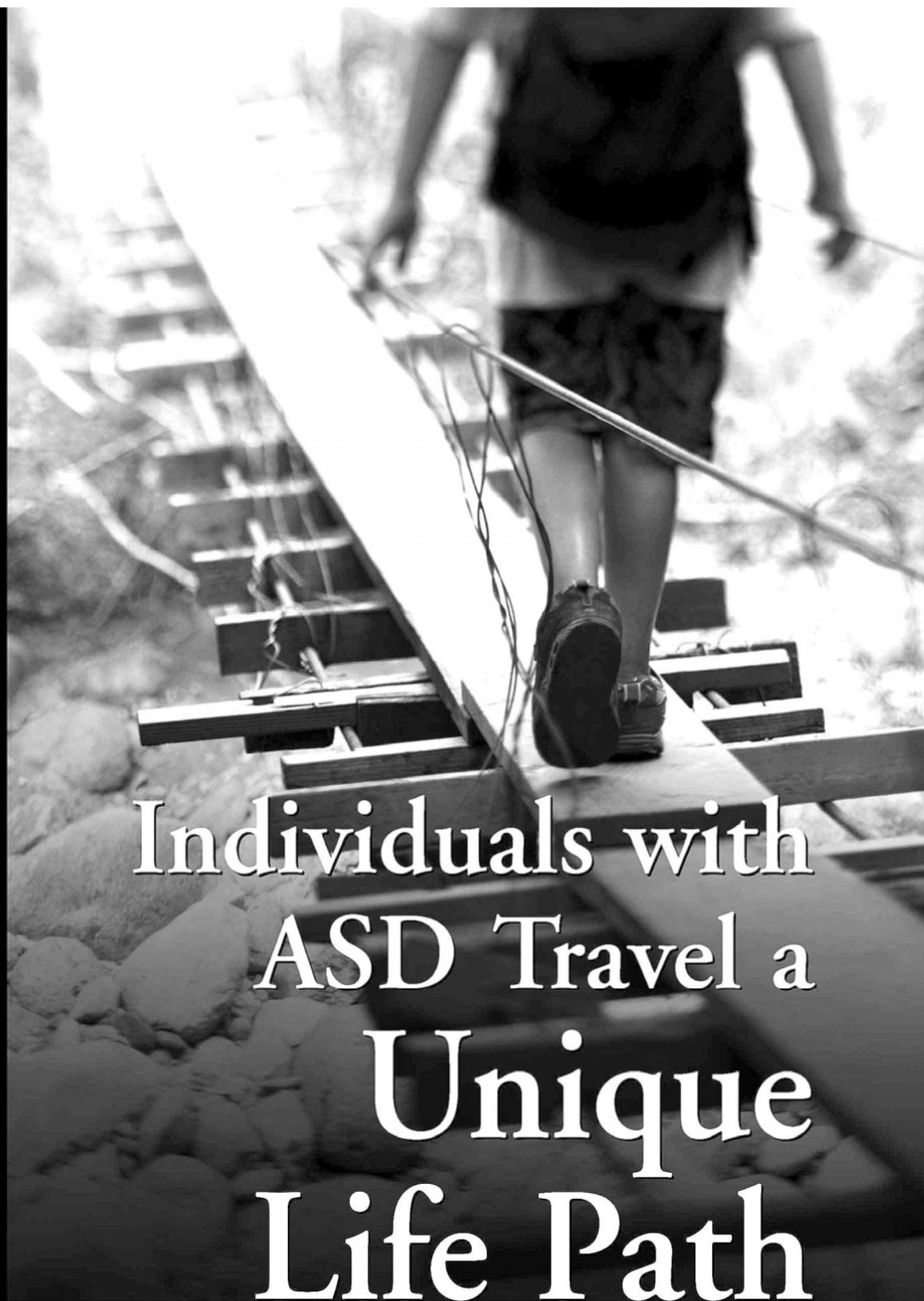
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Supporting Grandparents of Children with ASD

The Story of a Grandmother's Adult Daughter and Her 12 Year Old Autistic Grandchild

By Bonnie Graham, LMSW
Program Coordinator
WJCS Autism Family Center

Early on, doctors had given them little hope, announcing that her granddaughter would never talk, play with others, or make eye contact. She proudly tells the member of the Grandparents Support Group of children on the autistic spectrum that, although her granddaughter struggles, she is now in a mainstream class with an aide and recently had a play date. A few weeks later, a grandmother of a 3 ½ year-old child came to the support group and shared her feelings with other members by saying, "You've given me hope. I know our grandchildren are different, but you have given me hope that my grandchild will also make progress, even when those around us say that she won't."

The Westchester Jewish Community Services Autism Family Center (AFC) offers a variety of support services to individuals and families affected by Autism Spectrum Disorders (ASD). Recognizing their unique situation, the AFC created a support group specifically designed to address the needs of grandparents. Our experience with the AFC Grandparent Support Group is that it provides a vital link to a community of individuals who



Bonnie Graham, LMSW

know and understand their unique life experiences. When parents receive the diagnosis of ASD for their child, the entire family unit needs to adjust to the triumphs and challenges of having a child with ASD. In working with families af-

ected by ASD, we have learned the importance of being mindful of its impact on all family members, including grandparents.

Grandparents' Struggles

Grandparents' Roles and Expectations - In many cultures, the role of grandparent is revered. They are a source of experience, wisdom, and support that adult children can draw on as they begin to raise their own families. Most grandparents look forward to this role with great anticipation as their children become parents.

There are challenges and unique needs that having a grandchild with an ASD brings and this changes the typical grandparent role. When a diagnosis of ASD is given to a child, grandparents, along with their children, are thrust into a world where all that they expected has shifted. Grandparents who once thought that they would be teachers now must learn along with their adult children. Grandparents who may have been the occasional babysitters may become respite providers. Grandparents who may be living in retirement may become financial providers to help offset costly treatment and interventions for their grandchildren.

Grandparents' Involvement - Grandparents look forward to being involved in the lives of their adult children and grand-

child. When a child is diagnosed, grandparents may struggle with how to be involved given the unknown territory of autism. Grandparents may not be able to give the support they would like to due to lack of knowledge and understanding. This extends to both relating with their grandchild as well as being supportive to the family.

Grandparents may also struggle with being helpful to their adult children without being intrusive. There is a difficult balance between being supportive and interfering. Furthermore, grandparents may feel guilty for not being able to do more for their families, especially for those who live a distance from their grandchild.

Ways We Can Support Grandparents

Educate Grandparents on Autism Spectrum Disorders - Though the diagnosis has been around since the 1940's, autism has become more of our daily vernacular within the last 10 - 15 years. The field is constantly changing and expanding as new research is revealed. The wealth and breadth of information now available may be overwhelming and yet it is essential to the grandparents' well being and their ability to support their child. Knowledge is empowering and can allow grandparents to feel more confident as they proceed in

see Grandparents on page 36

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Alleviating the Stress of the Post Secondary Transition

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



Ernst O. VanBergeijk, PhD, MSW

Families with a child on the autism spectrum face adversity and stress on a daily basis. Transitions in particular can be extremely stressful for families who have a child with an ASD. The transition from high school is stressful for families with neurotypical children and is even more so for the families on the spectrum. Not only is the fear of change stressful for students and their families, but the limited number of post secondary programs that serve this population exacerbates the problem. However, there are a number of things that can be done to reduce this particularly stressful transition.

First, plan ahead. Visualize the behaviors that would lead a young person to live an independent life. Many of the behaviors that one would visualize involve activities of daily living (ADLs). Starting at a young age, encourage your child to engage in self-grooming and care. Use behavior modification and positive reinforcement to solidify these skills. Time management is a major ADL skill that college students must learn. This skill must be broken down into using alarm clocks, smart phone reminders, and calendars. As junior high and high school stu-

dents, students on the spectrum ought to be responsible for waking themselves up and getting ready for school. Checklists or visual reminders can be used to assist the student in remembering the various steps. Managing their bedroom space will help the student avoid conflicts with future roommates in the post secondary environment. Some students on the spectrum do not understand abstract terms like "neat"

and will need prompting of what is meant by this term. Creating a Power Point slide show with step by step written instructions coupled with photographs of what is expected can reduce the ambiguity and stress for the student on the spectrum. The slide show can be printed out and taped to the inside of a closet door. The management of laundry is a concrete skill that can be broken down into sorting laundry, washing, drying, folding and hanging laundry. A similar slide show can be created for the management of laundry. Recent research (Drahota, Wood, Sze, & Van Dyke, 2010) indicates that children on the spectrum who increase their adoption of activities of daily living (ADLs) and decrease their parental involvement in ADLs have lower levels of anxiety.

Second, give the student on the spectrum opportunities to exercise independence through summer camps and other types of sleep away programs. This intervention has a three-fold benefit. (1) It allows the student on the spectrum to practice the ADLs necessary to be successful in a post secondary environment. (2) Summer camps and college-based summer transitional programs offer the families respite from caring for their child on the spectrum thereby reducing stress and caregiver overload. And (3), college-based transitional programs help reduce stress for both the students and the parents by addressing the anticipatory anxiety surrounding what to do after high school.

The student and family will receive feedback on how the student will fare in a college like setting before committing to a 4 year college or some other post secondary program. Living in a residence hall is stressful for most college students and is even more so for students on the spectrum. Summer transitional programs can give the families feedback regarding the appropriateness of their son's or daughter's social skills in this group environment. It also prepares the student for the rhythms and schedules associated with being on a college campus. The experience can help the family make decisions surrounding the transition after high school by helping them decide whether to apply to a four year college with a residence hall experience, apply to a community college while working to strengthen independent living and social skills at home, or apply to a vocational training program.

Third, search for a post secondary program that not only has experience with supporting the ASD population, but also incorporates empirically based interventions to address stress and anxiety. These programs ought to teach higher functioning individuals on the spectrum anxiety management techniques such as diaphragmatic breathing (Reese, Sheldon, & Sherman, 1998), progressive muscle relaxation (Borkovec & Costello, 1993), guided imagery (Hanson et al., 2007),

see Transition on page 35

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The Four Faces of Overstimulation

By Nomi Kaim
Member
Asperger's Association of New England

The word "overstimulation" is not listed in standard collegiate dictionaries. In the lives of people with Asperger Syndrome, however, this little-recognized form of stress reigns supreme.

The ideas in this article are drawn from my own experiences – both living with Asperger's and interacting with dozens of other Aspies over the past six years.

What is Overstimulation?

Overstimulation (OS) occurs when there is "too much" of some external stimulus or stimuli for a person's brain to process and integrate effectively. This leads to an unpleasant sensation of being flooded and an impulse to escape the stimulus – or, failing that, to cry or scream or thrash about. Overstimulation is a form of pain.

No one knows exactly why Aspies are so often overstimulated by experiences neurotypical individuals find quite manageable. It may involve some combination of over-responsiveness and inefficiency at the brain level. The psychological consequence of this neurological vulnerability is *near-constant stress*. A person prone to OS moves through life in a



Nomi Kaim

continuous state of hyperarousal, waiting for the next unpredictable event to overpower him.

Most people are familiar with sensory OS, but there are other kinds: I have identified three more. Together, they make up what I refer to as the four faces of overstimulation.

Sensory Overstimulation

Sensory OS is triggered by hypersensi-

tive senses. It is impossible for the body to relax when it is subjected, or might at any moment be subjected, to a sensory assault. Just as a neurotypical individual would be fairly on edge in a world of erratic up-close explosive sounds, putrid smoky air, and sand-papery underwear, so Aspies (and others with sensory integration dysfunction) are continually on edge in *this* world.

My most sensitive sense is sound. Stepping outside, I clench my teeth as I take in the sounds of: moving cars, trucks, buses, trains, motorcycles, and airplanes; vehicles revving their motors and honking their horns; sirens from police cars, ambulances and fire trucks; construction workers' machinery; music stores, outdoor radios, and blaring car radios; and the mechanical voices of trolleys and traffic lights. These combine with insults to my other senses – bright sunlight, cigarette smoke, impenetrable crowds. The sensory onslaught of everyday city life can make it a torment to leave my apartment.

Emotional Overstimulation

Aspies frequently find it difficult to identify what we are feeling. This may be related to the finding that the brain of an individual with an autism spectrum disorder exhibits decreased long-range connectivity, in particular between the limbic system (where emotions originate) and the prefrontal cortex (where they become

conscious) (Geschwind, D.H., and Levitt). I often sense a thick fog in my head when asked to verbalize my emotions.

It seems almost paradoxical, then, that so many Aspies experience and absorb emotions with awesome force and rapidity. Tidal waves of feeling crash unexpectedly – and often unidentified – against flimsy barriers. Angry outbursts or crying fits may erupt when an Aspie's emotional reservoir overflows. Perhaps in part because Aspies cannot easily access our emotions, we cannot easily regulate them.

Emotional OS may be sparked by any number of everyday occurrences: a scary movie, a sad book, an intense psychotherapy session, a troubling lecture, a thorny conversation. Even joy – especially unanticipated joy, as in pleasant surprises – can be overwhelming in its intensity. All this makes Aspies quite averse to emotion. It is no coincidence that many Aspies would rather study and discuss neutral factual information than emotionally-drenched interpersonal matters.

Intellectual Overstimulation

The Aspie mind is always in motion. Such frenetically active minds can amass spectacular quantities of factual information and develop ingenious analytical powers. But they can also sink themselves in irrelevant details.

see Overstimulation on page 35

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*F.I.T. TOGETHER at the YMCA program developed by The Daniel Jordan Fiddle Foundation
Pictured here: Peer mentor and program participant*

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Divorce Rate from page 8

Dr. Freedman's presentation was held on Friday, May 21, 2010 at 1:30 p.m. Et during the Epidemiology 2 Session in the Philadelphia Marriott Downtown, Grand Ballroom CD Level 5 room.

In addition to Freedman, the research team includes Luther Kalb, of Kennedy Krieger Institute; and Ben Zablotsky and Dr. Elizabeth Stuart, of Johns Hopkins Bloomberg School of Public Health.

About Autism

Autism spectrum disorders (ASD) is the nation's fastest growing developmental disorder, with current incidence rates estimated at 1 in 110 children. This year more children will be diagnosed with autism than AIDS, diabetes and cancer combined, yet profound gaps remain in our understanding of both the causes and cures of the disorder. Continued research and education about developmental dis-

ruptions in individuals with ASD is crucial, as early detection and intervention can lead to improved outcomes in individuals with ASD.

About the Kennedy Krieger Institute

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individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Kennedy Krieger provides a wide range of services for children with developmental concerns mild to severe, and is home to a team of investigators who are contributing to the understanding of how disorders develop while pioneering new interventions and earlier diagnosis. For more information on Kennedy Krieger Institute, visit www.kennedykrieger.org.

Autism and Maternal Stress

By Abigail Connolly, MA, MSED and
Barbara Shaunessy, PsyD

Along with the countless rewards of parenthood come many stressors as well. The stress is compounded exponentially when the child is on the autism spectrum. In a study by Hutton & Caron (2005), "stressful" was the most used adjective to describe what it had been like to be a parent of an autistic child. Relief, grief, shock and self-blame were among the variable reactions to the initial diagnosis, according to the same study. Research indicates that raising a child on the autism spectrum is more stressful than most, or all, other disabilities (Holroyd & McArthur, 1976; Donovan, 1988). The reasons for this are many and this article will attempt to explore some of the possible reasons and offer suggestions to mitigate such distress.

