

# AUTISM SPECTRUM NEWS™

YOUR TRUSTED SOURCE OF SCIENCE-BASED AUTISM EDUCATION,  
INFORMATION, ADVOCACY, AND COMMUNITY RESOURCES

FALL 2012

VOL. 5 NO. 2

## The Importance of Early Intervention After Diagnosis

### Identifying Children with ASD and Finding Services After Diagnosis

**Catherine Lord, PhD, Director**  
Center for Autism & the Developing Brain  
NewYork-Presbyterian Hospital

**A**utism expert Dr. Catherine Lord is the Director of NewYork-Presbyterian Hospital's (NYP) Center for Autism and the Developing Brain (CADB). Opening in early 2013, CADB will be the region's most comprehensive center for diagnosing and treating patients with Autism Spectrum Disorders (ASD). Dr. Lord shared some of her insights on identifying children with ASD and how to begin the process of getting the right services.

*Q - A report by the Centers for Disease Control and Prevention has termed Autism Spectrum Disorders a national public health crisis, noting that one out of 88 American children is diagnosed with the developmental disability. What early signs and symptoms should parents look for in their child?*



*A - Most children with ASD will not develop signs until after their first birthday. Between 12 and 15 months, a child may act differently from other children but a*

*parent may not recognize it as ASD related. Some red flags in a child's behavior may include not wanting to be held or cuddled, staying in the crib, not respond-*

*ing to his or her name, staring, and not following objects visually. As the child gets older, these behaviors will become more pronounced.*

*Q - When does it become readily apparent that the child may have an Autism Spectrum Disorder?*

*A - Generally, ASD symptoms are apparent after the age of two. Symptoms typically revolve around impaired social skills, speech and language difficulties, nonverbal communication difficulties, and inflexible behavior. What separates a child who is developing normally from one with ASD is the ability to integrate language with social interaction. Signs of ASD include the inability to vocalize, socialize, and play in organized ways; very delayed language; and repetitive actions and body movements.*

*Q - What should a parent do when she thinks her child might have ASD?*

*see Identifying on page 22*

### A Practical Guide for Parents of Children with Sensory Processing Difficulties

**By Sheri Wolnerman-Bardos, MS**  
**and Natalia Appenzeller, PhD**  
Fay J. Lindner Center for Autism

**H**aving a child diagnosed with an Autism Spectrum Disorder (ASD) necessitates parents to make a host of lifestyle and emotional adjustments. Many of these adjustments are in response to behavioral challenges exhibited by their children due to difficulty appropriately processing sensory information. Children may overreact or underreact to environmental stimuli in unusual ways which affects their responses and dictates behaviors exhibited to help them feel more regulated. The goal of this article is to provide practical advice for parents as they adapt to having a child with unique sensory processing. Research has shown that parents who acquire information regarding their children's disorders

and how to best work with them will more likely benefit from improved and stronger parent-child relationships.

There is a continuous debate regarding the physiological basis for what happens in the nervous systems of children with sensory processing difficulties to cause dysregulation when faced with sensory information from the environment. Nonetheless, it is clear that the central nervous systems of people with ASDs do not consistently effectively integrate sensory information, where the central nervous systems of typically developing individuals automatically organize and properly interpret sensory information (Murray, 2009). Therefore, it is helpful for parents to understand that many of the behaviors exhibited by children with sensory processing difficulties are out of their control and to, accordingly, restructure their own thinking to a "can't versus won't" philosophy. As parents increase understand-

ing that their children's responses stem from difficulties not fully in their control, the more likely their patience will increase for their children's sensory difficulties (Dix, 1993).

The behavioral presentations of children with sensory integration difficulties can be classified into two categories. Some children are *sensory seekers*, meaning they have lower levels of arousal and their nervous systems require more input to reach satiating thresholds. Therefore, they seek input and sensation from their environment and engage in behaviors such as flapping their arms or hands, asking for excessive food, or moving around and spinning. On the other hand, *sensory averse* children have higher levels of arousal and are more easily overwhelmed by stimuli in their environment. They try to decrease the effects of sensory input by engaging in activities such as chewing on items in the environment, withdrawing to

small spaces, covering their ears, and squeezing their body parts. It is also possible for some children to be sensory averse in one area, yet sensory seeker in another (e.g., a child might seek out deep pressure, but find loud noises aversive).

Dr. Temple Grandin, renowned author and professor, who is diagnosed with Autism (1984) has written extensively about her own difficulties processing sensory information. She laments that she wished her parents understood her sensory sensitivities when she was a child. However, only now as an adult can she articulate what her experiences were like. Dr. Grandin was hypersensitive to some of her clothes and struggled to process their feeling against her skin. She describes that her Sunday church dress "felt like sandpaper on exposed nerve endings." Certain types of sounds and their accompanying

*see Guide on page 26*

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#### Winter 2013 Issue:

"Exploring Educational Challenges and Opportunities"  
**Deadline: December 5, 2012**

#### Spring 2013 Issue:

"Maintaining Skills During Summer Vacation"  
**Deadline: March 5, 2013**

#### Summer 2013 Issue:

"Supportive Housing for Adults with Autism"  
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# AUTISM SPECTRUM NEWS DESK

## New Targeted Drug for Treating Fragile X Syndrome, Potentially Autism, is Effective *Drug Treats Social Withdrawal and Challenging Behaviors in Fragile X*

By The UC Davis MIND Institute

**A**n investigational compound that targets the core symptoms of fragile X syndrome is effective for addressing the social withdrawal and challenging behaviors characteristic of the condition, making it the first such discovery for fragile X syndrome and, potentially, the first for autism spectrum disorder, a study by researchers at the UC Davis MIND Institute and Rush University Medical Center, Chicago, has found.

The finding is the result of a clinical trial in adult and pediatric subjects with fragile X syndrome. It suggests, however, that the compound may have treatment implications for at least a portion of the growing population of individuals with autism spectrum disorder, as well as for those with other conditions defined by social deficits. The study is published online today in the journal *Science Translational Medicine*. A second article by the manufacturer of the compound is included in the same issue.



**Randi J. Hagerman, MD**

The “first-in-patient” drug trial was led by internationally recognized fragile X

researchers Elizabeth Berry-Kravis of Rush University Medical Center and Randi Hagerman of the UC Davis MIND Institute. It examined the effects of the compound STX 209, also known by the name arbaclofen. The study was conducted collaboratively with Seaside Therapeutics, a Cambridge, Mass., pharmaceutical company that is focused on translating bench research on fragile X and autism into therapeutic interventions. Seaside Therapeutics is developing the compound and supplied it for the clinical trial.

“This study shows that STX 209 could become an important part of the treatment for fragile X syndrome, because it appeared to improve symptoms in those with significant social deficits or autism as well as fragile X syndrome,” said Hagerman, medical director of the MIND Institute. “Additional studies also are suggesting that STX 209 could be helpful for autism without fragile X syndrome. Until now, there have been no targeted treatments available for autism. This appears to be the first.”

Fragile X syndrome is the most common, known cause of inherited intellectual impairment, formerly referred to as mental retardation, and the leading known single-gene cause of autism. Social impairment is one of the core deficits in both fragile X and autism. The U.S. Centers for Disease Control and Prevention (CDC) estimates that about 1 in 4,000 males and 1 in 6,000 to 8,000 females have the disorder. An estimated 1 in 88 children born today will be diagnosed with autism, according to the CDC.

“There are no Food and Drug Administration-approved treatments for fragile X syndrome, and the available options help secondary symptoms but do not effectively address the core impairments in fragile X. This is the first large-scale study that is based on the molecular understanding of fragile X and suggests that the core symptoms may be amenable to pharmacologic treatment,” said lead study author Elizabeth Berry-Kravis, professor

*see Drug on page 32*

## Diagnosis Often Missed for Hispanic Children with Developmental Delay and Autism *Broader Outreach on Developmental Milestones Needed*

By The UC Davis MIND Institute

**H**ispanic children often have undiagnosed developmental delays and large numbers of both Hispanic and non-Hispanic children who first were thought to have developmental delay actually had autism, researchers affiliated with the UC Davis MIND Institute have found.

The study, one of the largest to date to compare development in Hispanic and non-Hispanic children, is published in the journal *Autism*. The results lead the study authors to recommend increased public health efforts to improve awareness, especially among Hispanics, about the indicators of developmental delay and autism.

“Our study raises concerns about access to accurate, culturally relevant information regarding developmental milestones and the importance of early detection and treatment,” said Virginia Chaidez, the lead author and a postdoctoral researcher in the UC Davis Department of Public Health Sciences when the study was conducted. “Autism and developmental delay tend to go undiagnosed when parents are not aware of the signs to look for, and the conditions are often misdiagnosed when parents don’t have access to adequate developmental surveillance and screening.”



**Virginia Chaidez, PhD**

Developmental delay is diagnosed in children who lag behind others in reaching important mental or physical milestones, while autism is characterized by deficits in social interactions and communication behaviors. The symptoms of both disorders can be improved with targeted interventions, with the greatest improvements seen when interventions begin early in life.

In conducting the study, the researchers used data from the Childhood Autism Risk from Genetics and the Environment (CHARGE) Study, a population-based study of factors that increase risk for autism or developmental delay. The current study included 1,061 children living in California who were between 24 and 60 months of age. They were divided into three groups: children with autism, children with developmental delay but not autism, and children with typical development. All diagnoses were confirmed or changed based on evaluations by MIND Institute clinicians.