An autistic child's level of communication, or lack thereof, has an impact on parental stress. In fact, some authors believe that the severity of communicative impairment of a child with autism may be the greatest source of family stress (Bristol, 1984; Garfin & Lord, 1986). The dyadic song between mother and child begins from birth and there is virtually instant communication between the two, which fosters bonding. An attuned mother can elicit such magical responses such as



social smile, meaningful babbles, protodeclarative pointing, referencing, joint attention, response to name, etc. When the mother cannot elicit the typical "returns," such as in the case of a child with autism, the mother may become depressed and stop making as many overtures. This cessation, in turn, renders the child less likely to develop socially (Kaplan, 1978) and sets off a cyclical pattern of behavior.

The behavior of a child with autism also influences a parent's level of stress. When investigating comorbid psychiatric disorders within the population of children with autism, Leyfer, et al (2006)

found that the average number of comorbid diagnoses was three. The comorbidities found, in descending order of frequency were: specific phobia, obsessive compulsive disorder, attention deficit disorder, separation anxiety, social phobia and oppositional defiant disorder. Additionally, Summers, Houlding and Reitzel (2004) found that families identified externalizing disorders (e.g. attention problems, aggressive behavior) as a primary concern. The research concerning parental stress connected with autistic children's internalizing behavior (e.g. emotional reactivity, anxiety, depression) is not as

fully researched as externalizing behavior. But the high prevalence of these symptoms in children with autism begs investigation in terms of its possible impact upon parental stress (Bristol, 1984; Summers, Houlding and Reitzel, 2004; Tamanik, Harris and Hawkins, 2004).

Comorbid conditions can only exacerbate the stressful situation. In Barbara Shaunessy's many years of experience working with parents of children on the spectrum, she found that parents harbor fears, frustration, anger, resentment and guilt about the sacrifices they make to care for their autistic child. Moreover, fear about having a second autistic child also causes concern when parents are considering increasing their family.

Hutton and Caron (2005) found that families of children with autism reported that there was little to no time for family fun or vacations which they reported as stressful. Even the most mundane activities, like haircuts, can have highly charged responses. As one mother told Shaunessy while hysterically crying, going to a neighborhood parade caused the most intense response from her autistic child. She mourned the lack of ability to easily do "normal family things." The effect on the family cannot be overstated and may cause more parental stress in the form of guilt for a misappropriation of time and attention, and possible concomitant

see Maternal Stress on page 24



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My Child Has Autism - Now What?

Help for Parents of Children Newly Diagnosed with Autism

By Kristin V. Christodulu, PhD,
Melissa L. Rinaldi, PhD, and
Anthony Malone, MD
University at Albany CARD



Kristin V. Christodulu, PhD

To meet current needs in the Capital Region of New York State, the University at Albany Center for Autism and Related Disabilities, in collaboration with Capital-Care Developmental-Behavioral Pediatrics, is developing and delivering an educational program for parents of children newly diagnosed with autism (ages 12 months to 5 years). Given the importance of families in the development, education, and behavioral support of children with this disability, it is imperative that programs aimed at increasing parent knowledge, decreasing parenting stress, and improving family quality of life be available in a timely manner in a format that is both efficient and effective.

Research indicates that parents of children with autism spectrum disorders experience greater levels of stress than parents of typically developing children and even parents of children with other disabilities and chronic illness (Hassall et al., 2005; Tomanik et al., 2004). In addition, parents of children with pervasive developmental disorders have been found to report a lower quality of life compared to

parents of typically developing children (Mungo et al., 2007). Recent studies suggest that providing parents of young children with autism information about the diagnosis and effective treatment practices through parent education programs and support groups can decrease parenting stress (Keen et al., 2009; Tonge et al., 2006) and improve overall quality of life (Shu & Lung, 2005).

Our parent education program is designed to assist families in accessing critical information on 5 topics specific to autism. Training modules for the program were selected from topics recognized by the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Autism Society of America (ASA), as well as other leading autism organizations, as important for parents and families. Topics include: Overview of Autism, Medical/Developmental Issues, Accessing Services and Resources, Treatment Options and How to Choose, and Living with Autism. In an effort to minimize the amount of time parents wait to access resources/services following a diagnosis of autism in their child, the parent education program runs on a continuous schedule where each month two different two-hour education programs are offered to parents. With this model, parents are able to start the series within 6 weeks of receiving their child's diagnosis and receive all information offered in a 4 to 5 month period.

There are several special features of our parent education program that distinguish it from other programs that might be available for families. First, the program is designed specifically for parents of newly diagnosed children. While a few parent support groups exist in the Capital Region of New York State, none focus on

the unique needs of parents who have just heard that their young child has a diagnosis of autism. Second, multidisciplinary collaboration among medical, psychological, and educational professionals has resulted in a state-of-the-art program curriculum. Third, the parent education program is being offered on a continuous cycle so parents can access important autism information in a timely manner. Fourth, incorporated into the parent education program is a measurement protocol designed to evaluate program outcomes using tools that are both reliable and valid.

The results of this project will underscore the significant role that working in partnership with parents play in improving outcomes for families of children newly diagnosed with autism. Specific aims of the education program include: 1) increase parent knowledge of critical information specific to autism; 2) decrease parenting stress; 3) improve family quality of life; and 4) identify areas/domains for educational and treatment planning for the child with autism.

Impact of the proposed project on children and families affected by autism is significant. Providing services at a young age is critical for children with this disability (National Research Council, 2001), and because autism spectrum disorders

see Now What on page 37

Stress and Coping from page 15

but the failure to actively generalize across environments often limits our success. As clinicians, we need to evaluate the nature of the behavioral challenge, the skill set of the parents, and the need for in situ training in the target environment. Our decision about where such training should take place should be guided by the assessment of these factors.

What about other types of support services? As providers, we may want to provide ancillary services that may help families cope. Examples of these services are parent support groups, which facilitate parents meeting one another and enable them to get the unique support that can only come from those who share similar experiences. It may also be the case that support groups could focus on skills that might ameliorate stress. Helping parents to identify and build networks of support might help them feel less isolated, perceive necessary support as available, and access support as needed.

Individual Factors

It has been suggested that certain individual characteristics insulate people from the negative effects of stress by providing and fostering such comfort and meaning. Having a strong belief in one's own ability to control events is linked to better coping, as it reduces feelings of helplessness and leads to effective problem-solving. (This may be why parent training is such a central support/training service, as it directly builds skills and increases effectiveness in interactions with the child.) Holding philosophically comforting life views is also associated

with positive adjustment. For example, many families note the positive benefits of the experience and identify important meaning in their family experience. A high level of involvement in helping one's own child and/or other individuals with autism seems to help families adapt. Families who involve themselves deeply as members of their child's instructional team report are often less stressed. On a broader level, families who involve themselves in the larger autism community may feel an overarching sense of purposefulness or a sense of contributing at a broader level. Finally, having an optimistic attitude toward life's challenges may help protect individuals from succumbing to the negative effects of stress (e.g., Albanese, San Miguel, & Koegel, 1996; Gill & Harris, 1991; Weiss, 2002).

What Does This Mean for Clinical Practice?

We have already reviewed how parent training can facilitate coping in multiple ways. Parents should also be encouraged to participate in the educational team, and to guide treatment decisions including the selection of target behaviors and skills. While fostering characteristics and beliefs associated with coping may not seem to be the purview of clinicians who serve the child with autism, programs can provide experiences that are congruent with these goals. For example, providing roles for parents to contribute to the organization helps both the center and (potentially) the parent, as it provides a way for parents to contribute more broadly to help individuals with autism. From a clinical perspective, parents who seek more formal indi-

vidual or group services may be helped by a focus on stress management, including ways to increase adaptive thoughts and feelings and counter pessimistic thoughts and feelings of hopelessness.

Summary

Having a child with an ASD in a family is intrinsically stressful. Families must immediately and permanently adapt to a formidable challenge that will present ongoing challenges. How can we ensure that the clinical supports provided are those that make the most significant difference? In terms of concrete and meaningful support services, we should provide parent training that increases skills and improves self-efficacy. In terms of individual characteristics, we should nurture the qualities associated with more successful adaptation. Our interventions need to have a family focus. We must assess and treat both the family context and the individual learner. Our commitments to effectiveness and efficiency should also influence our interactions with and services provided to families.

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Coping With and Avoiding Stressful Situations

By Michael and Carol Buffa
Parents

A friend of ours once told us that two strong "Is" make a strong "We" in the context of marriage. Putting it in the context of a family dealing with autism spectrum disorders (ASD), parents should be mindful to allot enough time for themselves so that they are strong individually and as a couple. That gives strength and patience for caretaking and all the other challenges that come with ASD stressors in family life. For couples, this means the parents can act as a strong unit; they are there to support each other when one of them is depleted.

We facilitate in the marriage preparation program (Pre-Cana) for our parish. The first thing we discuss with our engaged couples is communication. It is the building block that ensures that the marriage will last through life's challenges that eventually do come. Interestingly, we learn a lot from these engaged couples. They face many difficulties in today's world, not the least of which is juggling careers and financial issues. Life today is demanding, fast, expensive and stressful. It takes commitment, but most of all open communication, to handle it all. Open communication includes expressing feelings, not minimizing or dismissing the other person's feelings, and fighting fairly (no name calling, raising of



Carol, Emily and Michael Buffa

past history and the like). One may not agree with the other person's viewpoint (feelings), but the feelings exist and they have to be acknowledged. After that, the feelings have to be addressed in a positive, constructive manner. Likewise, a family dealing with ASD must communicate its feelings to get them out and dealt with. Sometimes people have negative feelings or beliefs that are erroneous, and just having another person say that those feelings are baseless relieves stress. Keeping the feelings bottled up

only perpetuates the negativity, guilt, etc.

The predominant issue we see is that one parent is accepting of the ASD diagnosis, but the other is not. That is a recipe to divide and conquer the unit that must come together to work positively. The lack of cohesion affects the child's education as well as the medical and therapeutic treatment the child will receive. Additionally, the extra cost associated with a special needs child (special medical care providers who may not take insurance at all or not the insur-

ance the parents have, special classes like social skills classes, special needs groups, etc.) is a stressor as well. If the parents do not have the financial ability to pay the additional costs, that child does not benefit from these associations. Parents should be advised of and take advantage of the free services available to their children through local libraries (craft classes, etc.), town programs, after-school activities, and family support services (after-school activities, respite, etc.) through their state developmental disabilities office, such as the New York State Office of Mental Retardation and Developmental Disabilities (NYS OMRDD).

Another critical item is networking. A parent cannot go this journey alone. At the very least, they should join their local Special Education Parent Teacher Association Network (SEPTA) to network with other parents who have blazed the trail before them – and it's never too early to join. These parents are an excellent source of information – what challenges they faced and how they handled them, who are the "good" professionals versus the "not so good," what programs/services are offered through school as well as learning about organizations that provide support services, such as the Asperger Syndrome and High Functioning Autism Association's (AHA) support groups.

see Coping on page 32



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Autism Support Groups: Benefits and Challenges

By Lenore Powers, MA, BAC
Family Counselor
Parent's Place

Support groups for parents of children with autism spectrum disorders (ASD) can be an excellent resource for families dealing with the overwhelming challenges of raising children on the spectrum. As both a family therapist and the mother of two sons with autism, I have learned firsthand the value of community support in coping with this difficult diagnosis. Members of a support group can provide each other with understanding and emotional support which is crucial in dealing with the chronic stress of caring for children with autism. In addition, members can offer each other practical advice on various treatments, doctors, therapies and diets that may or may not have worked for them. Feelings of isolation can quickly be alleviated when first joining a group. Members can relate to other members who understand what it is like having a child on the spectrum. Lifelong friendships and deep bonds between both parents and their children can be forged through a cohesive autism support group.

Support Groups Themselves Can Be Stressful

On the other hand, joining a support group can also be a difficult and even



Lenore Powers, MA, BAC

painful experience for some parents. Participation in the group necessitates both talking and listening to parents talk about their most stressful life situations. Parents are prompted to discuss their feelings of sadness, loss, frustration and even despair. They must then listen, absorb and respond to other members' similar painful thoughts and feelings. Parent members are

often reminded of both the physical impairments and cognitive deficits that their child struggles with daily. These discussions can sometimes leave parents feeling hopeless at the prospect that their children may never be "typical." Parents also report feelings of loneliness and isolation when first entering the group. At first members may feel like they are the only family having to deal with this problem. In addition, some members come to the group feeling extremely anxious to find a way to "fix or cure" their child's autism. Parents may leave the first meeting feeling more hopeless because they did not get the concrete answers they needed to help their child.

Another common problem that comes up in a group is that a parent may often compare their own child's progress or level of functioning with another group member's child. This problem of comparing each other's children may lead to even greater feelings of inadequacy and incompetence on the parent's part. Children on the spectrum vary so widely in abilities and functioning. It is understandable that a parent may sometimes feel like their child is not making as much progress as another group member's child. Members might think to themselves, "I am not doing enough to help my child, like so and so is doing." In addition, parents may feel discouraged or guilty if they do not have the income or time to try the same expensive treatments, diets or therapies that

other parents in the group have access too for their children. Parents will sometimes report feeling resentment or even jealousy of another group member's child who is functioning at a higher level. Some members may express guilt, lack of patience and even irritation when hearing other members complain about their children who are clearly more developmentally advanced than their own child. On a final and practical note, parents who have one or more autistic child at home simply cannot physically get out of the house at night to attend a meeting. Childcare for children on the spectrum can be both expensive and difficult to find.

Suggestions for a Positive Support Group Experience

The first step to tackling some of these common problems that a parent may experience in an autism support group is to specifically define and label what the actual focus and purpose of the group is. For example, if the group is meant to offer families a place to gather information, learn about new treatments, therapies, diets and educational issues, then the group should probably be called a "workshop" or "weekly informational seminar." These types of informational gatherings are extremely useful in giving parents direction and practical advice in

see *Support Groups* on page 36

Parents



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Parent-Only Evening Support Groups

These groups provide opportunities for sharing information, resources, and feelings; decreasing isolation by meeting with others "in the same boat;" and developing strategies to cope with children's behavioral challenges.

Groups are facilitated by Lenore Powers, Family Counselor.

Family Days: 2:00 – 4:00 pm on Sundays

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**Lenore Powers - 914-309-0933 (cell) - lenorepowers@yahoo.com
Pam Ancowitz - 914-282-1118 (cell) - parentsplace@verizon.net**

Groups are drop-in, but RSVP is encouraged, as it helps us plan

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Believe, Because I Believe in You

By Carrie Cariello
Parent

My journey to the Boston Marathon started long before I committed to run the best-known race in America. It began on a particularly low Saturday in November 2007.

Our family had relocated to New Hampshire less than a year earlier, and although he had been officially diagnosed with Autism and was receiving services, life with our three-year old son Jack was still uncertain and tumultuous. While we'd adjusted to the diagnosis, we were still learning to accept the daily challenges of life with a child on the spectrum – alarms on the doors in case he escaped, a lock on the refrigerator to keep him from experimenting with eggs, tactics to diffuse the outbursts that put our household in a tailspin.

On this chilly gray afternoon I was paying for a haircut when I noticed a display of inexpensive necklaces at the front desk of the salon. They had little inscriptions like “dream” and “peace” inscribed in silver circles. I saw one engraved with *Believe* and thought, why not? For \$29, I could use a tangible reminder of my commitment to soldier on and believe in the unknown.

Something magical happened with this inexpensive piece of silver. During one



Carrie Cariello with her son Jack

of Jack's legendary tantrums, I held the small circle up and asked him, “What does Mommy's necklace say?” He focused on it just long enough for me to say, “Believe. It says believe, Jack, because I *believe* in you.” Over the course of the next year, he and I both turned to that exchange to calm ourselves if he started to spin out of control. Repeated probably a hundred times by now, our dialogue is unchanged: “What does Mommy's necklace say?” He unfailingly

answers, “Believe, because I believe in you.” I'm not sure which of us needs these words more.