The evaluations of Hispanic children were conducted by bicultural and bilingual clinicians in Spanish or English, depending on the primary language used at home. The results for children with at least one Hispanic parent of any race were compared to the results for children of non-Hispanic white parents.

“Our goal was to use the CHARGE Study to help fill the gaps in research on autism for Hispanics so we can better understand what autism is like for this growing U.S. population,” said Irva Hertz-Picciotto, professor of public health sciences, researcher with the UC Davis MIND Institute and principal investigator of CHARGE. “No other study of autism has included such a large proportion of Hispanic children.”

When the outcomes for Hispanic children were compared to non-Hispanic children, the results revealed more similarities than differences in terms of autism profiles, including diagnostic scores, language function, whether or not children lost acquired skills and overall intellectual, social and physical functioning.

A striking outcome, however, was that 6.3 percent of Hispanic children enrolled in the study who were selected randomly out of the general population met criteria for developmental delay, compared with only 2.4 percent of non-Hispanic participants, which is the expected percentage. This raised concerns among the researchers that many Hispanic children with developmental delays may not be getting the services they need.

For both Hispanic and non-Hispanic children, there was a high percentage (about 19 percent overall) of Hispanic and non-Hispanic children recruited for the study with developmental delay who actually met criteria for autism, raising concerns about adequate access to accurate developmental assessment.

When the analysis was restricted to bilingual children, a significant relationship also emerged between secondary language exposure (when a child was spoken to 25 to 50 percent of the time in a

*see Hispanic on page 24*

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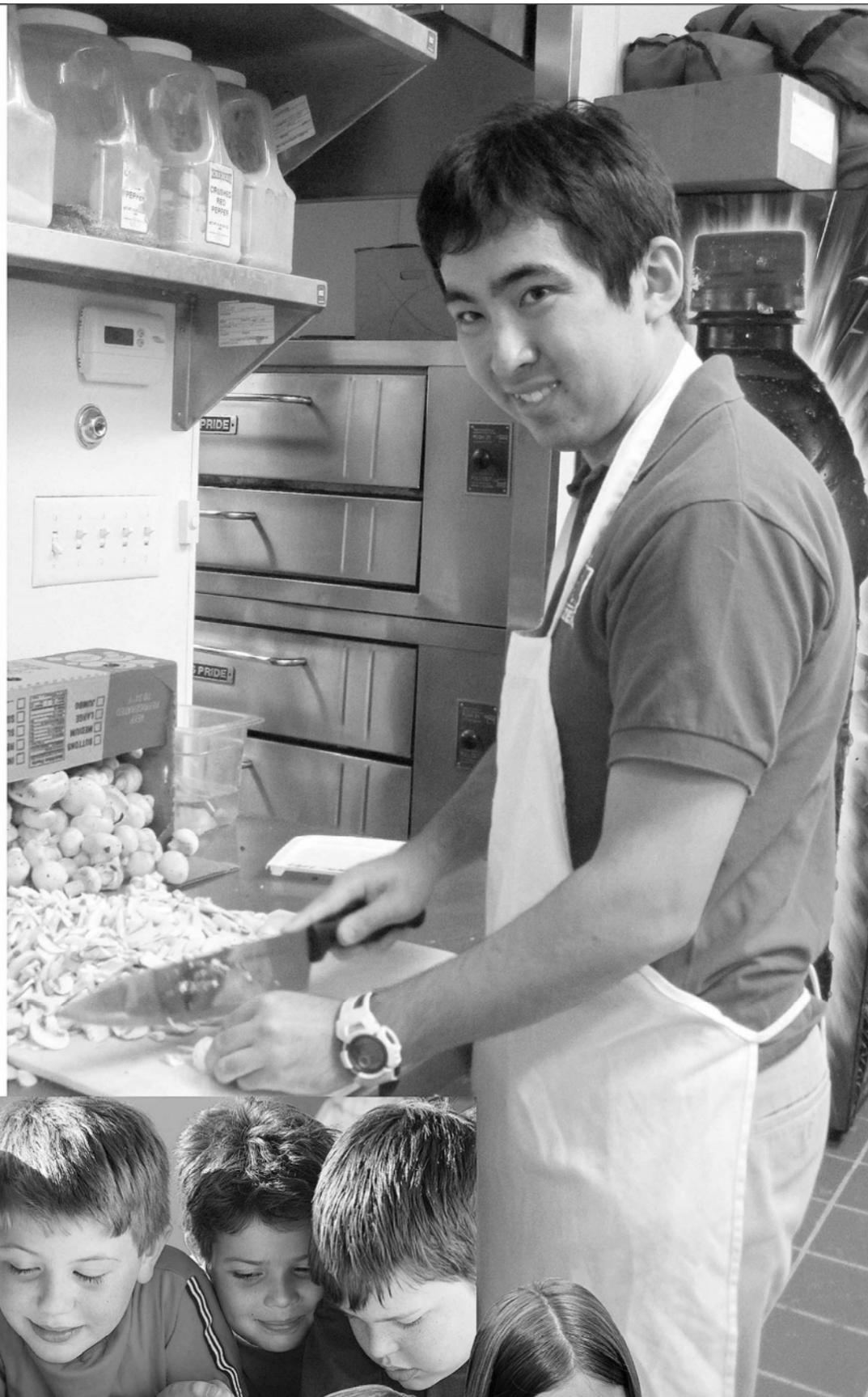
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# AUTISM SPECTRUM NEWS DESK

## Insomnia and Anxiety May Be Linked in Individuals with ASDs

By Margaret C. Souders, PhD, CRNP  
Assistant Professor  
University of Pennsylvania

**M**ore than half of children with Autism Spectrum Disorder (ASD) also experience clinically significant problems with anxiety (Sukhodolsky et al., 2008). New research conducted at the Center for Autism Research (CAR) at The Children's Hospital of Philadelphia and the University of Pennsylvania (UPENN), School of Nursing suggests that ASD which co-occurs with anxiety can have another harmful consequence: insomnia. Insomnia is defined by difficulties falling and/or staying asleep with impairments in daytime behavior. In a recent study, CAR researchers including Dr. Margaret C. Souders found that children with ASD who received an additional diagnosis of an anxiety disorder were significantly more likely to have insomnia as compared to children with ASD without a diagnosis of anxiety. This preliminary data also showed that there were no significant differences between typically developing children's sleep latency and night waking, compared



Margaret C. Souders, PhD, CRNP

to children with ASD without an additional diagnosis of anxiety. Anxiety in this study was diagnosed by a team of CAR psy-

chologists using the gold standard tool for anxiety the Anxiety Disorders Interview Schedule (DSM-IV) - Child/Parent (ADIS-C/P) (Silverman & Albano, 2007).

Adequate sleep is critical for the most advantageous neurobehavioral and physiological development and functioning (Banks and Dinges, 2007, Goel, et al 2009). Poor sleep has been shown to have harmful effects on cognition, behavior, mood, and attention (Gozal, 1998, Maquet, 2001). The prevalence of sleep problems in children with ASD is 60-80%, two to three times the rate of typically developing children (Souders, et al, 2009). There are many possible causes for sleep disturbances in ASD. Researchers think that the core deficits of ASD and their underlying neurobiology may predispose children with ASD to having sleep problems (Souders, et al, 2009). The two predominant sleep disorders identified in children with ASD are Behavioral Insomnia of Childhood (an insomnia caused by external factors) and Insomnia Secondary to their Pervasive Developmental Disorder (PDD) (an insomnia caused by internal factors) (Wiggs and Stores, 2004, Souders, et al, 2009). Insomnia due to a child's ASD would be diagnosed when robust behav-

ioral techniques are used by the family, behavioral insomnia is ruled out, and no identifiable medical condition is disrupting sleep. This sleep problem is best described as insomnia due to PDD (Diagnostic Code 327.15) (Souders, 2009).

One of the main emerging hypotheses for insomnia caused by internal factors in ASD is synaptic pathway abnormalities. Scientists think that anomalies in the excitatory neurotransmitters in the synaptic pathways of the brain may account for "arousal dysregulation" in individuals with ASD. This means that an individual's brain and neurological system does not sufficiently and consistently regulate or control the internal levels of anxiety, fears and sensitivity thresholds to environmental stimuli (for example, sounds, clothes, tastes and smells) experienced by children with ASD. Arousal dysregulation may be contributing to difficulties in initiating and maintaining sleep and daytime behavior. Arousal dysregulation in children with ASD may produce a constellation of behavioral symptoms including anxiety, sensitivities to sensory stimuli, inattention and insomnia.

see *Linked on page 29*

## Autism Science Foundation Issues New Request for Scientific Grant Proposals *Grants Will Fund Pre- and Post-Doctoral Autism Research Fellowships*

Staff Writer  
Autism Spectrum News

**T**he Autism Science Foundation (ASF), a not-for-profit organization dedicated to supporting and funding autism research, today announced that it had issued a new request for scientific proposals. ASF is inviting applications for Pre- and Post-doctoral Training Awards from graduate students, medical students and postdoctoral fellows interested in pursuing careers in basic and clinical research relevant to autism spectrum disorders. In the past three years, ASF has funded over \$700,000 in pre and post-doctoral grants.

"Pre- and post-doctoral fellowships not only build our knowledge about what causes autism and how best to treat it, but

also build our future by encouraging outstanding young investigators to dedicate their careers to autism research," said Alison Singer, president of ASF.

"We are so grateful to all our donors and volunteers who have come together to support autism research and who make these grants possible," said Karen London, co-founder of ASF.

The proposed training must be scientifically linked to autism. ASF will consider for training purposes all areas of related basic and clinical research including but not limited to: human behavior across the lifespan (language, learning, communication, social function, epilepsy, sleep, repetitive disorders), neurobiology (anatomy, development, neuro-imaging), pharmacology, neuropathology, human genetics/genomics, immunology, molecular and cellular mechanisms, studies em-

ploying model organisms and systems, and studies of treatment and service delivery. Applications must be received by November 16, 2012.

Additional information about the RFA can be found at [www.autismsciencefoundation.org/ApplyForaGrant.html](http://www.autismsciencefoundation.org/ApplyForaGrant.html).

The Autism Science Foundation is a 501(c)(3) public charity. Its mission is to support autism research by providing funding to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.

Grant applications will be reviewed by members of ASF's Science Advisory Board (SAB) and other highly qualified

reviewers. Current SAB members include Dr. Joseph Buxbaum (Mt. Sinai School of Medicine); Dr. Emanuel DiCicco-Bloom (UMDNJ-Robert Wood Johnson Medical School); Dr. Sharon Humiston (University of Rochester); Dr. Bryan King (University of Washington, Seattle); Dr. Ami Klin (Emory University); Dr. Harold Koplewicz (The Child Mind Institute); Dr. Eric London (New York Institute for Basic Research); Dr. Catherine Lord (New York Center for Autism and the Developing Brain); Dr. David Mandell (University of Pennsylvania/CHOP); Dr. Kevin Pelphrey (Yale Child Study Center) and Dr. Matthew State (Yale Medical School).

*To learn more about the ASF's grant programs, and to read about projects funded through this mechanism in prior years, visit [www.autismsciencefoundation.org](http://www.autismsciencefoundation.org).*

### Do you have a child with an Autism Spectrum Disorder and noncompliant behavior or hyperactivity?

Yale Child Study Center is conducting a research study comparing parent training and parent education for young children with ASD.

Eligible children are **between 3 and 6 years with ASD** accompanied by **irritability and noncompliant behavior**.

**CONTACT: 203-785-5805. Yale IRB # 0411027217.**



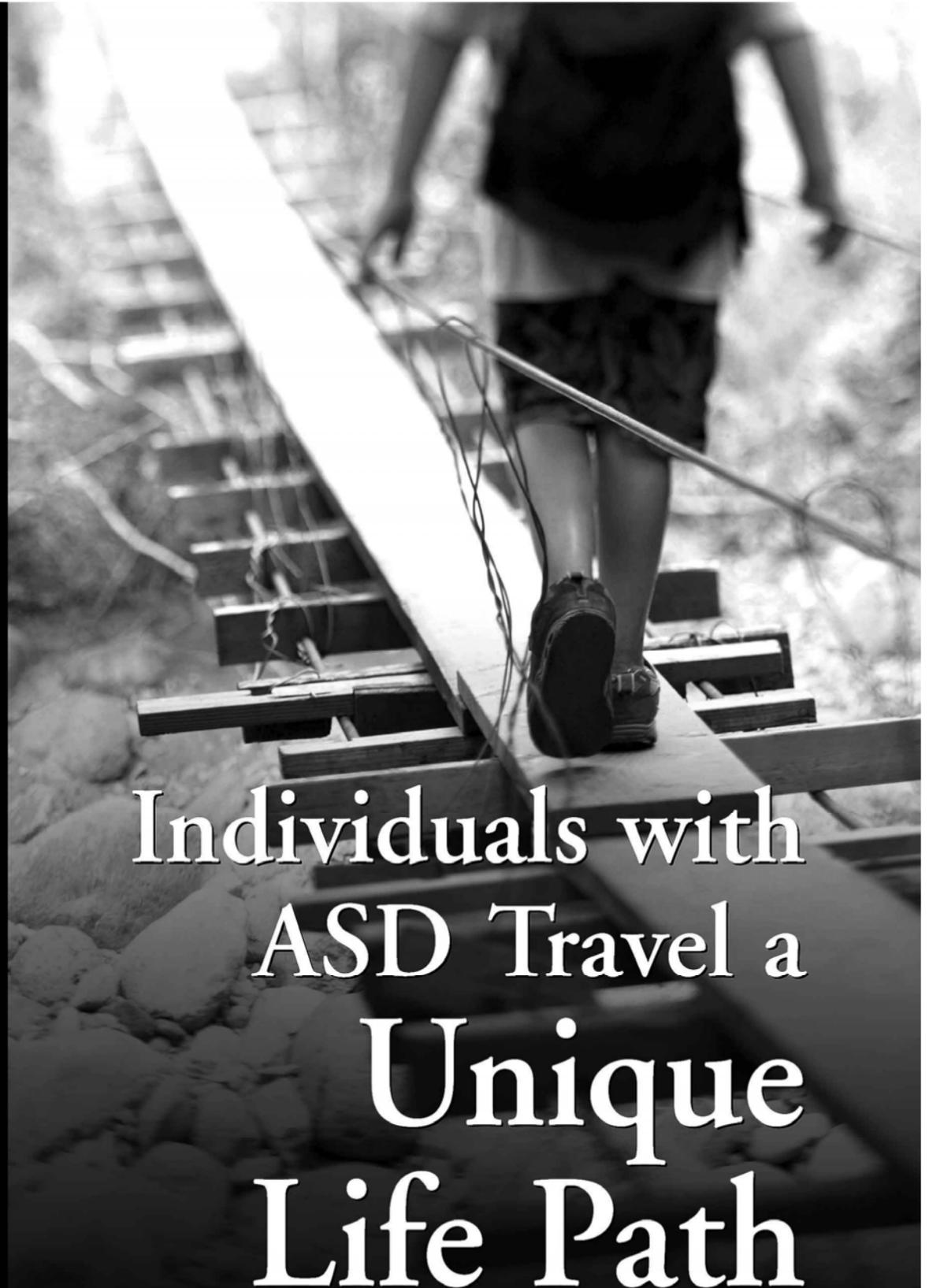
Yale Child Study Center is also conducting a research study to test the effectiveness of a **non-stimulant medication**, extended-release guanfacine (Intuniv®), for children with PDD and hyperactivity. Eligible children are **at least 5 but younger than 14 years old**, with **autism, Asperger's, or PDD-NOS**, and clinically significant **hyperactivity**, currently medication-free or on ineffective medication. **CONTACT: 203-737-5317. Yale IRB # 1001006172.**

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# Special Needs Family Planning<sup>SM</sup>



## Tips for Families with Special Needs

By **Stuart M. Flaum**  
Financial Representative  
MassMutual Westchester

**W**hat is the sign of a good decision?® It's creating a life care plan for a special needs child. A gift of cash from grandma, grandpa or anyone else could end up costing special needs families thousands of dollars in lost government funding and services – benefits that are critical in helping families pay the huge expense of caring for and educating their children with special needs.

Assets over a certain dollar amount may affect qualification for government benefits.

### Key Considerations

Consider the following tips for families and friends of children with special needs.

1. Do not give or accept financial gifts or assistance in the name of a child with special needs.
2. Deposit gifts into a special needs trust that benefits the child.
3. Be aware: there is no difference between gifts of cash, bonds, stock, property, inheritance, annuities, art and automobiles; they all count against the child's net worth.
4. Plan ahead: any of these gifts can legally be given to the trust of a child with special needs and will not jeopardize government benefits if the trust is properly drafted in compliance with any particular state's requirements.
5. Carefully monitor the child's assets. Interest appreciation could increase their account value to exceed the \$2,000 limit.



**Stuart M. Flaum**

6. Volunteer to help care for a special needs child, so parents or guardians can have some time to themselves. Caring full-time for children with special needs can be very intense, expensive and demanding.
7. If your child has special needs, create a "Letter of Intent" to document exactly how you want he or she to observe the holidays and with whom, if you pass away – what type of gifts should or should not be given to them and what kind of life they want. A "Letter of Intent" template is available at: [www.massmutual.com/specialcare/resources](http://www.massmutual.com/specialcare/resources).
8. Consult an attorney specializing in special needs planning with regard to the feasibility of establishing a Special Needs Trust and ask a financial professional for help funding the trust.
9. Review your life insurance, making sure the policy does not benefit the child directly; proceeds that are generally tax free may be paid into the child's trust.
10. Offer to become a trustee, a very special personal gift to help families and children who need sincere, reliable, dedicated people to manage their children's trusts and future.

Creating a special needs trust is the first step in creating a life care plan for

a special needs child. This type of planning is crucial, yet highly complicated and difficult to do without help, because the issues and laws are complex. Services by an attorney specializing in special needs planning are essential. Your financial professional can help assemble an integrated team of professionals experienced in the area of special needs and, ultimately, assist in funding the trust.

*This article is provided by Stuart Flaum, a financial representative with MassMutual Westchester, a MassMutual Agency; courtesy of Massachusetts Mutual Life Insurance Company (MassMutual). Stuart may be reached at [sflaum@financialguide.com](mailto:sflaum@financialguide.com).*

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## Ten Questions When Planning for Financial Security

By **Stuart M. Flaum**  
Financial Representative  
MassMutual Westchester

**W**hat is the sign of a good decision?® It's clarifying what you want to achieve, what you value and how uncertainties affect plans and aspirations – turning plans into action and goals into reality.