Nearly three years have passed since I bought the necklace, and I wear it faithfully. I wear it if I know we'll be in a situation that's challenging for Jack and I'll need some strength to get us both through. During this time Jack has developed into a different boy entirely. He can hold a conversation, share a joke, and ask appropriate questions.

One snowy day this past December I was baking cookies when my friend Pam called and asked me to run the Boston Marathon on her team for the Doug Flutie, Jr. Foundation for Autism. I agreed, mostly because I wanted to get back to eating my macarons without interruption, but also because it seemed boorish to turn the offer down when my own child was on the spectrum. Before I could say biscotti, Pam dropped off a crazy-looking training schedule and I was off and running. Literally.

My training was everything you would expect from trying to get a body that's birthed five children to run 26.2 miles without collapsing or failing in some embarrassing way (think “runner's trots”). It was exhilarating and frustrating, challenging and rewarding. It forced me to grow both emotionally and physically and served as a constant reminder of how hard Jack's life must be sometimes.

Before I knew it, race day was upon me. Aside from some minor hip bursitis, I felt prepared to go the distance. I'd kept to the training schedule religiously and sailed through a 20-mile race in March. I thought I was ready.

I was wrong. Although I did everything I could to prepare for this day, the Boston Marathon course owned me from the first mile. I was unused to bobbing and weaving through crowds of runners

see Believe on page 37

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development of over-responsible siblings.

High functioning autistic children and those with Aspergers Syndrome present a more complicated problem. They often have higher intellectual functioning and vary widely in their social language skills. This disparity can obscure, rather than facilitate, the understanding of these children's functioning (Twactman-Cullen, 2000). This, in turn, can cause more stress to the parents of autistic children with higher intellectual functioning. Indeed, Schopler and Reichler (1972) (as cited in Bristol, 1984) reported that disparities in the abilities of higher functioning autistic children make it more difficult for the parent to know what to realistically expect from his/her child. This, in turn, leads to disagreements within the family as well as in the community at large. This results in parents feeling uncertain and leads to higher stress levels.

Koegel et al. (1992) studied stress profiles across mothers of children with autism who ranged in age from 3.1 years to 23.1 years and who had a wide range of intellectual functioning. Results suggested that there is a common stress profile for mothers of children with autism. Major differences between the mothers of a child with autism and the mothers of normative families were on the dimensions of dependency and management, cognitive impairment, limits of family opportunity and life span care. The authors suggested that these results show the importance of developing treatment programs aimed at reducing stress specific to parents of children with autism.

Several studies have found differences in the stress levels between mothers and fathers of children with autism. Moes, Koegel, Schreibman, and Loos (1992) ran a study to compare stress levels of mothers and fathers of children with autism. Mothers showed significantly more stress than fathers on each inventory. This response pattern suggested that stress may be related to the differing responsibility assigned to child rearing for each parent. Herring, et al. (2006) compared maternal and paternal stress levels in parents of children diagnosed with PDD-NOS and a non-PDD-NOS group. The authors found that child emotional and behavior problems contributed significantly more to the mother's stress than learning of their child's diagnosis. Compared with mothers, all fathers reported significantly less stress in relation to parenting their child.

Hastings, et al. (2005) explored how mothers experienced stress differently than fathers. They found that children's behavior problems and husbands' depression predicted maternal stress. Interestingly, mothers reported more depression but more positive perceptions about their children and the children's impact on themselves and family members than did fathers.

Turning Research into Applied Therapy

The point of studying maternal stress in autism is to use the information gleaned from the studies to develop programs that would help alleviate some of it. Hastings and Johnson (2001) and Brookman-

Fraze (2004) and Williams and Wishart (2003) point out that the trend in therapeutic techniques in the field of autism is to train the parent to take on more of the responsibility for the delivery of therapy in order to enhance generalization. This has been an outgrowth of the “Parent Empowerment” and ecoculture movements (National Research Council, 2001). Programs which advocate that a parent be a significant partner in his/her child's therapy also proved to decrease observed stress, improve maternal confidence, and increase more positive affect and appropriate engagement in the children (Brookman-Fraze, 2004).

Presently, there are several therapeutic approaches that teach parents and families to be the therapists for their child with autism. Although some results were equivocal, it was generally found that not only did the child improve, but the parents' stress levels were reduced. Greenspan's Floortime (Greenspan & Weider, 1988) and Gutstein's Relationship Development Intervention (Gutstein & Sheely, 2002) approaches are programs which attempt to lovingly invade the child's isolative world and make relating fun and rewarding for the child. If the parents are rewarded with these emotional dividends they are likely to feel more connected, more successful, and, perhaps, less stressed. Another program is the Sunrise Program that advocates turning a whole room into a working therapeutic space. Additions to these programs are techniques such as Social Stories (Gray, 2010) and social skills groups for the child. Whatever the combination of therapies a parent assembles for his/her child, it is

important that the parent be comfortable with the services provided. Research has found that one of the most important aspects of relieving stress is the parent's view of the efficacy of the therapeutic “package” (Hastings, Kovshof, Ward, Espinosa, Brown, et al. 2005).

In an airplane parents are always directed to put on their own oxygen mask before they do so for their child. In the same vein, if a parent fails to care for him/herself, his/her ability to help their child diminishes. Therefore, parents are urged to seek out local support groups as well as ones run by organizations such as the National Autism Association, YAI Autism Center, Autism Speaks, and the Center for Autism and Related Disorders, and read newsletters such as *Autism Spectrum News*. Respites can also be found through these organizations when the pressure is just too much. Seeking one's own marital or family therapy can go from a mere suggestion to a necessity. Joining advocacy groups can help parents feel more empowered and can help them network with families sharing similar issues. Yoga, relaxation and deep breathing exercises may also be helpful.

As we have seen, language and behavior levels of children with autism can impact parental stress and family functioning. If mothers of children diagnosed on the spectrum between the ages of six to twelve years are interested in participating in a study concerning the relationship between these functioning levels and maternal stress and family functioning they can contact Abigail Connolly at connollycuny@aol.com.

ASD Law and Policy: What Parents Should Know

By Sheryl Dicker, JD, Professor
Albert Einstein College of Medicine

The high prevalence of Autistic Spectrum Disorders (ASD) has had an unrecognized impact on law and policy. While the thousands of vaccination cases - virtually all lost by parents - have received most of the public attention, important legal and policy activities have occurred in the courts and legislatures concerning education and insurance issues. This article will highlight those trends to help parents of children with ASD to be effective advocates.

Children with Autism under IDEA

The words Autism or ASD do not appear in the 1975 Education for All Handicapped Children's Act (EHA) or in its 1986 amendments. It was not until 1990 that the word Autism first appears in the federal law that guarantees all children with a handicapping condition a "free appropriate public education (FAPE)." Until 1990, as a low-incidence disability, children with ASD were usually categorized as "severely emotionally disturbed" or "otherwise health impaired." In recognition of the growth of Autism, it was listed as one of the disorders categorized under the term "children with disabilities" in the 1990 reauthorization of the EHA (renamed the Individuals with Disabilities



Education Act, or IDEA). The regulations promulgated under the 1990 IDEA define Autism as a developmental disability significantly affecting verbal and nonverbal communication and social interaction, often characterized by repetitive and stereotyped activities, resistance to change and unusual responses to sensory experience that adversely affects a child's educational performance. Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

By contrast, the DSM-IV definition adopted in 1994 provides a more in-depth description of the various behaviors a

child with Autism must exhibit by age 3 and does not focus on educational deficits nor does it exclude children with primary emotional disturbance. The court decisions, however, are **unanimous** in holding that the IDEA definition, not the DSM-IV definition, must be used to obtain an autism classification.

Services Required Under IDEA

The Supreme Court has determined that the Individualized Educational Plan (IEP) or Individualized Family Services Plan under the Early Intervention Program (EI) for Infants and Toddlers with Devel-

opmental Delays known as Part C (IFSP) has to be reasonably calculated to provide only some educational benefits to the child. This is important since courts have rejected parents' proposals for the "best" program or the program that will "maximize their child's potential."

This definition limits the services children with ASDs are guaranteed. Most of the controversy in the courts has involved a child's entitlement to ABA. Many courts have held that a child is not necessarily entitled to an ABA program - even when parents can prove the effectiveness of this program for their child - if the school provides an alternative program that gives the child *some* meaningful benefit. In every case, decisions must be based on the needs of the *individual* child. Thus, school districts are not permitted to institute a policy refusing to provide ABA-type programs or any other program to children with ASD.

Parents Bear the Burden of Proof in IDEA Appeals

Further compounding the challenge to parents, the United States Supreme Court recently held that parents have the burden of proof in all cases under IDEA. In the past, school districts or lead EI agencies had the burden of proof in all appeals. Thus, those entities were required

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Helping Parents of Children with ASD Cope with Stress

By Mary Jo Hebert
Regional Coordinator
Capital District Office of
Parent to Parent of NYS

As parents of children with special needs, we all want what is best for our children - the best teachers, the best therapists, the best doctors, and the best service providers. But how often do we stop to consider if our child deserves a parent who is at their best? One who has the energy, focus, and enthusiasm needed to meet the challenges of parenting a child with Autism Spectrum Disorder?

Being a parent at our best requires balancing our child's needs with our own need for fulfillment and rejuvenation. Finding that balance has been a goal in our family since our son was born with developmental disabilities and epilepsy 18 years ago. For us, it all begins and ends with discovering positive ways to cope with and effectively manage stress.

Like most families of children with special needs, our life is unpredictable. To manage, we have tried to create predictability where we can by simplifying our weeks and developing routines. Friday night is grocery shopping and Saturday is the day we visit Grandma. Because eating in a restaurant can be more stressful than relaxing, once a week we bring the restaurant home to us. Saturday night is takeout night. Everybody gets a break and there are no dishes to wash when we're done.

I work fewer hours at my job than I once did, but discovered that stability at home paid more in the long run than a larger paycheck. I say no a lot more often than yes, and I've stopped apologizing when I turn down another invitation to join a committee or attend a meeting. Honoring my personal priorities is less stressful than saying yes now and regretting my decision later.

Because we spend a lot of time at home, we try to make our home as comfortable as possible. Friends who visit our backyard garden are envious and ask how

they can have the same. It takes staying close to home, I tell them. While we miss taking the vacations other families do, we've created a place for rest and rejuvenation in our very own backyard.

My best coping skills are the internal ones, the messages I tell myself and my attitudes toward being the parent of a child with disabilities. I try to live one day at a time and strive to accept life the way it is, not the way I want it to be. I've given myself permission to admit that while I love my son, it is not always easy being his mother. I've learned to appreciate the sacrifices we make on his behalf and the courage it takes to let go of things we cannot change.

Focusing on the positive and reminding ourselves of all the ways our son has enriched our lives provides our life with greater meaning. Being the parent of a child with special needs has prepared us well for when life deals one of its hard blows. No strangers to adversity, we regain our balance faster, stay on our feet longer, and know from experience that this too will pass.

Parenting a child with special needs requires the discipline and dedication of a world class athlete, one whose event is played out not on the field or in the gym, but in the halls of schools and doctor waiting rooms. Children with special needs require exceptional amounts of energy. Getting rest, eating well, and carving out time for exercise is critical to preserve the stamina and energy needed to keep all the balls in the air.

The quest to make our lives more manageable is ongoing. Adding our own needs as parents to our family's never ending to-do list does not come naturally; it's something we have to work at. The payoff is that the better off we are emotionally, physically, and spiritually, the better off our families will be. To keep from cheating our families, we must take care of ourselves. We owe it to our children.

Mary Jo Hebert is the Regional Coordinator for the Capital District Office of Parent to Parent of NYS. She can be reached at cdp2p@verizon.net or 1-800-305-8817.

Autism Spectrum News

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www.mhnews-autism.org

Pick-Up Time

By Jeff Stimpson
Journalist

We consider it sort of lucky that our autistic son Alex, 11, provides what General George A. Custer referred to as “a target-rich environment” in the world of picking up - in other words, a lot of stuff on the floor. “We’re going to pick up now, Alex!” seems to set the right mood these days for teaching this valuable life skill. Alex is learning. Last night, he put away newly done but undried laundry hanging in the bathroom. I found my long johns this morning on the floor of his closet, but he tried. We’ve developed a few methods to help him pitch in on picking up:

Explain with Specifics, and Repeat: “Put the comb back in the bathroom, please, Alex, put the comb back in the bathroom. Pick up that magazine, please, and give it to mommy. Give that magazine to mommy.” Keep in mind that the person you’re talking to may have trouble initially understanding even what may seem to us simple and clear instructions.

Rewards: I’m not a big fan of this and have read advice against rewards regarding proper behavior during family events,



Jeff Stimpson

but by God you often have to bend the rules with autism in the house. Offer Alex a bowl of pretzels or Chips Ahoy and he’d probably shine the floor with his tongue. Ration rewards, though: Dole them out skimpily with each task completed. Beware too of cagey behavior. Today’s a snow day from school, for instance, and I

just saw Alex fly past with an empty bowl and the bag of Utz Dark Specials Pretzels. I stopped him, and in exchange for the next handful of pretzels I got the couch cushions, two blankets, and Jill’s metal yardstick off the floor.

Empower Siblings: Alex has a typically developing 9 year old brother, Ned. It is interesting to note how Alex is much more efficient than Ned, who seems yet to understand the drudgery of the work world, at picking up and putting away. Nonetheless, Ned seems to be a model for Alex when the pick-up commences; the older brother appears to follow the lead of the younger. We’ve also tried to give Ned, who often complains that he has to pick up messes Alex has made, a further notion of the work world by offering him “promotion to foreman,” whereby he gets to tell Alex what to put away. But as I said, Ned doesn’t understand many aspects of drudgery yet.

Use a Pointer: This seems to help Alex understand what needs to be picked up, as does the use of colors and names of objects. When I say, “Alex, please pick up the blue and white shirt. The blue and white shirt, Alex,” I touch the shirt on the floor with the tip of the bat, sometimes tapping, too. I use Ned’s yellow wiffle ball bat. I did use Ned’s toy wooden and

metal flintlock rifle until I almost accidentally conked Alex on the forehead with the barrel (be careful how a kid deep into pick-up can dart around).

Monitor on Both Ends: Alex excels at putting away laundry. “Alex, put the pants in the top drawer of your dresser, please. In the top drawer of your dresser.” A few minutes later I’ll check the drawer, and sure enough there will be the pants - stuffed in and freshly wrinkled, but there. This technique works best when one grown-up or foreman stands at one end of the pick-up and another stands near the area where the crap must be put away. In November, I bought four pair of new winter gloves for the boys, and one evening while home alone with him casually asked Alex to put them away in his bedroom. We’re still looking for them.

Jeff Stimpson, 48, is a native of Bangor, Maine and currently lives in New York with his wife Jill and two small sons. He is the author of Alex: The Fathering of a Premie and Alex the Boy: Episodes From a Family’s Life With Autism (both available on Amazon.com). Jeff maintains a blog about his family at www.jeffslife.tripod.com/alextheboy and is a frequent contributor to various websites on special-needs parenting.

Parenting a Child with an ASD Can Seem Overwhelming

One Parent’s Perspective for Achieving Balance in Life

By Dorothea Iannuzzi, LICSW, BCBA
Milestones Inc. School for
Accelerated Learning

There is no job more arduous, demanding and totally consuming than the job of parenting. The demands on a parent exponentially increase when their child is diagnosed with an autism spectrum disorder. Every parent has dreams and expectations for their children, whether articulated or kept silent in one’s soul. Receiving a diagnosis of ASD shatters the dreams, and forces a parent to grieve an unexpected loss of an ideal. How parents manage this period varies tremendously and has a lot to do with the individual’s baseline psychological wellbeing.