### Ten Questions and Answers

When thinking about how to protect your livelihood or build the financial resources you will need to live life as desired, answer these 10 questions first.

1. What is important to me?

Before thinking about the right financial products for your needs, clarify what's truly important to you – the people you care about, the aspirations you have, the things you want to protect, and the support you'd like to give

to others. Whether you reflect on this question by yourself, with family members, or alongside a financial professional – answer this first, as it will create the framework around which your financial strategy can be built.

2. Who depends on me today and who might depend on me tomorrow?

This question should be at the core of your decision making process and should be answered well before you consider what financial products you need and in what amount. Spouses and children are often thought of as the most obvious dependents; however, there can be others – for example, parents, in-laws or siblings who, due to age, disability, or other circumstances, may be unable to care for themselves. Even individuals without a family have dependents – namely, themselves – since their well-being depends on their own ability to earn an income. With your list of current and potential dependents in hand, you will be better

prepared to plot your course toward greater financial security.

3. Who is providing for my dependents now?

Does someone in your family provide valuable non-financial support to those you care about? Think of the stay-at-home parent – they may not support their family with earned income, but the support they do provide is just as valuable as any paycheck. If a stay-at-home parent were unable to provide that support, it would surely be expensive to replace. Account for all who provide essential financial or non-financial support to your dependents.

4. What risks have I overlooked or not fully considered?

People may concentrate on the risk of premature or accidental death and overlook other risks to their well-being and livelihood (for example, a breadwinner unable to work due to

illness, an aging parent unable to care for themselves, a retiree dealing with rising healthcare costs, a business owner faced with a succession problem). As you work to construct your strategy, be sure to think broadly about the financial risks you face today, or may face in the future.

5. Are my plans flexible enough?

There are ways that financial product solutions can be structured to provide future flexibility and adjust with your evolving needs. When speaking with your financial professional, ask about flexible solutions that can be upgraded (or downsized) as events in your life unfold.

6. How do I pick the right financial professional?

When choosing a financial professional, work with someone who is not

*see Ten Questions on page 28*



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## The Early Identification of Young Children with ASD

By Sam Goldstein, PhD  
and Jack A. Naglieri, PhD

In developed countries, a child's initial assessment for ASD typically takes place before they enter elementary school. Usually the question asked at that point is whether or not the child suffers from Autism and what can be done as the child prepares to enter an organized school setting. Typically parents of such children seek assessment after having observed another child with ASD or been told by others that their child's pattern of behavior and development may in fact meet one of the ASD diagnostic criteria.

It is still the case that many parents are upset and significantly impacted to learn their child has ASD. In particular, the outcome data of children with ASD grown-up has failed to demonstrate the significant success of educational programs in preparing these children for normal adult life. However, there is reason for optimism as an increasing body of scientific evidence has demonstrated that early identification and comprehensive intervention appears to have a positive dramatic impact on the social and related behavior of children with ASD.

The study of any psychological disorder is dependent upon the tools that are used as these tools directly influence what is learned about the subject in research as



Sam Goldstein, PhD

well as clinical practice. As in all areas of science, what is discovered depends upon the quality of the instruments used and the information they provide. Well-developed assessment instruments yield more accurate and reliable information. Instruments that uncover more information relevant to the subject being examined will have better validity and ultimately will more completely inform researchers, clinicians and treatment providers. The tools used for



Jack A. Naglieri, PhD

diagnosis of a condition such as ASD will have a substantial impact on the reliability and validity of the information obtained and the decisions made. Simply put, the better the tool the more valid and reliable the decisions, the more useful the information obtained and the better the services that are eventually provided.

As our understanding of ASD is evolving emerging research has demonstrated that the key to successful intervention

requires not only an evidence based treatment program delivered with fidelity but also delivered early in a child's development. In order for children to be appropriately identified and determined to be eligible candidates for effective programs, research proven assessment tools are needed. The Autism Spectrum Rating Scales (ASRS) were designed to measure behaviors of youth aged two through eighteen years reported by parents and/or teachers associated with ASD. As such, the ASRS helps guide diagnostic decisions and can be used during treatment planning, ongoing monitoring of response to intervention and program evaluation. The ASRS includes items related to Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise as specified under the current DSM-IV-TR. The symptom items included in the ASRS are also generally inclusive of the proposed items for the next diagnostic guidelines contained in the DSM-V to be published sometime in 2013 or 2014.

The ASRS can be used as an aid in the diagnostic process. Standardized scores from the ASRS allow clinicians to effectively compare children to a normative group in an objective and reliable manner. Scores can be integrated with other information to form a complete understanding of the child. When used in combination

*see Identification on page 30*

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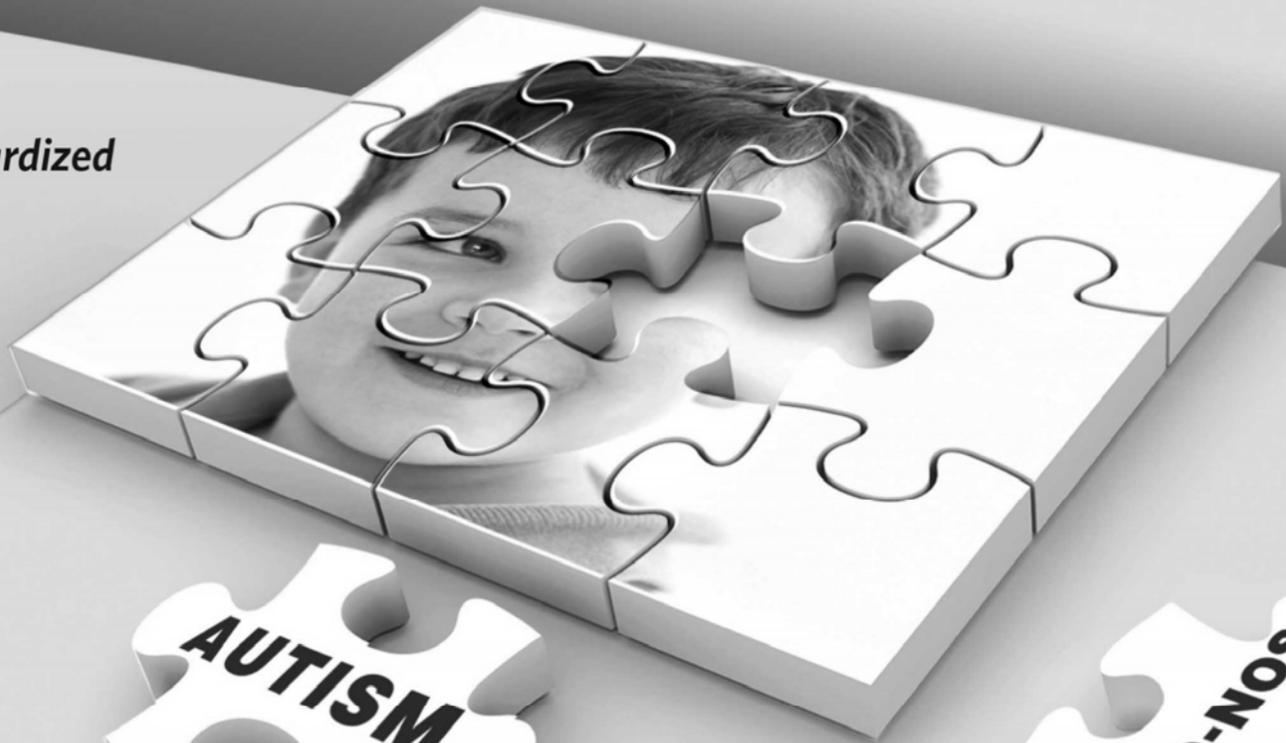
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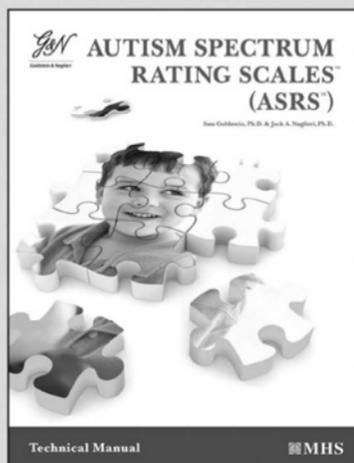
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## What Are Your Legal Entitlements Now That Your Child Has Been Diagnosed?

By Maria C. McGinley, Esq  
Mayerson and Associates

**T**he Individuals with Disabilities Education Act (IDEA) is the federal law that governs the education of children with disabilities, including developmental delays. Your child with autism has the right to a free appropriate public education under the IDEA. Each state must provide all eligible children with a public education that meets their *individual* needs.

Part C of the IDEA – which governs Early Intervention (E.I.) – authorizes the federal and state governments to act on behalf of infants and toddlers (birth to three). Part B of the IDEA – which governs preschool students – authorizes federal and state governments to act on behalf of young children (three to five) with disabilities.

### Early Intervention Services

The IDEA provides states with federal grants to provide E.I. programs to children younger than three who have an eligible disability. If a child is determined to be eligible, these E.I. services must be provided to the child at no cost to the child's parents or family.

The services provided should address and meet a child's unique and individualized needs and thus, cannot be "rationed" or otherwise arbitrarily limited only to



**Maria C. McGinley, Esq**

what is claimed to be "available." An Individual Family Service Plan (IFSP) is a written plan identifying your child's needs and the services that will be provided. Prior to developing an IFSP, comprehensive evaluations should be conducted to establish your child's current levels of functioning, anticipated goals and objectives and the specific services that will be provided to your child and family.