In an instant, often immediately following the receipt of the diagnosis a parent is asked to complete the herculean effort of coordinating educational, medical, and allied health services for a child with complex needs. In order to accomplish this, a parent must often advocate and fight for services through both third party insurers and school districts. Both of these service delivery systems, as a general rule, have a primary mission of containing costs and attending to the bottom line, rather than providing the care and services an individual child’s needs.

This is a time of action as the parent is faced with attempting to coordinate care from a myriad of providers, while also



Dorothea Iannuzzi LICSW, BCBA

advocating for appropriate school-based services. A parent must be wary of treatment options that are not evidence-based and have claims of success and cure that are anecdotal in nature. While trying to be an informed consumer and research all evidence-based treatments, a parent with a child that carries an ASD diagnosis must also look at the metabolic and medical profiles of their child in an effort to deter-

mine what medical issues could be affecting behavior and learning. Often times a parent can encounter resistance on the part of the medical community regarding exploring diagnostic and medical evaluations for a child with an ASD diagnosis because the primary care practitioner sees all of the presenting issues as part of the autism diagnosis and is hesitant to carefully evaluate the child medically. Many of these children are difficult to manage in a clinic setting and the medical staff can be dismissive of parental concerns in an effort to move along and see the next patient in their schedule.

A parent at this initial stage is often eager to try anything and everything that could possibly help their child. In many cases, a parent will spare no expense or resource in an effort to leave no stone unturned. During this initial phase a parent is also being bombarded with the message that the sooner an intervention starts the better the likely outcome. In other words, the clock is ticking and everything should have been started yesterday as each and every minute from the moment of diagnosis is valuable and should not be wasted. The pressures to do it all, do it now, or better yet, do it yesterday are overwhelming and all consuming.

Another aspect of this perfect storm of stressors is that the treatment professionals that parents take their children to see may be able to advise a parent on treatment options, but many times will have no answers to the many difficult questions on a parent’s mind: Will my child develop

expressive language? Will my child be able to attend public school with his peers? Will my child ever learn to make friends? What does the future hold for my child and the rest of the family? These are the questions that keep parents up at night and often are not possible to answer.

In many respects the expectations that are put upon parents are unrealistic and can leave a parent vulnerable to feeling defeated by the larger systems they have been forced to battle. The key to maintaining a sense of well-being during this time is to set small and reasonable expectations each day and resist the impulse to do it all; strive to do the very best you can for your child each day. Parenting a child on the autism spectrum is not a sprint but a marathon.

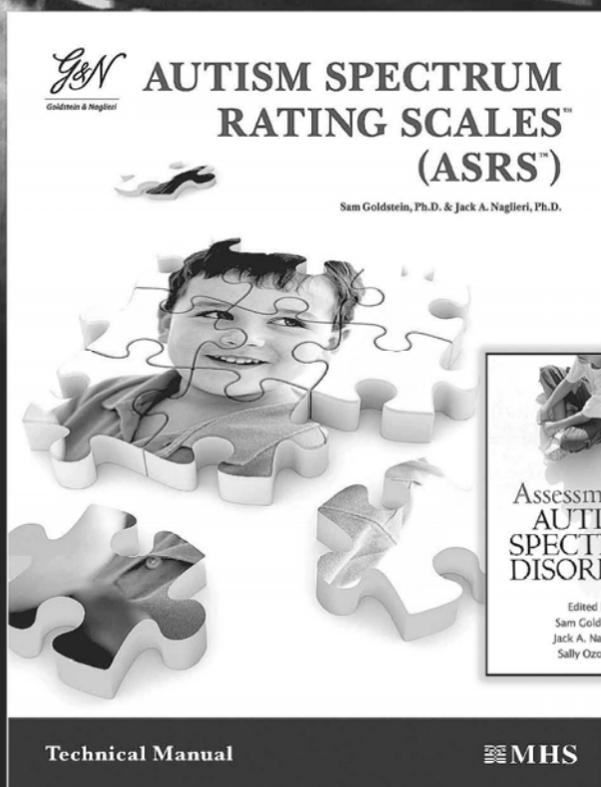
My own experience as a parent of a fifteen-year-old boy on the autism spectrum has taught me that more is not always better, and sometimes the best intervention is no intervention. I try to see my son as a child (adolescent) first, and not judge all his behavior through the lens of autism, but use the lens of what is typical behavior for a fifteen-year-old boy.

We are all works in process regardless of our age or diagnosis. No one knows what tomorrow is going to bring. As human beings we strive to make each day the best it can be with what we have to work with. Living with a child with an ASD diagnosis can provide opportunities to see the world from a perspective of simplicity amidst the chaos. It can force us to

see Overwhelming on page 37



Paving the Way to New Insight

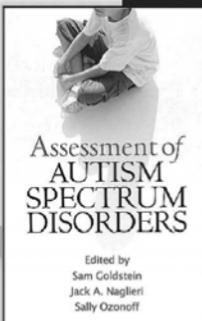


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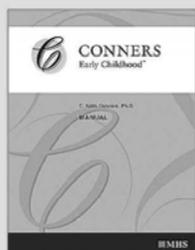
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Secret from page 14

Parents can and should ask that parent counseling and training be listed as a related service on their child's IEP. The frequency and duration of the parent counseling and training depends on what your child's needs are. A student with autism with many severe

behaviors should have intensive parent counseling - a half hour once a month is not enough. Parents should present an expert report at the IEP meeting or have an expert participate at the meeting who can recommend the level of parent counseling and training that is appropriate for the disability you are supporting at home.

Parent counseling and training, as obligated under federal law, should not be the best kept secret and, hopefully now, the cat is out of the bag.

Tracey Spencer Walsh, JD (Fordham University School of Law, '94) is the Senior Counsel at Mayerson & Associates, a New

York law firm dedicated to representing children and adolescents on the autism spectrum, and assisting families in accessing the education and related services necessary and appropriate for students. For six years, Ms. Walsh worked as an educator and served as an Upper School Dean of Students at an independent school in Rye, New York.

Social Literacy from page 14

social situations they might encounter outside the classroom. There is an emphasis on feedback and support so that each participant is given encouragement to improve his/her social skill repertoire. Most of the classes have had 6-10 participants who were young adult males and females (under 30 years) however, there were also a few older participants. The participants lived in the Philadelphia metropolitan area (including New Jersey and Delaware) and most recently the New York metropolitan area. The education level ranged from college-bound high school graduates to graduate and professional school students with the majority of participants being college graduates.

It is acknowledged that the population that participated in this program was high-functioning in general and not representative of all those with the diagnoses of Asperger's disorder, high-functioning autism, nonverbal learning disorder or social phobia. Much of the literature regarding more severely affected adults, such as Dr. Patricia Howlin's study (1999), does not reflect the positive outcomes that have been reported for this program's participants. The program is typically conducted in an outpatient setting and therefore, is not accessible to those with more severe disabilities. It is a future goal to expand the options for these individuals through collaboration with vocational rehabilitation centers, residential settings and organizations such as Autism Living and

Working (www.autismlivingworking.org) that support those with greater social disabilities. The program can be modified to meet the needs of various populations by eliminating more complex aspects of the curriculum (i.e. internet dating, career selection) or focusing on areas most relevant to a particular group. An additional goal is to expand the program to include more female participants. The ratio of males to females with Asperger Syndrome's Disorder is 8:1. However, research data suggests that Social Phobia is more prevalent in females (Heimberg & Becker, 2002) and clinicians/researchers suspect many females are undiagnosed (Baron-Cohen, 2010). Currently, 16% of the program's participants have been female.

There are many with social learning

disorders that could benefit from this program as past participants have. Our research has indicated that the program reduces social anxiety and increases social motivation for most participants. These two factors are fundamental in breaking the cycle of social isolation and social avoidance that many are experiencing. Over the past seven years it has been gratifying to see these individuals achieve a sense of social literacy and thereby improve their self-image and become a part of the social world around them.

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

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Autism Insurance from page 9

As a result, these New Yorkers will no longer be forced to choose between an impossible financial burden and the proper health care for a family member."

To view the press conference announcing this legislation prior to the vote visit www.youtube.com/user/nysenateuncut#p/u/1/2JeVVZqoY98.

The Centers for Disease Control have now estimated that the number of children with autism is 1 in 110 nationwide, up from previous estimates of 1 in 150. The numbers are even more stark in New York, with the autism rate for children increasing by about 15-percent per year. Recent studies have shown that close to 1 in 90 children are affected by autism. Currently, there are 17,000 students ages 4 to 21 classified by New York schools as having autism.

Senate President Pro Tempore Malcolm A. Smith said, "There are many challenges facing the parents of autistic children and this simple fix will greatly help to alleviate the financial burden on them. I commend Senator Breslin for his dedication to making sure that children with autism are able to receive the coverage that will allow them to be diagnosed earlier and treated for as long as necessary."

Senator Thomas K. Duane (D-Manhattan), chair of the Health Committee said, "This bill is an enormous first step forward. By requiring that insurers cover services that have passed a level of evidence-based clinical scrutiny, those who are living with autism will receive better coverage and, at the same time, insurers will not be required to cover clinically unproven treatments. Today's passage of S7000B is a proud moment for this legislative body."

Senator Suzi Oppenheimer (D-Mamaroneck) said, "This legislation is an important step in providing insurance parity for thousands of New Yorkers who are affected by autism spectrum disorders. I applaud Senator Breslin for his leadership in moving this vital health insurance initiative through the Senate."

Senator Craig M. Johnson (D-Nassau) said, "Every day I hear the horror stories from families who have re-mortgaged their homes and taken second and third jobs in order to pay for the autism-related treatments that their children need. Insurance companies are supposed to be there to help families during times of crisis. Today, we are ensuring that these companies live up to their responsibility."

Senator David J. Valesky (D-Oneida) said, "Often, families affected by autism are forced to pay for medical treatment on their own without the support of insurance agencies. This legislation gives families the ability to rely on their insurance to help alleviate some of that financial impact."

"For the increasing number of families affected by this issue, the challenges presented by autism should not be compounded by a lack of treatment options and financial fears. As insurance chairman, it is my hope that this bill will bring peace of mind to parents and a higher degree of care and hope for children on the autism spectrum," said Assemblyman Joseph Morelle (D-Irondequoit), Chair of the Assembly Insurance Committee.

"Providing care for a family member with autism should not result in a choice between financial hardship and access to medical assistance. Sadly, that has been the case for too long. This bill will ease some of those burdens. It is my hope that these

changes will result in better outcomes, improved quality of life and better access to vital services for families," said Assemblyman Harvey Weisenberg (D-Nassau).

Assemblyman Mark Schroeder (D-Buffalo) said, "Public awareness is growing about the prevalence of autism spectrum disorders, and with that awareness there is a rising demand that insurance companies recognize the obstacles presented by these disorders. Chairman Morelle's and Senator Breslin's bill is an initial step toward the parity these children and their families deserve."

"People often lament the political gridlock in Albany, but this legislation is an important reminder of what our elected officials can and will do to help New York's families," said Bob Wright, co-founder of Autism Speaks. "Families here and around the country are literally going broke trying to give children the therapies they need and deserve to meet their full potential. It's time that we eliminate this unfair burden and end insurers' blatant discrimination against children with autism in every state in America."

"The passage of S7000B is an important step toward coverage of evidence-based autism treatment for New York families who have historically been discriminated against by the very health plans to which they pay premiums," said Judith Ursitti, Autism Speaks regional director of state advocacy relations. "We thank Senator Breslin, in particular, for his commitment and leadership on this issue."

"The Autism Science Foundation is proud to support S7000B, which will enable thousands of New York families to receive the benefit of evidence based, clinically proven interventions and treatments

for autism spectrum disorders, like Applied Behavior Analysis therapy (ABA), as well as screening and diagnostic services" said Alison Singer, Westchester County resident and President of the Autism Science Foundation. "Research has shown that evidence-based intensive behavioral therapies like ABA can result in significant improvement in the cognition, communication and well-being of people with autism spectrum disorder."

"We enthusiastically support Senator Breslin and his colleagues in their efforts to bring equity in insurance coverage to children and adults who are challenged by autism and autism spectrum disorder," said Dr. Henry Schaeffer, Chair of the American Academy of Pediatrics, District II, New York State. "The more than 5,000 pediatricians across the state who provide health care to more than 4 million children stand with you in your work to assure that all children and families, no matter what their physical, psychological or intellectual challenges, can get the health care they need to live productive and healthy lives."

"The Asperger Syndrome and High Functioning Autism Association celebrates the New York State Senate's actions in passing S7000B and affording autistic individuals access to quality health care," said Patricia R. Schissel, LMSW, President, AHA Asperger Syndrome and High Functioning Autism Association (AHA) Inc. "We welcome the Senate's willingness to stand with us in our undying support of those whose lives have been touched by autism."

You can view the original press release on the New York State Senate website at <http://www.nysenate.gov/press-release/fighting-ensure-children-autism-receive-medical-care-they-deserve-senate-passes-landma>.

De-Stress, Not Distress

By Sharon L. Mosenkis and
Karen Sperling Greene
ASPEN Adult Issues North New Jersey

Living every day and night with someone with an autism spectrum disorder (ASD) can be extremely stressful. We know this, but we often don't know how to deal with that stress successfully and in a practical manner.

Below are some suggestions from many people who have had to deal with stressors similar to yours. These are not the recommendations of specialists but of ordinary people fighting the same battles that you are fighting to get through each day as best they can for themselves and their ASD loved ones.

The Secret to De-Stressing: Make and Take One Hour For Yourself Every Day

Block off at least one hour in your daily plan EVERY day. You must carve out a chunk of time for yourself not spent caring for others or dealing with other people's problems. At first this will take some advanced planning and will feel like a great inconvenience to organize. For example, you may need to find a babysitter or modify other scheduled activities, but your hour will soon become a very rewarding part of your daily routine. If

your hour is regularly used for you and you only, it will soon begin to feel as though you have saved your sanity. You will begin to have more patience to deal with the upsets and daily crises of life.

OK, where do you find this hour? One parent wrote that she sets priorities: "I ask myself: what's really important in this situation - today - this week? It helps to clarify my thoughts." So advanced planning can help you squeeze out your hour per day.

Ask for Help - Ask for help if you need it to make time for yourself. Widen the network of people whom you ask. Most of the people you know well will certainly understand why you'd need a break in your day. You'll be surprised at the number of people who will be glad to help.

Lower Your Standards!! - This could be housekeeping standards, but it could also be any tasks that would take less of your time if done adequately rather than as perfectly as you'd like. We all need to face the fact that ASD makes for messy lives. Don't waste time trying for perfection. We've got more crucial issues to deal with.

Ways to Use Your De-Stress Hour

Now that you have your precious hour, what will you do with it? Do whatever relaxes you and reinvigorates you the most. Do something that excites you. Have some fun. Try something new or try these suggestions:

Get Physical! - Many, many people have discovered that getting more active physically is the best de-stressor. Strange as it seems, even if you feel you are tired most of the time, you are likely to feel less tired, both mentally and physically, after some serious exercise. If you aren't sure what to do, take a class at a local gym, YMCA or community center. Push yourself at least a little. One father told me, "When I'm angry, I go out and walk as fast as I can and as far as I can. I really push myself and I come home feeling much better and the anger is gone."

As an alternative, yoga has become a very popular way to both relax and stretch your muscles. Again, yoga classes are available at community centers, adult education programs and YMCAs.

But physical activity doesn't have to be in a class or a gym. One mother of an ASD adult swears by the therapeutic value of gardening. To her, gardening is far more than the outdoor physical work of planting, weeding and watering. She says planning her garden, purchasing plants, and then planting them are all very relaxing and take her mind off other problems. And, after the gardening is done, she gets continued satisfaction from eating her own produce and herbs, and admiring the beautiful flowers that her "work" has created.

The point here is not just about exercise, but about finding an activity that takes your mind off your stress-related

problems and enables you to focus on something that is personally rewarding.

Meditate! Visualize! - Your mind may need a breather as much as your body. If it seems impossible to take your mind off the troubles in your life, you may want to try meditation or visualization - mental stress reducers. There are many inexpensive audio CDs, DVDs and iPod downloads to guide you in meditation and progressive relaxation techniques. Remember, of course, that just buying the audio program won't fix anything. These techniques take a little practice. That is what your hour is for. So find yourself a quiet, comfortable place to stretch out by yourself and listen.

Re-Evaluate the Company You Keep

Socialize with positive, enthusiastic people. Avoid complainers, blamers and whiners. Don't let yourself be worn down by the negativity of others.

"No" Can Be a Good Thing

Learn to say no to the countless demands that others try to make on your time. Be gracious but firm. Then change the subject quickly, so you don't leave time to be talked into doing something you don't have time for. If this makes

see *De-Stress* on page 32

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Rituals from page 10

Years later, Karen realized that this is probably what her mother did to gain her father's acceptance of these activities. Embracing her husband's love of baseball, which her son gravitated toward, made it easier for her to reciprocate and share with her husband the world of music.

So, too, can families with children on the autism spectrum cherish the rituals that are passed down from their families and modify them in meaningful ways. And if their child is unable to participate - due to behavioral or health challenges - new rituals can be developed to fortify the family life.

Ask yourself, "What's important to how I define my family? What have I lost and how can I restore it? What's missing from his family traditions?"

Ivy and Craig's decision to have a bar mitzvah for their son Sam, who is on the spectrum, was made with heartfelt conviction and equal uncertainty. The traditional Jewish ceremony marks the coming of age as a 13-year-old boy enters adulthood. After speaking to their Rabbi, the couple

found a teacher willing to work with Sam and modify the service. Sam loves music, so they used song to help him learn his Torah passages.

Sam's parents had their doubts. How would their son, who has significant behavioral and language challenges, get through the ceremony? But Sam also loves parties, so Ivy kept reinforcing that there would be a big celebration with music afterward with family and friends. Ivy thought this encouraged Sam to practice with her.

Ivy and Craig prepared themselves for the possibility that Sam could wake up in a bad way on his special day, and not be able to go through with the ceremony.

Sam was surrounded by his family and a few close friends at his temple for his bar mitzvah. By limiting distractions, his family thought Sam would feel less pressure in case he was having a difficult day. Ivy was thrilled that Sam was able to chant his passages from the Torah. As the service concluded, the Rabbi asked Sam if he was proud of himself. Sam, who does not usually answer questions directly, responded with a gleeful, "Yes!" - A moment that no one in the family will ever forget.

This truly was a cause for celebration. A big party followed attended by family, many friends and members of the community. There was food, music, and dancing and Sam had a great time. Ivy, Craig and all of their guests were so proud of Sam. It was deeply moving for them, and they were delighted that they were able to share such an important family ritual with their community.

Transitions in the family life cycle punctuate the end of certain developmental tasks and the beginning of new ones, and provide a safe passage from one life cycle stage to another. Van Gennep (1960) was the first to clearly indicate the function of transition rituals. He coined the term "rites of passage," and believed that all transition rituals have the same structure: a departure from one area, a crossing of boundaries, and an entry into another area.

Some parents with children on the spectrum are inclined to give up traditions because they feel they will have no meaning to their child. I believe these transition rituals offer structure and stability that serve as road maps during chaotic and uncertain times.

Jennifer's children would always go out to dinner the night before starting sleep away camp. "They always got to choose whatever they wanted for dinner," she recalled. "It was just how we did it."

That's what makes family rituals so important. They develop meaning over time. "It's a time for all of us to just be with each other during the chaos of preparing to leave for camp," Jennifer said. "It seems to lower our anxiety about leaving. We did this before and we are going to do this again, and we get to have a fun farewell even if we are anxious."

When these family activities are celebrated and looked forward to, they begin taking on special significance and become family lore. Once they take on meaning, that's when they become a cherished family ritual.

Dr. Richard Cohen, Ph.D. is Chief of Mental Health Services at YAI/National Institute for People with Disabilities' Center for Specialty Therapy. For more information about services available through the YAI Network, visit www.yai.org or call 1-866-2-YAI-LINK.

Law and Policy from page 25

to present their case first at a due process hearing and prove that the proposed program would provide educational benefit for the child. The parent would have to rebut the evidence produced by the school district or EI lead agency. It is far more challenging for parents to prove that the proposed program will not provide educational benefit for their child.

Indeed, this decision adds additional hurdles for parents of children with ASD seeking services. Since there is a paucity of ASD treatment research, and no research on intensity (the number of days and hours needed), parents are in a limited position to advocate for intensive services. For example, several courts have rejected parents seeking 40 hours a week of ABA for a young child with ASD finding that far less intensity of services will provide the child with "educational benefit."

Placement for a Child with ASD

The IDEA requires that students with disabilities be educated in the least restrictive environment (LRE). Many courts have held that a school district can only place children outside the regular classroom if education cannot be satisfactorily achieved even with the use of supplemental aids and supports. Yet, it seems clear that for children with ASD, the more services enumerated on the IEP, the more restrictive the setting. This conclusion has led some courts to develop the idea of a superior placement, holding that the needed services could only be provided in a separate school placement. These rulings could result in more children with ASD in more restrictive settings, producing fewer opportunities for interaction with non-disabled peers.

Reimbursement

Ironically, most of the cases decided in the last decade concerning services and placement for a child with ASD have occurred in the context of a reimbursement claim. The U.S. Supreme Court has held that the IDEA authorizes reimbursement of parents if the court determines that the private placement, rather than the placement proposed in the IEP, is appropriate. Courts have held that reimbursement can be appropriate even when parents move a child to a private placement without consent from school district, though it is at their own risk. These decisions give an advantage to wealthy families who can afford to take the risk of paying for private programs without a guarantee of reimbursement.

To obtain reimbursement, a court must evaluate the sufficiency of the proposed IEP. If the IEP is insufficient, courts have been flexible in accepting various placements by parents. Courts have emphasized equitable considerations in determining not only if the private placement is appropriate, but if the parent has been cooperative.

Insurance

Children and adults with ASD have long had problems with insurance coverage. Often, insurance companies have denied benefits because of pre-existing conditions, the services requested are deemed experimental, not restorative or are special education related services. The 2010 Health Care Reform law will alleviate some of these problems. Insurance companies are required immediately to cover all children with pre-existing conditions such as ASD and adults will be fully covered by 2014. The

new law also will cover "behavioral health treatments" that are medically necessary and evidence-based, such as ABA, as part of the essential benefits package. States retain oversight of insurance programs in their states. Thus, the many state laws recently passed to address insurance issues for people with ASD remain significant.

A growing number of states have passed laws to ensure that insurance companies cover medically necessary diagnosis and treatment of ASD. Unfortunately, many of those state laws contain age restrictions - limiting the coverage to children under a certain age - and insurance spending cap. Few cover adults. This is problematic since most children can receive services under the IDEA while adults have no such entitlement. Some state laws contain important innovations. New Jersey, for example, has specific language prohibiting denial of coverage for services that are not restorative or are educational. It is critical that insurance reform legislation meet the needs of people with ASD—no age limitations or caps and specific language allowing an array of treatments.

Conclusion

The law has created enormous hurdles for parents seeking services for their children with ASD. While in the last ten years alone over 700 cases have been litigated in courts (thousands of additional cases went to due process hearings) involving ASD and IDEA, it is unclear whether litigation is the right route to vindicate children's rights or to develop new services. Additionally, as most litigation has been brought in the context of reimbursement, it has raised serious ethical questions about the unfair advantage of wealthy families. Instead, legislation has been a far more

productive route. Of course, the new federal Health Care Reform law clearly illustrates this strategy. Additionally, state legislation has not only addressed issues of insurance coverage but has reversed adverse IDEA law. For example, a Michigan statute requires that an IEP be designed to address the "maximum potential" of a child with ASD. In New Jersey and New York (except in tuition reimbursement cases) state legislation reconfigures the burden of proof, placing it back on school districts and EI lead agencies thereby enhancing parents' chances of prevailing in a due process or court appeal. It is imperative that organizations and parents analyze prospective legislative proposals to make sure they are fair to all and that parents bring litigation only as a last resort, with concern for the ramifications for others. Without a broad view of the needs of the entire ASD community, law may hinder development of new services and new rights.

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

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De-Stress from page 31

you feel somewhat guilty, remind yourself that you have a greater responsibility to be strong and energized to deal in the best possible way with your ASD situation.

Turn Down the Volume of the Outside World

Turn off the news for a while. It is nearly always negative. You will be surprised at how much more peaceful you will feel, and you may find that you are better able to focus. If there is a lot of loud television or radio in your environment, try to turn that down as well. You may feel more peaceful and the ASD person in your life may appreciate a break from the noise as well.

Treat Your Body Better

To achieve your maximum effective-

ness and stress reduction, take a realistic look at what you eat and drink. If you consume a lot of caffeine, alcoholic beverages or sugars, consider gradually reducing these items in your diet. Although foods and drinks with these ingredients may feel comforting or energy-boosting for the moment, they may be hurting your overall well-being, focus, and energy level over the long run. So cutting back in these areas may help you be more effective in all aspects of your life as well as help you be healthier.

Live and Let Live

Life with a loved one on the spectrum can be frustrating. You may not like the way they dress or tackle projects. Rather than letting them do things for themselves, you may either criticize their appearance or decisions or do their tasks yourself to make sure they are done prop-

erly. Take a step back and ask yourself if that is the best approach. Perhaps you need to loosen the reins, be a bit less critical, laugh more and try to appreciate your loved one for the person that he or she is, rather than the person they're not. Don't fall into the nagging and disappointment rut. Make a list of your loved one's unique attributes and remember to appreciate those strong points, celebrate the positives, and live and let live.

Support Groups

Look for ASD support groups in your area. These groups are great places to find suggestions of practical ways to handle some of our most stressful problems; emotional, educational, financial, medical and many more. In the right support group you will find people who truly understand what you are going through. Often members of these groups will be able to help

you come up with solutions to problems you didn't think could be solved, or they can just listen and provide a shoulder to lean on. It can be a great comfort to know that you are not alone. If the first group you try is not the right one for you, visit other groups until you find one that feels like home.

There are certainly many more ways to de-stress than we have discussed above. What helps you to calm down? What do you recommend to other ASD families and caregivers? What do you do to prevent stresses from wearing you down? Email dminot@mhnews.org to share your ideas to help other ASD families.

Sharon L. Mosenkis is a Parent and a Steering Committee Member of the ASPEN® Adult Issues North in New Jersey. Karen Sperling Greene is a Family Member and Partner in Sperlinggreene PR and Marketing in New York City.

Coping from page 23

Michael Buffa, Vice-President of AHA, and his wife Carol are both at-

torneys and co-wrote this article. The Asperger Syndrome and High Functioning Autism Association (AHA) is a well established parent and profes-

sional support and education organization based in New York serving the autism community nationwide through our hotline, website (www.ahany.org),

listserv and conferences. The majority of the members of the board of directors have a family member on the autism spectrum.

Interview from page 1

A: The simple answer is 'absolutely.' People often ask the question, "What has changed that Pfizer would begin research into autism treatment?" At the forefront has been advancements in our understanding of the human genetics underlying risk. We have known that autism is among the most heritable neuropsychiatric disorders out there, and a steady flow of large genetic studies in recent years have helped to reveal quite a number of well replicated findings implicating specific genes underlying risk in certain subsets of patients. These are valuable clues to enable research into novel therapeutics. For example, we have been able to translate key genetic findings in humans back into the laboratory through the development of novel animal models that can be used in drug discovery. Research is also being enabled by investigating rare syndromes of monogenic origin that have high rates of autism co-morbidity like Fragile X Syndrome, Tubular Sclerosis, and Rett's Syndrome. By investigating possible commonalities in biology across these genetically defined patient groups, we may uncover important clues that inform our development of treatments for the larger idiopathic Autism.

Q: What are some of the challenges in the process of developing new pharmaceutical agents?

A: As I frequently tell folks in our organization, "There is no roadmap for what we are about to do," as we move forward with the development of medicines for



Robert H. Ring, PhD

autism. Every step we take forward, whether it involves the design of basic experimental strategy or discussions with regulatory agencies is charting a new path, one that will undoubtedly shape how other companies will follow. That is both challenging and exciting. From a personal and professional perspective, I couldn't be happier working for a company like Pfizer that is willing to lead into a new field rather than follow. Specifically, in the near term we are faced with a number of challenges. We need to work with external experts to reach consensus on what are

the most tractable symptoms for us to target given the available science. For example, if I was to go to a room of physicians, parents, or caregivers, and ask, "If we could take one shot at developing a drug today, what specific symptom(s) should we target to bring the greatest benefit to the most patients today? (And it would be a target that the FDA would recognize and approve a label for). Would it be anxiety symptoms in autism, would it be reversal of social deficits in autism, what would it be?" It is not clear that there is a real consensus out there to help establish priorities for the field. We know that there is an unmet need, but in order to align our research, we need to understand which clinical targets represent the best match of feasibility and impact to the population of individuals with autism spectrum disorders. So understanding what the physicians and caregivers believe are the most important areas to address will be essential for us in defining what we need to be doing. We also face challenges with how to design clinical trials that accurately measure benefit of experimental drugs to patients and understanding the regulatory paths that must be paved to bring completely new classes of drugs to market. At the end of the day we also are acutely aware that we proceed forward with a clear strategy that also ensures we return value to the investment made by our shareholders.

Q: What are the Pfizer Autism Research Unit's primary goals and expectations?

A: Our primary goal is the discovery and development of medicines that improve the

quality of life for patients with autism spectrum disorders and their caregivers. At the end of the day, we will succeed if we can translate the basic research into therapeutics that address core symptoms such as social deficits and repetitive behaviors, but also recognize the benefit of bringing forward agents that specifically address associated symptoms like anxiety, attention, irritability - anything that causes disability to these patients or interferes with the success of behavioral therapies, etc.

Q: Will the Pfizer Autism Research Unit be working together with the autism community and any outside government agencies?

A: Absolutely. There is very intense interest in what we are doing at Pfizer from the external autism community, whether from parents who stop you on the street to talk to you about what Pfizer is doing to more formal participation in open forums, we come to understand some of the basic needs of patients and challenges that face the community. I have been enormously encouraged by the excitement and support we have received from parents who have been very eager to understand more about what we are trying to do. There is also no shortage of interest from experts such as physicians and scientific researchers who are eager to work with us to help us advance our efforts towards the clinic.

Clearly one key part of our strategy for success is to build collaborative networks of partners on the outside. I can't just reach out to the pharmaceutical industry and pull out an expert in autism because

see Interview on page 39

Genetic Test from page 8

genetic testing in 2006, 2007 and 2008.

Half were Children's Hospital Boston patients who had their samples submitted to the hospital's DNA Diagnostic Laboratory, and the others were recruited through the Autism Consortium, a research and clinical collaboration of five Boston-area medical centers. Nearly half of the patients were diagnosed with autistic disorder, nearly half with PDD-NOS (pervasive developmental disorder - not otherwise specified) and about 3 percent with Asperger Syndrome. Ages ranged from 13 months to 22 years.

Testing included the two currently used tests (G-banded karyotype and fragile X), as well as CMA. When the researchers compared the tests' diagnostic yield, they found:

- Karyotyping yielded abnormal results in 2.23 percent of patients
- Fragile X testing was abnormal in 0.46 percent
- CMA results were judged to be abnormal in 7.3 percent of patients when the entire length of the chromosomes (the whole genome) was sampled

Extrapolating from these results, the researchers estimate that without CMA, genetic diagnosis will be missed in at least 5 percent of ASD cases. CMA performed best in certain subgroups, such as girls with autistic disorder, and past studies indicate that it also has a higher yield in patients

with intellectual disability (who constituted only 12 percent of this sample).