Some examples of E.I. services may include, but are not limited to, speech and

language therapy, occupational therapy, physical therapy, Applied Behavior Analysis (ABA), Special Education Itinerant Teacher (SEIT) support, and counseling. Services for families often are recommended in E.I. and may include parent counseling and training to help reinforce and "carry over" your child's newly acquired skills, implement behavior plans and modifications at home, and provide additional support to your child.

### What Are Your Rights in E.I.?

To receive an updated guideline of your rights, you should contact your Early Intervention Coordinator. Generally speaking, parents have a number of rights in E.I., including but not limited to:

- Being an active team member and participant throughout the E.I. process
- Consenting to evaluations and receiving all copies of evaluation results
- Refusing consent to evaluations or the ability to withdraw consent at a later date (if appropriate)
- Refusing specific services without risking other services that are being offered
- Receiving written notices of any changes that are going to take place in your child's program

- Discussing your child's program and services with an advocate or attorney and challenging the proposed program if needed.

### The "Turning 3" Phase

The IDEA requires a minimum six month transition period from E.I. to preschool (i.e., the six month period leading up to your child's third birthday). This period allows for additional evaluations and meetings allows parents to build a positive relationship with the school district personnel.

It may be difficult for families to transition from "Part C" where family involvement at the E.I. phase is compulsory and parents are expected to make decisions about and advocate for their child's needs, to the "Part B" programs where the school district's committee on preschool education assumes the primary educational responsibility. It is important to start thinking about the transition planning as early as possible. In preparation for your child's transition from E.I. to preschool, you should ask your E.I. coordinator and providers what specific changes you can expect.

Special education services pick up where early intervention services leave off at age 3. Your local school district provides these services through their special

*see Entitlements on page 28*



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

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

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

**The Elija Foundation** provides advocacy support, educational outreach and comprehensive workshops in Applied Behavior Analysis for educators and family members. [www.theelijahfoundation.org](http://www.theelijahfoundation.org)

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## Steps to Empower Families to Access Early Intervention

By Bernadette Murphy Bentley, MPA  
Autism Resource Specialist  
Tufts Medical Center

In my six years as Autism Resource Specialist in the Center for Children with Special Needs at Floating Hospital for Children in Tufts Medical Center in Boston, I have met with hundreds of families in the moments after their young child receives an autism spectrum disorder (ASD) diagnosis. Although each family is unique, my goal for every one of them is the same -- to provide them with the support, encouragement, and information to empower them to get the services their child needs as quickly as possible.

There will always be parents who are able to take the recommendations from the diagnosing clinician and swiftly do what must be necessary to help their child. But there are far more parents who are challenged by their emotional reaction, confused by all the information, overwhelmed by everything else going on in their lives, and/or can't overcome the bureaucracy. Consequently, they remain stuck while their child does not get services.

Empowering these families is the key to ensuring that they are able to follow clinician's recommendations without delay. Empowerment at this early stage is also critical because it builds a strong foundation for the advocacy that all families will have to engage in throughout



Bernadette Murphy Bentley, MPA

their child's youth for his or her educational, medical, and community needs.

The definition of "empower" I like best is: "To give an ability to." Through my work, I am giving parents the ability to help their children, an essential skill for the journey on which they are embarking. We could provide a case manager to each

family who would be responsible for finding service providers, setting up meetings with the school, filling out applications, and acting as the child's advocate. But what does that teach the families? That they can't do it themselves. And for most families, that is not true.

If families have a clear road map with a knowledgeable and compassionate person to reach out to when they get lost or hit a dead end, they will find their way. Some families, however, have barriers they can't overcome on their own and will require a guide to ensure that their child gets necessary services quickly. In those circumstances, we do assign a social worker because our goal is for every child to have early access to the intervention he or she needs.

### Steps to Empowerment

So how do I empower families to access intervention quickly?

*The first step is meet them without expectations.* I never presume to know what a family is thinking or feeling or might need before I speak with them. I review the chart, talk to the clinician, and often watch the feedback session, but until I am with the parents, I do not know how I can best support them.

There is misconception that if parents are expecting the diagnosis, they are better able to handle it. I have sat with count-

less parents who are certain their child had autism even before the evaluation or who have come for a second opinion after already getting a diagnosis, and their reaction can be even more powerful than those who are not expecting it. On the other hand, many families are relieved and even happy to get the diagnosis because they finally know what is wrong and now have the key to unlock the door to services.

Whatever the parents' state of mind, I validate their reaction, help them process their feelings, and determine whether they are ready to move on to the next steps in the empowerment process. For some families our meeting focuses solely on the emotions they are experiencing, but even if that is the case, ALL families are given at least one action item when they leave to get them on the path to getting intervention for their child.

Another misconception is that if a family is highly educated, they are better able to get services for their children or conversely, if they have a limited educational background, they will require more assistance. I have found that the determining factor in how quickly parents are able to access intervention for their children is whether they are given the information they need in way that works for them.

*Thus, the next step in the empowerment process is to listen.* I'm not there to tell

see *Empower* on page 31

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## Early Intervention Services for Toddlers with ASD

By Debra Reicher, PhD  
and Carolyn Waldecker, PsyD  
The Hagedorn Little Village School  
Jack Joel Center for Special Children

Receiving an Autism Spectrum Diagnosis (ASD) can be an extremely stressful family event. Once the reports are read it may help to put them away for future reference and begin to focus on intervention. The shift from feelings of helplessness during the diagnostic process, to feelings of hopefulness as the appropriate interventions are planned, can be an essential therapeutic shift for the entire family. It can also be somewhat overwhelming, as it is difficult to know what interventions your child should receive.

If you had your child evaluated through the Department of Health, your case coordinator will recommend a treatment plan including various types of therapies and recommended frequencies. These services will be elaborated at a meeting including your family, one or more of the evaluators and the case coordinator, and will be outlined in a document called the I.F.S.P. (Individualized Family Service Plan). If you had your child evaluated privately, the diagnostician will have made specific recommendations for your child. These recommendations are likely to include one or more of the following services: speech and language



Debra Reicher, PhD

therapy, occupational therapy, physical therapy, special education and/or Applied Behavioral Analysis (ABA), family training, parent and me class, center-based special education and support groups. It may be difficult to imagine that a child as young as a toddler is actually able to benefit from therapy. Early intervention specialists are a select group of clinicians and therapists with extensive training and ex-



Carolyn Waldecker, PsyD

perience in very young children. They will use developmentally appropriate techniques to develop rapport, teach your child, and maximize social, communicative and cognitive development.

Communication deficits are one of the core symptoms of ASD. Speech and language therapy provided to toddlers on the Autism Spectrum aims at increasing total communication. Most children with ASD

struggle with communicating their wants and needs which can be extremely frustrating for both the child and family. The speech and language therapist will work on assisting the child in increasing his or her ability to communicate through a variety of means. This may include using sign language, Picture Exchange Communication system (PECS, a system where a child is taught to utilize small pictures to communicate), and verbalizations. It is important to remember that introducing sign language or PECS does not mean the therapist is "giving up" on teaching your child to speak. Such techniques actually increase the likelihood that your child will verbalize. Many children with ASD also have difficulty comprehending language so the therapist may work on teaching your child to follow simple commands, point to familiar objects and pictures and point to body parts.

Occupational therapy provides therapeutic intervention in the areas of fine motor and sensory functioning. Occupational therapists can help your child with activities of daily living, such as self-feeding and dressing, as well as completing simple puzzles and coloring with a crayon. Many children with ASD have difficulties processing sensory information. This can result in being over-reactive or under-reactive to sensory input such as touch, sound, smell, taste, or

see *Toddlers on page 31*

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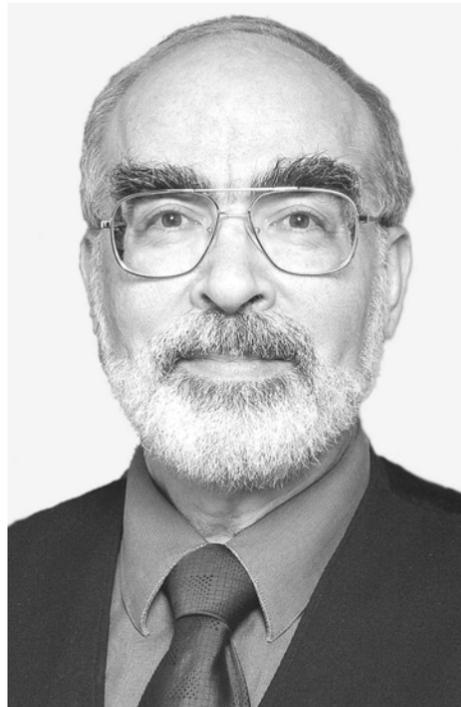
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## Seeing ASD in 3D: A New Clinical Schema to Describe ASD

By James Coplan, MD  
Developmental Pediatrician

In 1943, Leo Kanner (Kanner 1943) published an article described 8 boys and 3 girls, ranging from 3 to 8 years in age, with what he dubbed “an autistic disorder of affective contact.” Kanner described all the features we recognize today as core elements of ASD, including social isolation, impaired language pragmatics, repetitive behavior, and unusual processing of sensory stimuli. Remarkably, Kanner’s paper was also a longitudinal follow-up study: “Between the ages of 5 and 6 years,” he wrote, “they gradually abandon echolalia and learn spontaneously to use personal pronouns...Language becomes more communicative, at first in the sense of a question-and-answer exercise, and then in the sense of greater spontaneity of sentence formation...Food is accepted without difficulty. Noises and motions are tolerated more than previously. The panic tantrums subside. The repetitiousness assumes the form of obsessive preoccupations...Reading skill is acquired quickly, but the children read monotonously, and a story or a moving picture is experienced in unrelated portions rather than in its coherent totality... Between the ages of 6 and 8, the children begin to play in a group, still never *with* the other members of the group, but at least on the periphery *alongside* the group [emphasis in



James Coplan, MD

the original]...All of this makes the family feel that, in spite of recognized ‘difference’ from other children, there is progress and improvement.”