"CMA clearly detects more abnormalities than other genetic tests that have been the standard of care for many years," says Miller. "We're hoping this evidence will convince insurance companies to cover this testing universally."

In all, roughly 15 percent of people with autism have a known genetic cause. Establishing a clear genetic diagnosis helps families obtain early intervention and services for autism, and helps parents predict the possibility of having another child with autism.

In addition, by pinpointing bits of chromosomes that are deleted or duplicated, CMA can help researchers zero in on specific causative genes within that stretch of DNA. They can also begin to classify patients according to the type of deletion or duplication they have, and try to find specific treatment approaches for each sub-type of autism.

"Just in the last two years, a number of studies have revealed the clinical importance of ever smaller chromosome deletions and duplications found with advanced microarray technology," says Wu. "These new, highly-efficient tests can help in the evaluation or confirmation of autism spectrum disorders and other developmental disorders, leading to early diagnosis and intervention and a significantly improved developmental outcome."

Two known chromosome locations - on chromosome 16 (16p11.2) and chromosome 15 (15q13.2q13.3) accounted for 17 percent of abnormal CMA findings.

Both chromosome abnormalities were initially linked with ASDs by Children's Hospital Boston and collaborators in *The New England Journal of Medicine* and *the Journal of Medical Genetics*, respectively, in 2008. Children's Hospital Boston now offers specific tests targeting both of these "hot spots."

However, the researchers note that most copy-number changes were unique or identified in only a small number of patients, so their implications need further study. Many of them are presumed to be related to ASDs because they involve important genes, cover a large region of the chromosome, or because the child is the first person in that family to have the change.

"Some deletions and duplications are rare and specific to one individual or one family," says Miller. "Learning about them is going to be an evolving process. There won't be one single test that finds all genetic changes related to autism until we completely understand the entire genome."

The paper's co-first authors were Autism Consortium members Yiping Shen, PhD, of Children's Department of Laboratory Medicine and the Center for Human Genetic Research at Massachusetts General Hospital, and Kira Dies, ScM, LGC, of the Family Research Network of the Autism Consortium and Children's Multi-Disciplinary Tuberous Sclerosis Program. A number of specialists from Children's Departments of Neurology, Developmental Medicine and Clinical Genetics and physicians from other medical centers in greater Boston were also authors on the study. The research was

supported by the Nancy Lurie Marks Family Foundation, the Simons Foundation, Autism Speaks and the National Institutes of Health.

Families interested in scheduling an appointment at Children's Hospital Boston may call the Developmental Medicine Center (617-355-7025) or the Department of Neurology (617-355-2711).

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Children's Hospital Boston is home to the world's largest research enterprise based at a pediatric medical center, where its discoveries have benefited both children and adults since 1869. More than 500 scientists, including eight members of the National Academy of Sciences, 13 members of the Institute of Medicine and 12 members of the Howard Hughes Medical Institute comprise Children's research community. Founded as a 20-bed hospital for children, Children's Hospital Boston today is a 396-bed comprehensive center for pediatric and adolescent health care grounded in the values of excellence in patient care and sensitivity to the complex needs and diversity of children and families. Children's also is the primary pediatric teaching affiliate of Harvard Medical School. For more information about the hospital and its research visit: www.childrenshospital.org/newsroom.

Cope With Stress from page 1

stage may be repeated during different phases of your child's development but I would say at the time of diagnosis you will feel this most acutely. There is a sense of alarm at the unknown of the future for your child and your family. You may find yourself on hyper-speed trying to get as much information as possible. There are many life altering discussions suddenly foisted upon you and the feeling that no matter how early you may have received this diagnosis...it may not have been early enough. You are constantly feeling behind the eight ball in terms of making those therapeutic, medical and educational decisions. Much of this is done without the support of other families who have gone through this before.

In this next phase called *resistance*, you may find yourself second guessing what you have put in place. Those necessary coping mechanisms will be your saving grace. I can guarantee the stressor will persist as there is currently no cure for autism and our resilience will be called into action over and over again.

Lastly *exhaustion*: In the Wikipedia model this stage sounds dire. I think we should work on the second stage and define those essential coping strategies so the last stage of exhaustion can be kept at bay. Yes, there will be times when all of the complexities we must maneuver through will get the better of us. Yes, there will be times when we feel overwhelmed by the scope of the diagnosis, but with strategies in place for ourselves and our family, we can navigate successfully through an undoubtedly complex field of life challenges an autism diagnosis presents to us.

Oftentimes the real burden of this diagnosis falls to the Mom caregiver. I mean no disrespect to the Dads out there who I am calling on to be present in every aspect of your new normal called autism. The reality, however, is that much of the research into, and ultimate program or therapeutic and medical decision making, will fall on the shoulders of our Mom caregivers. You may find yourself feeling like the warrior superpower Mom one day and the guilt ridden martyr Mom the next. When things are going well and you observe progress you are the warrior superpower Mom. When things seem derailed and you are not seeing progress or, worse, there is a new behavior and a loss of skill, you are the martyr Mom. What did I do? What didn't I do? What didn't I do enough? Did I make the right decisions and choices? Is there something new out there I should try? If I try something new, will it help or harm? Whom do I trust to help me make these difficult decisions?

Peer Support

First and foremost find a network of supportive peers you can bounce ideas off of and commiserate with when those difficult days become overwhelming. I have found that as time goes on you may discover that your peer group will change.

These relationships in your life are so vital that your friends who do not have an affected child may not be the ones you can rely on for your support. Even those peers who have a child with autism may change. If for instance your child is on a different educational trajectory, or you or your peer are at odds in your therapeutic approaches, you may find yourself needing peers who follow in the same circles both educationally and therapeutically. Having friends who are truly walking in your shoes is so important. An example of my own experience happened early on upon the path of autism. My son had a particularly brutal day filled with numerous bouts of tantrum activity filled with self-hitting and head banging. He was three and one half year old at the time. I had just gotten him down to sleep, by rocking him cradled in my arms with a blanket wrapped tightly around his flailing body to keep his arms contained.

I was scratched, bruised and exhausted. I received an urgent call from a dear friend. She was distraught and needed to talk about her day. Though I was tired, I called her to find out what was going on. She related the story of how distressed, to the point of tears, she was that her daughter had not made the cheerleading squad and what an emotional and social tragedy this was for the poor child. How was she ever going to cope with the fallout?

Though I was thoughtful in my response I could not put myself into her shoes, and she most assuredly could not put herself into mine. I found that it was vital to my self-preservation to surround myself with empathic sounding boards for the many difficult times ahead. Do not think for one moment, however, that I am the bearer of doom and gloom. I am endlessly practical. I will not sugar coat the family impact this diagnosis will have. The impact is great and lifelong. But also know, along with the difficult times there are potentially countless times of great elation at the hard won progress against insurmountable odds. I needed that encouragement and shared delight when my son made those incremental achievements which were to us herculean strides forward. It is all about the perspective. Sharing the joy is as important as sharing the pain. There is great joy and love and beauty in autism. Sometimes the price to be extracted between those times of beauty and joy may be high. Never doubt, however, that there is always great love.

Family Awareness

Make everyone in your family aware of what you are going through. Do not be apologetic at family get-togethers. Ensure that you are accommodated and welcome. You will be welcome if you are open and concrete in what they can expect from your visits and encounters. The term autism is derived from the Greek term 'autos', meaning aloneness. There are so many times when the isolation of autism will surround you. Do not isolate yourself from those who can truly support you:

your family. But to make this experience a positive one, you must educate them on how they can be a support to you. You may need to limit the time of your visits. You may need to prepare your family for the often counter-intuitive behaviors which are often present with autism. You must get them on board to your chosen therapeutic and educational treatment methodologies so everyone is on the same page when there are encounters together.

Educate Yourself

Educate yourself as much as you can. Learn the law and let that be a guide to receiving the recourses which are your child's and your family's right to receive. Again, do not be apologetic for seeking services. You need them. Your child needs them and they are your right under the law. We are ultimately consumers of the services we use. Those services may be health related, therapeutic or educational. Be an educated consumer!

Organization is Essential

Another vital strategy in the planning of autism is organization. With the amount of evaluations and testing for school programs alone you may very well find yourself overwhelmed by the onslaught of paper from evaluations and reports. There are needs assessments and speech evaluations, plus Occupational Therapy reports and Psychological testing of many sorts and description. There are medical evaluations and study team reports. The list is endless. Create an organized filing system. I would encourage you to have a filing cabinet with an entire drawer devoted to autism. If you do not have a filing cabinet, I would at minimum have two expandable legal files. I want you to make sure you have at least two copies of all evaluations and reports organized in an easy to access place. You may want to organize these folders sequentially by year.

Start each year with the IEP, or Individualized Education Plan. Your child will have one if he or she is receiving special education services through the school system. Most of our children with a diagnosis of autism spectrum disorders (ASD) will be found eligible for special education services and have an IEP. A child over three years of age who is found to be eligible for this service will have a plan. I am amazed at how many families do not read and review this document. The IEP is often the most important document about your child in your possession and one which you have the most influence over. If you have not done so, take it out and read it cover to cover. You must understand everything that is written inside. If you do not, you must ask for an explanation! The school's obligation to you and your child is to educate your child. No more, no less. How that will be done is delineated in that document. Progress is monitored and reported. If you do not know what the school is expected to teach your child or how that will be ac-

complished, how will you ever know if they are meeting their obligations?

The more organized you are, the more effective you will be in advocating for your child. There may be a lot of chaos in your world as you traverse through this path. The more organized you are the easier your life will be. If you are an unorganized individual this may be challenging, but I implore you to give this a try. This can bleed over into other aspects of your life. Having an organized home and an agreed upon schedule for your child's daytime and evening routine can reduce the chaos and stress at the end of the day. Believe me when I tell you, implementing these types of strategies into your life can have a positive impact on everyone. There are so many times you will feel powerless over this, yet if you are organized and structured in your environment you can carve out at least a small area of control into your life.

Remember to Take Care of Yourself

The other important piece of the coping with stress puzzle is **self care**. It is very easy and even compelling for us to put ourselves last. With all there is to do and to learn and to know that is understandable. I cannot overstate the obvious. If you are not taking optimal care of yourself you cannot be optimally effective in caring for your child. Do not put off your well doctor visits. When was your last visit to the Gynecologist? Are you up to date with your mammogram? At the end of a very stressful day do you go for the box of chocolates and a glass of wine or a brisk walk around the block to clear your head? Both, I think may be effective. The key here is balance. Are you using healthy food to fuel your system? Are you using unhealthy food to help you cope?

Making healthy choices for ourselves is so important to how we feel and cope with the stress of raising a child with autism, in all its manifold incarnations.

Being proactive in the creation and implementation of strategies will put the power and control back into your life, when so much of what is autism may seem so out of your control. Autism may be the new normal, but how we cope with the stress will be the difference in how we perceive what can be a wondrous journey of discovery about our children and ourselves.

As a final note, my son is now seventeen and entering his senior year in high school. We are currently searching for the four year university that will meet his needs and his goals. He is interested in a communications major. There is assuredly some irony in that.

Take good care with my best wishes for you and your child's success.

B. Madeleine Goldfarb, MA serves as the Director of Outreach and Education for The Autism Center, New Jersey Medical School / University of Medicine and Dentistry of New Jersey. You may contact Ms. Goldfarb at goldfabm@umdnj.edu.

Genetic Mechanisms from page 12

The results appeared in the June 10th issue of Nature.

For more information about Mount Sinai's Seaver Autism Center, please call 212-241-9061, Email: theseavercenter@mssm.edu, or visit: www.seaverautismcenter.org.

Dr. Joseph D. Buxbaum, PhD, is Director at the Seaver Autism Center for Research and Treatment and the G. Harold and Leila Y. Mathers Professor at the

Departments of Psychiatry, Neuroscience, and Genetics and Genomic Sciences at Mount Sinai School of Medicine in New York.

Transition from page 19

yoga (Bower et al, 2005), and meditation (Goldin & Gross, 2010) - all of which have well documented research supporting their use to relieve stress and anxiety. Stress and anxiety can also be managed through exercise programs. Physical exercise increases general cardiac health (Fletcher et al, 1996), reduces the risk of obesity, diabetes, and certain cancers (Rundle, 2010), but also increases the body's production of natural analgesics known as endorphins (Steinberg & Sykes,

2002) and also decreases the production of stress related hormones, namely cortisol (Thuma et al, 1995). Consequently, the individual who exercises decreases his or her stress naturally without the aid of medications. Although organized team sports may not be an idea form of exercise for individuals on the spectrum, using a pedometer and walking 10,000 steps a day may be an excellent way to teach individuals with ASDs to incorporate exercise into a healthy lifestyle (VanBergeijk, 2009).

A final way to reduce the stress associated with the transition to a post second-

dary environment is to identify programs that will work with the student's existing support network. Some college-based transitional programs work with the parents and other caregivers to ease the transition into the world of independence. Through the use of release forms and team meetings, the programs work with family members, therapists, doctors, and psychiatrists to alleviate the student's and family's stress and anxiety.

The transition to post secondary education can be stressful, but it does not need to be a crisis-producing event for the family

of a child with an ASD. By planning ahead, giving the person with an ASD opportunities to practice independence and preview programs, and identifying programs that incorporate research-based stress and anxiety management techniques, the transition to life after high school can be well managed and relatively stress free.

Dr. Ernst VanBergeijk, Ernst O. VanBergeijk, PhD, MSW is the Associate Dean and Executive Director of New York Institute of Technology's Vocational Independence Program.

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Overstimulation from page 20

Many Aspies' intellectual lives are dominated by an inability to focus on what matters - a product of our infamous weak central coherence. Poor executive functioning only confounds the problem. Aspies struggle with prioritizing and organizing in every realm - taking notes at school, structuring projects at work, sorting papers at home. The average neurotypical would not memorize textbook page numbers when studying for an exam. But Aspies must filter and classify masses of information with a flawed sieve and faulty grid - a perpetually exhausting and overstimulating task.

I would speculate that many Aspies' intense interest in one or two topics, and the narrowness of focus for which we are both renowned and notorious, may be unconscious efforts to regulate intellectual OS by engaging deeply with material that need not be prioritized or structured very much. I certainly find evolutionary genetics refreshingly straightforward - and not at all overstimulating!

Social Overstimulation

Social OS is actually a composite of intellectual, emotional, and sensory OS. Social interactions are rife with rapid exchanges of verbal (intellectual) information, ever-shifting nonverbal (emotional) messages, and the sensory experiences of close-up bodies, loud voices, and the occasional mandatory hug.

The multimodal nature of social intercourse makes it supremely challenging for Aspies. There is so much to process at once - and it all moves so quickly! Interactions

that flow intuitively for most neurotypicals can leave Aspies feeling breathless and stunned. Little wonder we sometimes say the wrong thing. Often what I most need to say is, "Slow down! Wait for me!"

Managing Overstimulation

There is currently no reliable medical treatment for OS. Nonetheless, some Aspies may be pleasantly surprised to discover how much calmer they could be by leading deliberately low-stimulation lives.

Simplify - To simplify, à la Thoreau, means to strip life down to its absolute pleasures - and absolute necessities. Aspies, who are highly stimulated by almost everything, will never enjoy low stress unless we learn to avoid the avoidable.

There is usually no good reason for an Aspie to go to an amusement park, attend a wild party, watch a horror movie, or take on an extra-heavy course load if these activities cause OS.