We are indebted to Kanner for his lucid and enduring description of the clinical features of ASD, his insightful description of ASD as an *inborn* disorder (not, as others would subsequently claim, the result of

abnormal parenting), and for his prescient observation that the symptoms of ASD change over time, in a highly predictable fashion – what I refer to as the “natural history” of ASD (In medical parlance, the clinical course of a disorder from onset through resolution constitutes the “natural history” of that disorder.)

Nearly 30 years after his original report, Kanner succeeded in tracing 9 of his original 11 patients. The range of outcomes was remarkable: 1 had died, 6 were receiving institutional care, and 2 were living with their parents. One of these two had earned a Bachelor’s degree and worked as a bank teller. Kanner’s observations have been borne out by numerous large-scale follow-up studies: most children improve, but the degree of improvement varies markedly. Why? The answer is twofold: First, ASD itself can cause any degree of impairment, from mild to profound: How “off” is the eye contact? How rigid is the “insistence on sameness”? How intense are the stereotypies? How impaired is the individual’s language?

Second, ASD of any degree can be accompanied by any level of general intelligence from Genius IQ to Profound Intellectual Disability. The importance of IQ as a driver of outcome for children with ASD was first articulated nearly 40 years ago, by Lawrence Bartak and Michael Rutter: “In terms of scholastic progress, social competence, and work opportunities, the child’s IQ level is as influential as the

presence of autism.” (Bartak and Rutter, 1976) When measuring intelligence in persons with ASD, we need to avoid items that will be selectively impaired due to the person’s ASD (verbal abstraction, for example). We also need to avoid “inflator scores” in areas where a person with ASD may have isolated islands of ability (single word naming, for example). Either type of testing error may result in under- or over-estimating the intellectual ability of a person with ASD. What we are generally left with are non-verbal skills such as object permanence, tool use (spoon, crayon), self-care skills, and some play skills.

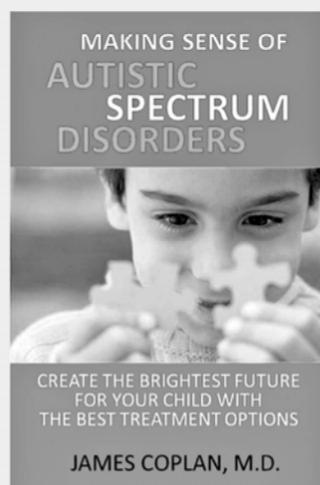
Now let’s combine these ideas – ASD varies in severity from profound to mild, and IQ is a major co-factor driving prognosis - into a graph (Figure 1A on page 33).

We can also map the commonly used DSM terms onto this graph (Fig 1B on page 33). The DSM-V may do away with all of the individual labels (autism, PDD-NOS, Asperger Syndrome). If this turns out to be the case, then the 2D graph will become even more important as a way of anchoring our thinking about any given person’s level of function/degree of impairment.

Finally, we add age (time) as the third, or Z axis (Figure 2A on page 33). This yields a 3-dimensional map on which we can plot the progress of individual children over time.

see ASD in 3D on page 33

### James Coplan, MD Clinician, Author, Public Speaker



*I'm so deeply grateful for this book. . . I just finished reading 'Making Sense of Autistic Spectrum Disorders' and had to take a moment to thank you. The information in the book was easy to understand, comprehensive, and helped me calm down and focus on the steps I need to take to help my son.*



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## Turning Fifty and Matching Progress Within the Field

By Frederica Blausten, MA, MS  
Executive Director  
Association for Metroarea Autistic  
Children, Inc.

**B**ased on media coverage, it seems that with the advent of each month, a new understanding into the root causes of Autism Spectrum Disorder is discovered. While it is exciting to anticipate a day when autism can be prevented and/or cured, the front and center work of the 50-year-old Association for Metroarea Autistic Children (AMAC) continues to be on the early intervention and education of those with Autism Spectrum Disorder.

### College-Bound

For Naresh, it was his maternal great grandmother who first noticed something was wrong when he was little older than one year. "My grandmother was old school from Virginia – they're the ones that notice things like that. Naresh had no language. She urged me to bring him to a doctor," says Michelle, Naresh's mother.

At 18 months old, Naresh was diagnosed with Autism Spectrum Disorder and by 20 months old, he was one of the first children in New York City to benefit by a new approach, Applied Behavior Analysis (ABA). Through its accountability, efficiency and consistency of approach through every level



**Frederica Blausten, MA, MS**

of care giving, "ABA poked a hole in the disorder and slowly Naresh flourished. It gave him his voice, literally, and he soon said his first word, 'me.'"

After Michele learned about and toured AMAC, she immediately felt that it would be, "...accountable for everything that Naresh needed to succeed and excel. What I liked about the school was its hands-on, multidisciplinary and high tech

approach. It gave him an environment in which to grow," Michelle recalls.

Naresh enrolled in AMAC as a third grader in 2003, was one of the first students at its high school when it opened in 2007. He is now a sophomore at Lehman College.

Naresh is just one of the many children helped by AMAC since its inception 50 years ago. Over the many years, we've seen many changes in the field. When we first began, there was much finger pointing as to who was to "blame" for autism and societal pressure to keep a family secret. Thankfully the understanding of Autism Spectrum Disorder "spectrum" with multiple components is exponentially helping parents, educators and doctors recognize its signs earlier and, as a consequence, provide better support and effective early intervention services.

### A Growth Parallel: AMAC and the Field of Autism Spectrum Disorder

In 1962, two parents sitting in a doctor's waiting room, Barbara Bloom and Gloria Mellon, discovered that they both had children diagnosed with what was then considered a rare form of childhood psychosis called infantile autism. They bemoaned the fact that there were no services to support autistic children and families beyond the private early childhood schooling in which they were enrolled. Out of that chance encounter, and the ensuing efforts of those parents, the AMAC was born.

With little societal understanding of what autism was, it became critical to AMAC's mission in those early years to provide social support and part-time recreation care for autistic children. Summer sleep away camp was added on to fill the gap between summer school and the fall term. This vital addition to AMAC services provided families much needed respite.

Some of AMAC's young children moved to available community placements. For teens, local education programs were not prepared to accommodate their needs in large junior and senior high schools. Parents often turned to residential schools or had no other choice than to institutionalize their sons and daughters.

Local services focused on a generic special education model. As with younger children, special education was non-categorical - "label jars not children" - and the cause of this rare disease was open to various theoretical designs so the unique nature of autistic people went unrecognized. AMAC developed more specialized services. At other locations, children and teens were mixed with other special needs populations, but not at AMAC. Researchers and parents began to question: Did anyone recover? Or out-grow autism? Services to adult autistic people became part of AMAC's program to address a new group of underserved.

*see Fifty on page 30*



## AMAC Celebrates Fifty Years From Classroom to Community

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list in formation!
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**1:30 Workshops**

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# The Transition Into Adulthood: Guiding Families Toward Successful Outcomes

**Suzanne Muench, MSS, LCSW**  
**Director of Admissions and Family Services**  
**Melmark**



**Suzanne Muench, MSS, LCSW**

One of the favorite things in my role as Director of Admissions and Family Services at Melmark is talking with parents about their children and helping families maneuver the complicated web of supports available to them. One of the most challenging parts, however, is helping families understand how dramatically different services and supports are in the post-21 world. Many parents just don't realize what they will face when their loved one graduates from a school program. To help alleviate some of this stress, Melmark has developed a systematic way of assisting families in addressing the various tasks necessary for a smooth transition into the adult system.

We have defined the key ages in transition related services to be 14, 16, 18, and 20. At each of these critical benchmarks, we have laid out specific tasks that families can complete, with the help of the school and county support personnel. Transition goals are reviewed at the student's annual IEP; goals such as obtaining a state ID, determining who will serve as guardian for the individual with special needs, obtaining Supplemental Security Income, and working with an attorney to set up a special needs trust. Melmark

meets with families to help guide them through these processes to ensure a successful transition.

Despite our team's guidance and all the supports focused on the post-21 transition, this particular change comes with the greatest amount of angst. While parents watch their typically developing children meet major milestones - getting their driver's license, graduating and moving off to college - they are reminded daily that their

child with special needs may never reach these milestones. The reality that their child may need lifelong care is becoming evident in ways many parents never could have imagined, and this coincides with the loss of major services and supports previously provided through an IEP. While services to children meeting special education eligibility standards are an entitlement through the Individuals with Disability Act (IDEA) via an IEP, services to adults with developmental disabilities are not guaranteed. Service levels and availability vary greatly, depending on the specific need of the individual, the state or county the person resides in, and the family's ability to advocate. There is a significant gap in what is needed and what is accessible to families.