Aspies need not compare ourselves to neurotypicals in these areas. Neurotypicals seek out more stimulation because their baseline arousal is lower.

To reduce the overstimulating activity of staying organized (or dealing with clutter!), I keep my apartment empty of all but the essentials. My home is a "low stimulation zone." I also try to simplify my life by maintaining a regular (yet modest) weekly schedule for social obligations, fun, self care, and home care.

Plan Everything - Aspies get overwhelmed by surprises and spontaneity. One powerful antidote to OS, then, is to plan ahead whenever possible.

Planning ahead means scheduling appointments and engagements well in advance and balancing our calendars so there is never too much stimulation in a given day - or week. It means tracking our activities as well as our moods and knowing when we need to cancel, to throw in the towel and rest.

Planning ahead also means that when Aspies cannot, or choose not to, avoid something sure to be overstimulating, we set aside time before and after the event to "destimulate." Adequate down time is essential surrounding any stressful event - whether it is unpleasant but necessary (a root canal) or highly pleasurable (a successful date).

Be Proactive - When we do purposely engage in highly stimulating activities, Aspies can often reduce OS by respectfully asking for what we need.

In a society becoming increasingly sensitive to the needs of Aspies, a polite proactive Aspie can wield a good deal of power. We can ask others to speak more quietly, turn down the music, not touch us, or give us more space (reduce sensory OS). We can ask for ideas to be repeated or clarified, instructions written down, or tasks broken into steps (reduce intellectual OS). We can ask to change the subject of a depressing conversation (reduce emotional OS) or politely excuse ourselves for a few minutes at a social gathering (reduce social OS).

Where sensory OS is involved, Aspies can also use physical measures to protect the senses - sun glasses, ear plugs or headphones, soft dress clothes for a party. A concise explanation will soon orient anyone who might be per-

plexed by an Aspie's use of these items.

Stay Healthy - Caring for our bodies by eating well, exercising, and getting sufficient rest and sleep also keeps our brains fit. Poor overall health or even just missing a meal reduces our thresholds for stimulation.

I have found that my body and mind are far less readily flooded after rigorous exercise. Indeed, if I did not exercise regularly, I feel I would drown in the treacherous waters of my own mind.

Be Patient - The novelty of the world is part of what makes life overstimulating for young Aspies. Our tolerance for stimulation generally increases as we grow older. Aspies graduate from surviving to thriving as we adjust to life's surprises - and discover new ways to turn down the volume of the world.

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Nomi Kaim was diagnosed with Asperger Syndrome at age 20 and currently volunteers at the Asperger's Association of New England (AANE) in Watertown, MA, where she is a member. Nomi has spoken about her experiences with Asperger Syndrome at conferences, workshops, and schools. For a DVD of Nomi's recent presentation, "Anxiously Alive," at the March 2010 "Anxiety and Asperger's" conference in Cambridge, MA, go to www.aane.org.

Grandparents from page 18

their relationship with their grandchild and adult children. Grandparents can be educated themselves through books, publications, internet resources, workshops and interactions with other grandparents.

Include Grandparents in the Conversation - Because grandparents are learning about ASD along with the family, it is important to make them a part of the conversation. Many grandparents want to be involved in this process; others may be more reluctant due to their fears and concerns. However, it is essential to encourage conversations that increase their understanding of their grandchild, provide needed support to their adult children and empower them to be part of this process.

As parents learn the language of ASD (i.e. ABA, RDI, etc.), they should be encouraged to include grandparents, either by having them attend doctor's appointments, school-based and other evaluations, support groups, and grandchildren's treatment and therapies. Sharing evaluations and reports with grandparents is another helpful way to increase their participation in the "ASD conversation."

Recognize Their New Role and Unique Experience - Because this is a stressful experience for all, grandparents may be hesitant share some of their concerns and fears about their new role and experience. Families can be supportive to grandparents by discussing these changes with them as well as taking an active role to educate, demonstrate, and involve grandparents. Also, Grandparent Support Groups provide the opportunity to be heard, to safely express feelings, and to learn that they are not

alone. In the support group offered by the WJCS Autism Family Center, grandparents of different aged grandchildren with different forms of autism and with varying levels of involvement are able to come together to share joys and triumphs as well as challenges and difficulties. The grandparents are supportive of each other, learn from one another, and provide hope and solace.

Acknowledging Grandparents' Grief - While much has been written on how parents grieve the loss of "normalcy" with a child who has autism, less attention has been paid to the loss of dreams and hopes grandparents have for their grandchild. In some ways, the grief of a grandparent can be even more complicated as it applies not only to their grandchild but also to the adult child. Some grandparents may not allow themselves to grieve because of their need to provide a supportive role to their adult children. Others may feel that they cannot grieve if the child's parents are choosing not to acknowledge or experience their own grief. Grandparents should be encouraged to express their feelings to extended family members (if possible), to seek professional help, or to attend a support group designed specifically to address their needs.

Ways That Grandparents Can Support Families

Draw Upon Grandparents' Experience - As part of the life cycle, most grandparents hope to guide their adult children as they navigate through their own parenthood. Though parenting a child diagnosed with ASD is a unique experience, there still may be common themes of experience that can be helpful for grandparents

to share. At some points, all parents have struggled with their children. The lessons learned from these struggles still have value whether or not the child's difficulties were related to ASD. Parents and professionals should encourage grandparents to share these experiences and lessons as a way of supporting their family.

Use Grandparents as Supports Inside the Family - With the right tools, grandparents can be an excellent source of respite for parents and are often willing providers. Grandparents can also be an excellent support within the extended family. Families often talk about the difficulties of attending family events because other family members lack understanding of the issues. Grandparents can be excellent educators and advocates. Prior to a family occasion, they might be able to advise about special diets, certain behaviors, and other relevant information that could ease tensions. They can impart knowledge when their adult children are reluctant or too exhausted to do so themselves.

Use Grandparents as Supports Outside the Family - Grandparents attending doctor's appointments, meetings, evaluations, and therapies can be helpful in multiple ways. They represent an extra set of hands and ears in case parents become overwhelmed. They may also be able to contribute thoughts and ideas that others may not have suggested. Their participation in therapies and treatments allow them to learn and use some of the techniques and skills taught, thus providing continuity of care for their grandchild. Grandparents can also be a support in social events. By having a sense of their grandchild's behavior in these situations, they can be relied on if

a child is having a difficult time.

Conclusion

In a recent support group meeting, grandparents came together and caringly asked each other for updates on their grandchildren. One asked another, "How was that appointment for your granddaughter?" Another asked, "How is your grandson doing in his new school?" The conversation continued as all members gave their updates and everyone listened attentively. Eventually, one grandmother told of her 4-year old grandchild who had recently strung together three words to ask for chocolate pudding. The group rejoiced in hearing the progress her grandchild had made, sharing the experience as if it were their own and providing understanding, support, and suggestions.

Agencies and non-profit organizations should be encouraged to create support groups for grandparents. The ability of such groups to support, acknowledge and empower grandparents is enormous. Monthly groups offer stability, a lynchpin for grandparents to grab onto and a valuable sense of community with others who share a common experience. The groups can impart a sense that the world they have been thrust into need not be frightening or gloomy and that there can be much to celebrate in the uniqueness that autism brings.

Bonnie Graham, LMSW is the Program Director at the WJCS Autism Family Center in White Plains, NY. For more information on the Autism Family Center's monthly Grandparent Support Group, you can contact Bonnie at 914-761-0600 extension 228 or by email at bgraham@wjcs.com.

Support Groups from page 26

helping their children progress. However, the purpose and focus of these types of groups differ dramatically from that of a traditional support group. The traditional support group is designed to encourage members to openly and honestly discuss the difficult issues that they are struggling with in their daily lives. Members try to help other group members by offering their own suggestions, insights, and empathy regarding each other's problems. There are issues of confidentiality in the traditional support group which are vital in helping the group members bond and feel secure within the group setting. However, problems can arise when members come to a group seeking the emotional help of a traditional support group and are met with discussions of diets, supplements, therapies etc. Conversely, parents can feel frustrated and alienated if they are specifically looking for concrete information in order to help their child and are then asked to talk about the daily pain and stress of raising their children on the spectrum. Both types of groups are valuable, but they obviously offer different benefits.

Potential support group members should be told exactly what kind of group is being offered right from the beginning. This way, members will know what they can expect from the group beforehand and decide whether or not they want to join. Group leaders must be very diligent in trying to maintain the group's focus. If the group is a traditional support group, then the leader must keep discussions geared

towards helping members express and label their difficult thoughts and feelings. Group leaders must also model behavior that facilitates empathy and understanding among its group members. Finally, leaders must try not to let the topics of discussion stray or detract from the goals that the group is trying to achieve.

A second strategy in trying to minimize some of the problems that arise in an autism support group is to try to make the group as homogeneous as possible. In other words, the group members' children should be at similar levels of functioning. For example, parents who have high functioning children with Asperger's Syndrome should have their own designated groups. Children with Asperger's Syndrome have very different developmental issues and problems than children functioning at the lower end of the spectrum. Parents will be able to relate more to other members if their children are functioning at similar levels developmentally. Thus, members would be more open to both sharing their thoughts and experiences regarding their children's disabilities, as well as receiving support and help from other members. A stronger, more viable group identity could evolve if the members felt that their problems and circumstances were more related to other members in the group.

Another means of creating a more homogeneous group is to structure the groups not only by the children's levels of functioning, but also by their ages. Teenage children with autism have very different needs and issues than pre-school and elementary school age children with au-

tism. Parents with newly diagnosed children benefit enormously from contact with other parents whose children have also just been identified as having ASD. These differences in ages and issues of children with autism need to be handled in separate groups in order to offer the most appropriate support to each of the members. As mentioned earlier, parents with children on the spectrum have a difficult time finding appropriate childcare. Offering some type of childcare during a support group would make it a lot easier for parents to attend meetings.

Parents may sometimes be reluctant to even attend a support group at all. Parents may feel like they can handle the problems all by themselves or find their own answers. After their child receives a diagnosis, parents may still be in a state of shock or denial. They may also be in too much pain to talk about their child's disability with strangers. One solution that our organization has developed to assist in this above problem is to offer a monthly "Family Day" event. Family Day offers children on the spectrum, their parents, siblings, grandparents, etc. an opportunity to play, enjoy arts and crafts, listen to music and enjoy refreshments. The children are supervised and the play is facilitated by a team of trained childcare personnel. The childcare allows parents the opportunity to meet with other parents to socialize, network and share common experiences. Family Day provides an enjoyable and informal opportunity for parents to get an idea of the kind of help and support that is available to them and their child through

the interactions with other parents. Often, parents will then decide to join a parent support group because of the positive experience they had speaking to other parents who are "in the same boat."

In summary, we have discussed how autism support groups can offer invaluable assistance to parents struggling with raising children on the Spectrum. We have explored the difficulties and complications that arise within the traditional autism support group. We have offered solutions and suggestions that can minimize and resolve some of the problems that emerge from running a group for parents with children on the spectrum. Finally, it is important to mention that ASD affects every member of the family. This disability will affect a parent's work, marriage, financial resources and basically all aspects of an entire family's life. Whether a child is high functioning, moderate or low functioning, parents and siblings need as much support and assistance they can obtain. Parents and siblings need to recognize and properly manage the chronic stress they are under in caring for their loved one with autism. The entire family needs to find ways to relieve this stress so they can not only feel better themselves, but also be better able to give the best possible care to their child with autism. The more support and help the families can obtain for themselves, the greater the quality of life will be for both themselves and their child on the spectrum.

Lenore Powers, MA, BAC is a family counselor at Parent's Place, a program of the Guidance Center of New York.

Believe from page 24

trying to find my own rhythm, and the Dairy Queen Blizzard I enjoyed the night before kept my stomach on high-alert.

Like most people who run the Boston, I was amazed and invigorated by the crowds. Over 500,000 people gathered for the race, and it seemed they were there just to cheer my name. I slapped high-fives with countless people and at Wellesley College ran past the loudest throng of screaming girls I've ever seen. Boston

Now What from page 22

are pervasive, they typically result in a demand for a wide array of supports. Making available to parents an education program that provides information on the steps to take following a diagnosis of autism reduces the likelihood that families will need to wait long periods of time before learning about and accessing resources for their child. The expected result of this will be improved functioning for both child and family.

Effects of the parent education program on the outcomes stated above will be evaluated using reliable and valid tools. To assess level of stress, The *Parenting Stress Index-Short-Form* (PSI-SF; Abidin, 1995) will be given to parents. The *Family Quality of Life Scale* (FQOL; Summers et al., 2005) will be used to gauge family life. Assessment of the child's adaptive functioning will be completed using The *Vine-*

College was a blur of happy faces chanting and yelling encouragement; as I passed by our niece Jenny, she jumped in to run the rest of the race with me. I'd never been so happy to see someone in my life.

I hit one wall at mile 7 when my right hip started to tell me it was annoyed. I hit another wall at mile 15 when my left hip got jealous and started to make noise too. But I really, really hit the big wall at mile 22 when I heard bystanders shouting there were only four miles to go. It sounded like

land Adaptive Behavior Scales, Second Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005), which relate not only to day-to-day living skills but also to future education/ treatment planning. Although specific improvements in the child with autism are not targeted in the program outlined, assessment of the child's adaptive living skills will help identify whether the program - which is aimed at supporting parent/family quality of life - is subsequently improving the child's daily functioning. A test of general knowledge of autism will also be administered. Each of these measures will be completed by parents prior to and following participation in the education program. To assess overall parent satisfaction with the education program (social validity), a *Parent Satisfaction Survey* will be administered following completion of the program.

In addition to using the above measures to assess impact of the education

running to the Statue of Liberty and back.

Something special happened at this point. A spectator stepped in front of me, looked directly into my eyes and said, "I believe in you."

This moment was a profound turning point at the end of a long journey. Turning away from Jenny so she didn't see me dissolve, I had an instant to understand that in these four words, this unknown man was telling me everything I needed to know.

There are no accidents. It's no accident

I have a son named Jack who will forever interpret the world differently than most; it's no accident I reached for a necklace that would reaffirm my faith in myself as a mother of a child with autism. And it was no accident that a stranger in a crowd of strangers spoke his mantra to me at a pivotal time in a hard-run race.

I've always believed in Jack. Now I believe in myself.

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

of newly diagnosed children.

The University at Albany Center for Autism and Related Disabilities, in collaboration with CapitalCare Developmental-Behavioral Pediatrics, is pleased to be able to respond to a frequently expressed need in the Capital Region for parent education programs for families with newly diagnosed children. The program, funded by grant from the Office of Mental Retardation and Developmental Disabilities, will bring research and practice together in the community setting and expects to improve the quality of life of many families in the area.

Kristin V. Christodulu, PhD is Director and Melissa L. Rinaldi, PhD is Research Coordinator at the Center for Autism and Related Disabilities at the University at Albany. Anthony Malone, MD is Clinical Associate Professor of the Department of Pediatrics at Albany Medical Center.

Overwhelming from page 28

make priorities and to choose what is most important and what can be put aside.

Autism spectrum disorders are not well understood in regards to etiology and specificity of treatment. One of the complicating issues is the autism spectrum disorders are by definition a heterogeneous collection of diagnoses made by observation. At this point in 2010, we do not have any conclusive diagnostic tests that can diagnosis an ASD or specify a specific type of ASD that may respond to a specific treatment intervention. So in some sense we are dealing with a group of disorders in which no two presentations are the same and no two interventions result in the same outcome. What a dilemma!