The services that are available to support adults with autism have not evolved at the same rate as those for children. There is no unified system of funding that has taken responsibility for these young adults. Complicating an already difficult profile, many of these individuals may have higher cognitive abilities that leave them unqualified for services.

So what is a family to do when, regardless of how well prepared a child is in school for this transition, the opportunities for support do not meet their needs? The good news is that there are many innovative programs and supports being developed to address the issues raised thus far. Melmark directly answered the call for services for individuals who continue to need a high

level of support specific to challenging behaviors and intellectual disabilities. The Chris Maurer Vocational Program prepares young men and women for work environments, both on Melmark's campus and in the community, in a multitude of settings. Whether it's filing, copying or collating in the clerical room or working in the delivery and packaging areas, individuals who may require more intensive behavioral supports can still develop skills that can eventually lead to possible paid employment. The program, which involves intense behavioral supports within an evidence-based treatment model, has seen success with supporting individuals in food markets, office settings and delivery positions.

Other agencies are focusing on supporting the social and vocational needs of those who are higher on the spectrum in a myriad of ways. Many are utilizing technology as a way to prepare young adults diagnosed with autism for those social situations that may be more difficult to navigate. Still, other programs are creating apartments and alternative living situations for individuals who do not fit within the system as it currently operates. The ALAW (Autism Living and Working, Inc.) program has worked with families on alternative ways of supporting individuals in the community and to help support their growth and continued integration into the natural communities in which they live and work. It is

*see Adulthood on page 19*

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## Autism Spectrum News Welcomes New Editorial Board Member

Staff Writer  
Autism Spectrum News

Autism Spectrum News is pleased to announce the appointment of Patricia Rowan, LMSW, to the esteemed Editorial Board. According to David H. Minot, BA, Publisher of *Autism Spectrum News*, "I am so pleased to have Patricia Rowan join the Editorial Review Board. Pat exemplifies the outstanding qualities of leadership, commitment, and service to the autism community."

For the past 20+ years Pat has been serving children, teens, and young adults on the Autism Spectrum. Early in her career she trained at the University of North Carolina in the TEACCH Model. This is an approach that utilizes structure and visual schedules for students on the spectrum. Thereafter she developed and directed an interdisciplinary team and implemented a Structured Teaching Program in a school in New Rochelle for Special Ed. students K-21.

Pat is the founder of *Kid's Connection*, a well-recognized afterschool, social competency program for elementary, middle, and high school students.

With an ever growing population of transition-aged students and young adults, Pat developed *Opening Doors; a Socialization and Life Skills Group for Young Adults*. Groups are held twice a month at Westchester ARC.

Seeing the need for building partnerships with parents, students, and the schools, Pat became a *Student Advocate* attending CSE meetings and Team Meetings. She is active in educating and training parents to become the "experts" of their child that they truly are, while assisting them in CSE preparation and effective advocacy.



Patricia Rowan, LMSW

Post-graduation, one of the more challenging situations for students on the spectrum is finding a job that works for them. Encouraging independence and self-advocacy, Pat does *College Coaching and Vocational Training*. She guides young adults toward choosing the right career path, prepare for job interviews, and improve their executive functioning at work. Those students that are college-bound are guided toward schools that have supportive programs and a culture of acceptance.

Pat is also an active member of the Westchester Autism Advisory Committee. This group of Westchester parents and professionals are committed to bringing resources and services to individuals and families. The committee has just completed the Roadmap to Adult Services for People on the Autism Spectrum.

search for appropriate adult settings. Families should also connect with other families who are looking into similar supports and services. Developing a parent network organization can help divide the workload of researching available supports.

In the end, the most important decision will be a very private one, specific to each family and each son, daughter, sister or brother. For some, this may include residential placement in a group home. For others, it may mean independent living in the community with natural supports. In a system where there is too little support and resources to go around, families must focus on keeping an open mind, supporting each other, and continuously advocating for the most appropriate services.

*Melmark offers two distinct program sites in Berwyn, PA and Andover, MA. For more information about our PA location, please visit [www.melmark.org](http://www.melmark.org) and for information about our MA location, visit [www.melmarkne.org](http://www.melmarkne.org).*



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### OUTREACH PROGRAM

For those learners not enrolled in the school, The ELIJA School Outreach Program provides support, education and training to parents, family members, caregivers, and professionals—as well as conducting private consultations—within and outside of the school's community. ELIJA also participates in local and national conferences to help disseminate our knowledge and share valuable treatment designs with other programs that serve and care for individuals with Autism.

### THE ELIJA FOUNDATION

The ELIJA Foundation is a not-for-profit, 501c(3) organization serving parents, educators, professionals, and caregivers of children with Autism Spectrum Disorders (ASD) on Long Island, New York. Since 2002, The ELIJA Foundation has provided the community with educational opportunities that focus on improving the quality of programs and services available to children with Autism. In 2006, The ELIJA School opened its doors to extend the mission of the Foundation and start helping children with Autism. The Foundation's focus is to empower families and improve the competency levels of professionals, by providing training on the most advanced treatment and educational strategies that maximize the potential of those affected by Autism. The Foundation hosts workshops that give the community access to local and nationally recognized Autism professionals who present topics which will allow those with Autism to more fully participate in their families, communities and educational settings. The ELIJA Foundation is committed to offering the most comprehensive information that is geared toward improving the lives of persons with Autism and their families.

For more information on The ELIJA School, Foundation, Outreach Services, and Events, please visit [www.ELIJA.org](http://www.ELIJA.org)

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### Adulthood from page 18

creative thinking like this that will continue to drive the development of services and supports to adequately meet the needs of the most vulnerable individuals.

It is important for parents to advocate for their children early and often. During the IEP process during their child's school age years, families can begin to identify vocational skills, likes and dislikes. If this process is started early enough, by the time the child graduates, parents will have a good understanding of what vocational opportunities might be best for their child as they become young adults. Additionally, while many families have insisted on intensive staffing for students while in school, it is in their best interest to consider fading that level of support, because staffing ratios in adult programs are typically not as rich as those in school programs. Overdependence on staff prompting and direction can be a detriment to building student independence and can impede the

# It Starts with Feelings: Supporting Emotion Regulation and Mental Health in Young Children with ASDs

By Shana Nichols, PhD  
 Director  
 ASPIRE Center for  
 Learning and Development



Shana Nichols, PhD

As part of comprehensive ASD treatment, the overarching goal that must be kept in sight for all learners is a healthy quality of life. This approach to intervention begins at the moment of diagnosis or before, and continues far into late adulthood, the frontiers of which we currently know little about. As such, the question that should always be asked is whether a particular intervention, experience, or learning situation will ultimately play a role in improving a child's quality of life, either in the moment or further down the road. Renowned early intervention (EI) programs that follow an evidence-based model, are typically rooted in applied behavior analysis (ABA) as it is broadly defined. This includes such approaches as Pivotal Response Training (PRT), Positive Behavior Support (PBS), and Discrete Trial Teaching (DTT).

To achieve the overall goal of improved quality of life, each of these programs include focused intervention and skill building that varies according to many factors including the child's age, cognitive and language abilities, family

goals, readiness and motivation, and the target person of the intervention (e.g., the child, parent, teacher, peer). What many of the programs have in common is the desire to build specific skills in general areas. If you were asked, "What are the most common, global, and important targets for intervention for young children with ASD?", you would

probably easily be able to generate a list of domains that the intervention programs focus on. This list would likely include cognitive development, communication, social skills, behavior (appropriateness), pre-academic s, adaptive skills, gross and fine motor abilities, and play and leisure.

While we strongly believe in the importance of each of these target areas, we routinely see youth in our practice who, despite have participated in intensive early intervention, are missing some very important skills, contributing to the difficulties for which their parents are seeking therapy. The general domain under which these skills fall is "emotional abilities." Each of the comprehensive intervention programs incorporates some focus on emotions, however it is typically limited to identifying emotions in self and others by looking at photo cards of faces, or perhaps identifying situations that would cause someone to feel a particular way. A true emotions curriculum is extensive in both its breadth and depth, and is as important as each of the other target areas for intervention. At our clinic, we conduct an emotions assessment with each of our clients as part of beginning therapy. These assessments are very enlightening and provide us with a baseline of where to start therapy. For example:

Hilary (a composite case example) came to ASPIRE Center at age 7 because she was having daily meltdowns at home that were getting worse – more severe and lasting longer. She was also starting to break down at school. Hilary is a very bright young girl with an Asperger's diagnosis who had participated in a highly reputable EI program and was in general doing quite well. She loves safari animals, and has a best friend from school. We learned that Hilary had been seeing a therapist for over a year to help with her outbursts, with reportedly no noticeable improvement. What was most surprising was that her emotional vocabulary was limited to "feeling good" and "feeling upset;" she was unaware what she did when she was feeling upset, or of how it felt in her body. When asked, she could not make an angry face unless she could look at herself in the mirror. Ultimately essential for being able to regulate one's emotions and behavior, Hilary was unable to communicate what situations made her angry, which is essential for being able to regulate one's emotions and behavior. We now had many initial goals to work on while we started therapy.

Hilary's situation is not uncommon. In fact, we have teen and adult clients with

*see Emotion on page 27*

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## Alpine Learning Group's Parent Training Program: Be Your Child's Best Teacher!