It is important for parents to seek support from other parents who are facing the same challenges. Isolation is not a healthy strategy for managing this perfect storm. One word of caution is that it is important to find a group of parents whose views and priorities are in alignment with your own. As a rule of thumb, any parent support group or individual parent that is a zealot in their efforts to convince others that they have found the magic bullet should be approached with considerable caution. I can recall an interaction I had with a parent early in my journey who informed me that I was poisoning my son's brain by allowing him to eat wheat and casein based products. Anyone who casts blame on another parent should be

considered toxic and should be avoided at all cost. Always keep in mind that an intervention that is extremely effective for one child could be totally ineffective with another child. This being said, even if two children appear to be similar in nature, disposition, or behavior, their neurochemistry and circuitry could be completely unique. This is not a one size fits all world, and autism spectrum disorders have very little in common other than the category chosen to describe certain clusters of behavior.

The challenge is trying to do it all, while trying to achieve a balance. Self-care is crucial and critical. We need to ensure some balance as the demands of caring for a child with an ASD can be all

consuming. The persistent and unremitting uncertainty that goes along with this disorder takes its toll emotionally. I have been trying to manage the angst created by the uncertainty by acknowledging that life is filled with uncertainty, and whether a child has special needs or is "typical," everyone's course or path in life is uncertain. It is important to focus one's energies on the things that one has control over and let go of the rest.

Dorothea Iannuzzi, LICSW, BCBA is a clinical social worker at the Milestones Inc. School for Accelerated Learning in Waltham, Massachusetts. For more information, visit their website www.advancingmilestones.com.

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

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

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

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

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

For further information contact the facilitators:

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

Meeting Dates: 2010 - 9/26, 10/24, 11/21, 12/19 2011 - 1/23, 2/27, 3/20, 4/10, 5/22, 6/14

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

United Nations from page 9

Children with Special Needs), Excellencies, Distinguished guests,

Thank you for your kind words. I understand you had a very good discussion this afternoon. I thank moderator Riz Khan and all the panelists for helping to shed further light on this complex and inadequately understood disability.

I would particularly like to acknowledge all the families who participated today. You, your children, and all the educators, therapists and practitioners who work with you are the real heroes in the fight for awareness about autism.

An estimated one per cent of the world's people are on the autism spectrum. That's 67 million children and adults

around the world. That's right: 67 million.

Many have a double burden. In addition to the daily challenges of their disability, they must cope with the negative attitudes of society ... inadequate support for their needs ... and, in some cases, blatant discrimination.

We have a tool that can help us redress such bias -- the UN Convention on the Rights of Persons with Disabilities.

The Convention aims to promote equal enjoyment of all human rights and fundamental freedoms by persons with disabilities.

As of today, 144 countries have signed the Convention and 85 have ratified it. I look forward to the day when all countries support this important international instrument.

This is one of the goals of World Au-

tism Awareness Day. But of course, there is more that we must do -- much more.

I call on all Governments to provide the care and fund the research that autism sufferers need.

As we learn more, it is becoming clear that all children and adults with autism can lead full and meaningful lives.

By combining research and awareness-raising, we can provide persons with disabilities such as autism the protection, support and full membership of an inclusive society.

Ladies and Gentlemen, you here are already committed to fulfilling that promise. I applaud you. Let us spread the word.

This year I had a simple message for World Autism Awareness Day: Human rights are the responsibility of all.

Let us join persons with autism, their families and their advocates in a community of voices for greater awareness and understanding.

Let us look within, and re-evaluate our attitudes and those of our societies so we can remove the prejudices that discriminate against persons with disabilities.

Let us dedicate ourselves to creating a fair and caring society that affords true dignity and rights for all.

Thank you."

To view the UN webcast of the panel discussion, please visit www.un.org/webcast/2010a.html and navigate to: 22 April 10 - Special Event: Panel discussion on "The impact of autism on the family."

Read the Hat from page 16

invent his own hilarious solution. Like his latest encounter with another teacher, a new one. It involved a long standing permission to call his mother when he gets an anxiety attack. The agreement is: any time James has a new teacher, he must bring her a note from his mother granting the permission. Sure enough, it wasn't long before anxiety began to growl at James like a junkyard dog. He asked his new teacher if he could call his mother; the new teacher, as per her understanding, held out her hand for the expected note. James had forgotten it, or lost it, or crumpled it into a ball during his anxiety attack. The teacher asked him to sit down. He tried to, but the anxiety dog was crouching on his chair, teeth bared and snarling. James returned to the teacher, told her he couldn't sit, he absolutely HAD to call his mother. The teacher, now fearing the loss of her authority, ordered him to "SIT DOWN." Where?! How?! There was no way around that cur and there wasn't time to think about it. James took off his baseball cap, wrote on the visor "James has permission to call his mother," signed his mother's name, put on his cap back on,

strode up to the teacher, leaned over her desk so she could see the words, and said, "Read the hat."

The story made the rounds of the faculty who, knowing James, were vastly entertained. But not the new teacher. Apparently - God knows how or why - she actually believed the words on James' cap had been written by his mother. When she realized they were James', she felt tricked, which shows how fast established custom can fall apart, particularly when exacerbated by laughter. It also shows what a tricky opponent an autistic child can be when anxiety overwhelms accepted social procedure.

While most of us encounter each other hour after hour, day after day in an endless, effortless stream of social exchange, people with autism - even with instruction - find the smallest of these exchanges nerve wracking beyond belief - a nervousness that's increased by our uneasiness when confronted with their oddity. If we want to mainstream those with autism - and we do, we must - we have to teach the mainstream society what to expect and why. Only then will everyone's nervous system quiet down enough for us all to experience each other. And to my way of

thinking, that would be a real gain. For James and for all of us.

In addition, could we please give an assist to James' family? James' mother is a single mom and her solo journey with James, despite the moments of hilarity, has never been easy. I don't know why James' father left, but I know from listening to other dads how autism can swerve into a man's sense of honor, leaving heavy black skid marks of shame.

I think of a Latino dad, whose son had an epileptic seizure in the middle of a conference. The man felt doubly dishonored, first, because of the shame-making public display of his son's epilepsy. Second for what, in that shame-making moment, he himself felt toward his son, a boy in whom he had hoped to see a next generation mirror of himself.

I think of a similar situation with an Asian dad as together we watched his 12 year old son crawl obsessively around and over every chair in the deserted auditorium. "What do we do if we can't stand it?" his father asked.

Formal education for all children on the spectrum is invaluable, but it's important to take note that ASD is primarily a male

disorder, with a 4 to 1 ratio in autism and a 10 to 1 ratio in Aspergers Syndrome. As these boys approach manhood they will look to their fathers for support and guidance. That means fathers must become involved and, from what I've seen of fathers, chances are they will need help.

Since autism as neurological disorder that produces social disorder, the goal of organizations like Families Together is to help the entire family. It's a goal worth emulating.

Eustacia Cutler, the mother of Temple Grandin, received an English Literature BA from Harvard. She has been a band singer at the Pierre Hotel, New York City, performed and composed for cabaret, and written school lessons for major TV networks. Her studies in retarded and emotionally disturbed children led to two TV documentaries: THE DISQUIETED, on disturbed children, and THE INNOCENTS, a prize winning first on retarded children. Her current book, A Thorn in My Pocket, describes raising Temple in the conservative "Leave-it-to-Beaver" world of the fifties when children with autism were diagnosed as infant schizophrenics and frequently banished to institutions.

YAI Interview from page 10

become adults, there has been a dramatic increase in the number of aging parents who are still caring for them. It is important to plan ahead of time for adult services, particularly as there are a limited number of residential places and waiting lists can be long.

Q: What are your thoughts on the comorbidity of autism spectrum disorders with mental health disorders? Do you think this is something that needs more attention?

A: Absolutely. This is an area of distinct interest to me because this is my area of expertise. If you take a cross-section of a group of 10-year-olds who have autism, you will find 70-80 percent of them have a coexisting mental health issue. This may be anxiety, impulse control difficulties, attention issues, mood instability, or other emotional issues. So clinicians need to be aware of the possibility that there may be a coexisting disorder such as attention deficit hyperactivity disorder.

If you look at children longitudinally, you will see an emergence of new disorders that are similar to children without ASD. One example may be the onset of obsessive compulsive disorder or of bipolar disorder in late adolescence.

It is important to assess how the be-

haviors and symptoms have developed over time -- has there been an onset of new symptoms and behaviors? Clinicians must be aware of these two different dimensions of assessment in understanding emotional, behavioral, and mental health issues in individuals with autism.

Once the mental health issues have been identified, psychotropic medications may be recommended in certain cases, in a targeted way, to help with emotional and behavioral symptoms. We have a better understanding of which medications work in different situations.

But there also is another option that's just beginning to emerge. There is wonderful new work on the use of cognitive behavioral therapy for individuals on the spectrum, who are able to participate in a therapeutic relationship. We should think more about the use of psychotherapeutic relationships for people with high functioning autism and Asperger's syndrome who would benefit from forming this type of relationship, and working on important life domains such as employment, recreation, and independent living.

Q: Because many individual on the spectrum have difficulty expressing their feelings, is it hard to determine what is going on with the individual?

A: It can be difficult, but I will give you some examples of how we can diagnose and understand individuals with ASD without requiring that they verbally explain their symptoms. Eye contact is one of the diagnostic criteria -- the failure to make eye contact with others. It is interesting that eye contact in an individual with autism can be seen as lack of interest or active gaze avoidance. You may get a history that there is a distinct pattern of eye contact that is very different with family members in contrast to people with whom they are unfamiliar. While looking at unfamiliar people you may notice an increased anxiety. Even though the child may be non-verbal, this could indicate the possibility of significant social anxiety. Certain treatments can ease this anxiety and can significantly improve the quality of that individual's life.

So we look at signs and symptoms and explore what this mean for the child. Why are they presenting one way in one situation and another way in a different situation? In this way, you begin to look at patterns of mental health issues in individuals with autism.

Charles N. Cartwright, MD, is Director of the YAI Autism Center at the YAI

Network. He is an expert in the diagnosis and treatment of autism spectrum disorders in children, adolescents and adults. He is a board certified child and adolescent psychiatrist and a faculty member in the Department of Psychiatry, Child and Adolescent Division, at the University of Medicine and Dentistry of New Jersey.

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

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

For more information about the YAI Autism Center visit yai.org/autism or call 1-888-YAI-AUTISM (1-888-924-288476).

Interview from page 33

that is not an area in which we have worked historically. That is true from the basic biologists all the way to physicians, psychiatrists, and neurologists. So we have to look to the external community of expertise. What we are finding is that there is a very engaged and assertive community out there that is willing to help and work with us. What we have done is to identify and build collaborative relationships that expand our capability for success. In a short period of time, we have been able to build an external network of academic collaborators around the world that have enabled us to accelerate our internal research efforts. We have funded research through alliances with large universities like the University of Pennsylvania (UPenn). At UPenn we are working with Dr. Bob Schultz, Director of the Center for Autism Research (CAR), to help understand, using cutting edge imaging technology, some of the underlying phenotypes in human patients which may prove to be very valuable not just for Pfizer, but for the entire field in understanding how we can use these in clinical development of novel medicines. We are also interested in many of the public access databases that are being generated by various initiatives and are looking for ways to maximize the availability of that data to help drive our own research.

We are not just building collaborative relationships with academic centers to enable our research, but we are working to partner with nonprofit foundations such as Autism Speaks to advance some of the discussion in areas of strategic importance. For instance, we are co-sponsoring two upcoming meetings with Autism Speaks that will focus on translational research in autism. The first meeting will be focused on the development of outcome measures that will enable clinical trial design and prosecution because we think this is essential to get drug development moving for these patients. It shows how we recognize that this is a huge gap; it is not something that we will be able to

do ourselves. Dr. Tom Insel, MD, Director of the National Institute of Mental Health, is also on the organizing committee of one of the meetings that we are co-sponsoring with Autism Speaks.

Q: What age group will Pfizer be targeting for new treatment options?

A: There is no simple answer to this question. The public's awareness of autism has often focused on autism as a pediatric disorder, when in reality it is a lifetime diagnosis. In fact, patients with autism have life spans similar to those of typically developing individuals. Comparatively less is understood about adults with the disorder, and research in adults is lagging behind. This creates important gaps in understanding that can impact drug development. As disability exists across the spectrum of age, the development of treatments will likely need to take age into consideration. We are faced with important research questions how the biology underlying the disorder may differ between age groups, and where it may be the same. All that said, I would consider older children, adolescents, and adults alike as the patients we would like to develop new treatment options for.

Q: Does the Pfizer Autism Research Unit have a timetable for this project and a target date for the announcement of any new medications available for the autism community?

A: I want to stress that this is not a "project." This is a fully dedicated research unit within Pfizer Neuroscience, along side our two other research units Psychiatry and Neurodegeneration. The question involving 'when' is often asked. I was in a congressional forum sponsored by Autism Speaks earlier this year in New London, Connecticut and was asked by parents: "When are we going to see these drugs? When should we expect to see the first drug hit the market? When can I have access to this for my child with autism?" It is important to empha-

size to the community that we have entered into this with an invest-to-win intent, but it is essential to understand that the process takes time. It is a responsibility of ours to manage expectations by teaching the patient community about the process, and why it can take time. There can be no cutting corners to ensure the safety and effectiveness of new treatments, and although the process can be lengthy, it is intended to serve needs of patients. One needs to remember that the majority of drugs prescribed to patients with autism today are used 'off-label,' with little to no evidence supporting the safety or efficacy in managing the symptoms they are being prescribed for. This needs to change, and will change as we move forward. All that said, we are excited about by the approaches being taken at Pfizer, and believe we are in an excellent position to succeed bringing needed medicines forward to patients. Moreover, I strongly believe that our example will encourage other companies to see the opportunity and join Pfizer in this effort.

Q: What hopeful message would you like to leave with parents?

A: Two years ago, no drug companies were working to bring new medicines to patients with autism spectrum disorders. Things have changed, and Pfizer is leading the way. Folks in our Autism Unit at Pfizer are passionate about their research and show up every day mission-focused on using it to deliver medicines for patients. With members of our group who have family members on the spectrum, along with many colleagues across our Pfizer community, this is more than a job and provides a personal face to our journey. We are the largest pharmaceutical company in the world and we have made autism a priority for our neuroscience research.

Dr. Ring is originally from Southern California (Claremont) where he attended Westmont College in Santa Barbara, earning a bachelor's degree in

both Fine Art and Biology. After 4 years working as a studio artist, he returned to school with Master's work in Medical Genetics studying polygenetic vulnerabilities in Tourette syndrome and ADHD at the California Polytechnic University Pomona. He then went on to earn his Ph.D. in Molecular Neurobiology at the Beckman Research Institute, City of Hope National Medical Center in Duarte, California. His doctoral research focused on elucidating the transcriptional mechanisms underlying inflammatory responsiveness in the hippocampus. Prior to joining Pfizer, he led the Mood Disorders research group at Princeton. He has served as program leader for numerous drug development programs. During his 10 year tenure at Wyeth, Rob also headed the Molecular Neurobiology Group and focused much of his efforts on developing and executing new target ID/validation strategies for psychiatry illnesses. His primary research interests have been focused on central neuropeptidergic systems and their relevance to psychiatry drug development, with a specific focus on vasopressin and oxytocin. He is the author of numerous scientific publications and recent a book chapter on animal and translational models of Autism Spectrum Disorders.

Dr. Ring holds membership in the American College of Neuropsychopharmacology (ACNP), International Society for Autism Research (INSAR), Society for Neuroscience (SFN), Society of Biological PsychSociety (APS). Rob is also actively engaged iatry (SOPB) and American Physiological in the academic community teaching and consulting on grant applications. He holds two adjunct faculty positions, one in the department of Psychiatry at Mount Sinai School of Medicine (NYC) and the other in the department of Pharmacology and Physiology at Drexel University College of Medicine (Philadelphia). He is currently Senior Director, Head of Autism Neuroscience Research at the Pfizer Facility located in Groton, Connecticut.

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