**Angela Pagliaro MA, BCBA,  
Jaime A. De Quinzio, PhD, BCBA-D, and  
Bridget A. Taylor, PsyD, BCBA-D  
The Alpine Learning Group, Inc.**

**W**hy should parents receive training? More and more children are being diagnosed with autism before their third birthdays. Providing early, intensive, behavioral intervention at the point of diagnosis is beneficial to achieve the best possible outcomes for children with autism. Given that the amount of time a child spends with his or her parents far outweighs the time spent with professionals, parent training and education has long been established as a key element to the effectiveness of behavioral interventions for children with autism (McClannahan, Krantz, & McGee, 1982; Koegel, Koegel, & Ence, 2012). Research has documented that parent training and education has not only facilitated parents' ability to teach specific skills to their child such as toileting, social, and communication skills, but that parents acting as interventionists report reduced stress. Moreover, children whose parents are part of the therapeutic team are maximizing their time in intervention which could lead to an increased rate of progress.



**Angela Pagliaro MA, BCBA**

What is the PTEP Program?

As parents often have to wait for services to begin for their children, training parents to be confident, successful teachers, can promote the initiation of quality intervention at the point of diagnosis. This

is the goal of Alpine Learning Group's Parent Education and Training Program (PTEP), a skill-based parent-training and education program that provides parents with the skills necessary to feel confident to teach their children, promote better long-term outcomes for children by beginning early quality intervention, and decrease parents' levels of stress and anxiety. With proper intervention and assistance within the home, parents can become their child's best and most effective teachers.

The Alpine Learning Group (ALG) developed the PTEP in 2006 after receiving a foundation grant. Since that time, ALG has relied on generous grant support to continue this program and reach families who would otherwise not have resources to access the much needed support in the early days of diagnosis. The program works in conjunction with local physicians and care providers who are the families' first and often primary source of information about autism.

What Are the Goals of the Program and How Are They Measured?

The goal of the PTEP is to not only provide reliable information about autism and science-based treatments for autism to families of newly diagnosed children, but also to increase parents' accuracy in teaching their newly diagnosed children with autism adaptive skills and to teach parents

how to respond to challenging behaviors in a functional way. Alpine Learning Group hopes that providing the Parent Training and Education Program will increase the likelihood of positive treatment outcomes for the children as a result of quality teaching performed by their parents early on.

Outcomes of the PTEP are measured in two ways. A pretest and posttest measure is used to determine the parent's understanding of basic teaching strategies supported by the principles of Applied Behavior Analysis prior to and after the training has been completed. A social validity measure is also sent to parents at the conclusion of the program. This measure allows parents to indicate their satisfaction with the program and to rate their experience with the program. At this time, ALG has successfully served over 125 families in the Parent Training and Education Program.

How Does the PTEP Program Work?

*Phase 1 – Referral:* Participating hospitals and care providers refer parents of newly diagnosed children to the Parent Training and Education Program. Following a diagnosis of an autism spectrum disorder (e.g., autism, PDD-NOS), parents and caregivers are given the Alpine Learning Group's PTEP contact information.

*see Training on page 29*

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## Early Intervention Resources for Families with Young Children

By Lauren Agoratus, MA  
Parent  
Family Voices NJ

Research shows that early intervention (birth - age three) improves outcomes for children with autism and other special needs. Two good resources for families are:

- NECTAC (National Early Childhood Technical Assistance Center) with an overview of early intervention, data, and contacts for programs in their state at [www.nectac.org](http://www.nectac.org).
- ECO (Early Childhood Outcomes) center which has information on how children with autism are faring at <http://projects.fpg.unc.edu/~eco>.

Families need to know that in developing an IFSP (Individualized Family Service Plan) as part of the early intervention team, the focus is on the family, not just the child, and which supports are needed for success. Children may be eligible for therapies like speech/occupational/physical, audiology, assistive technology, nutrition, and other services to help them reach their developmental milestones.

The Statewide Parent Advocacy Network (SPAN), New Jersey's Parent Training and Information Center (PTI), Family



Lauren Agoratus, MA

to Family Health Information Center (F2F), and Parent to Parent (P2P) program, is implementing a project funded from the US Department of Health and Human Services' Health Resources and Services Administration (HRSA) as part of the Combating Autism Act to assist families of children with autism and other developmental disabilities to improve services and outcomes for their children, youth, and young adults. SPAN provides families with a "one-stop" for free help on education, health, and support.

The aim of our project is to "improve access to comprehensive, coordinated care" for the child and their family. We have 4 goals: 1) Strengthen the infrastructure needed to achieve and sustain an integrated, community-based system of services that achieves the six core outcomes for children with autism and other developmental disabilities; 2) Improve access to family-centered, coordinated, comprehensive care...through medical homes; 3) Increase effective transition to adult life services; and 4) Improve active participation of families...in all aspects of their children's care.

We are reaching these goals by basing our work on the MCHB (Maternal/Child Health Bureau) six core outcomes:

1) *Families will be engaged at all levels and satisfied with services.* Research shows that parental involvement improves outcomes. Our grant has an emphasis with targeted focus on the underserved, as data indicates that children of color are diagnosed later and early intervention is the key to best outcomes. For more information see [www.kennedykrieger.org](http://www.kennedykrieger.org) (go to news and click on research updates).

2) *Access to early and continuous screening.* This will improve referrals to start early intervention but parents must remember they can also refer themselves.

3) *Access to a medical home.* The medical home is not a place, but a concept, in

which a medical professional coordinates care that is high quality and cost-effective. For more information see [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org).

4) *Access to community-based services that are easy to use.* Again, support in their home communities results in better outcomes for children and their families. One of our key partners are the FQHCs (federally qualified health centers) which provide care for the uninsured and are found at [findahealthcenter.hrsa.gov/Search\\_HCC.aspx](http://findahealthcenter.hrsa.gov/Search_HCC.aspx).

5) *Adequate public and private insurance to pay for needed care.* Children with developmental disabilities may be eligible for employer based insurance as well as Medicaid; for more information see <http://finder.healthcare.gov>. For additional information on states that have specific autism insurance coverage see <http://www.autismspeaks.org/advocacy/states>.

6) *Support effective transition to adult systems of care.* It's important to note that it's not just "school-to-work" but can include healthcare and post-secondary education.

We recently presented at the AMCHP (Association of Maternal/Child Health Programs) conference on how to build systems of care for children with developmental disabilities (see [www.amchp.org](http://www.amchp.org)).

see Resources on page 28

### Identifying from page 1

A - As a first step, concerned parents should consult with the child's pediatrician. If the pediatrician suggests the child be evaluated, parents should ask for a recommendation for a psychologist specializing in ASD evaluations. During an ASD evaluation, the psychologist will administer standardized diagnostic and developmental assessment instruments, including interviewing the parents and child, and testing the child. The evaluation is not invasive, nor does it cause pain or discomfort to the child.

Q - When it opens, what services will the Center for Autism and the Developing Brain provide?

A - Our center will offer comprehensive care to patients of all ages with ASD and other developmental disorders of the brain, including a full array of evaluative, diagnostic, and multi-disciplinary services. In addition, we will provide "gap" services to aid families in planning for future treatment and community based care, and consultative services to agencies in the area. Our research will focus on the effectiveness of supports provided to people living with ASD in the community.

Q - What words of encouragement do you offer to parents of a child who has been diagnosed with an Autism Spectrum Disorder?

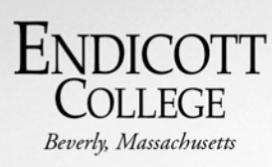
A - Although scientists are still exploring the causes of autism, the earlier ASD is diagnosed and intervention begins, the greater the impact will be in reducing the disorder's effects so the child can learn, grow, and



Catherine Lord, PhD

thrive. We will be here to guide, assist, and support parents and their families to improve the lives of their children with ASD.

Nationally renowned expert Dr. Lord is the Director of NYP's Center for Autism and the Developing Brain. A clinical psychologist, she co-developed some of the key diagnostic tools to help clinicians recognize autism in individuals of varying ages, and chaired the National Research Council's Committee on the Effectiveness of Early Intervention in Autism. She also is a member of the DSM5 Neurodevelopmental Disorders Committee.



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## Public Funding of Private Pre-School is a Mandated Early Intervention Service Required Under IDEA

By Gloria M. Satriale, Esq, BCABA and Thomas L. Zane, PhD, BCBA-D PAAL and Endicott College

**B**irth to age five, the time of early intervention services, is a critical time full of exploration, socialization and skill acquisition. For most children of this age in today's society, the bulk of their experiences take place in day care or pre-school settings. For children identified with autism and other developmental delays and who are eligible for early intervention (EI) services however, administrators often do not offer preschool as the environment of choice. Furthermore, notwithstanding the mandate of the federal law requiring the provision of preschool settings as a component of a free and appropriate public education (FAPE), many states continue to have policies "prohibiting" funding the cost of attendance at private pre-schools.

Part C of IDEA requires, "to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate" (34 CFR §303.12(b)). By definition, natural environments mean, "settings that are natu-



Gloria M. Satriale, Esq, BCABA

ral or normal for the child's age peers who have no disabilities." (34 CFR §303.18). In today's culture, "settings that are natural or normal for the child's age peers who have no disabilities" means preschool (for children 0 – 5 years of age). The era of June Cleaver and the stay at home mom who kept her child close to the apron strings until kindergar-



Thomas L. Zane, PhD, BCBA-D

ten are long gone. Staying at home until school age is no longer the norm; however, many states cling to that provision of the law referring to home based services to interpret "settings that are normal" as the home for very young children. Additional justification for the denial of a pre-school setting is made because no public preschool program ex-

ists. Parents should not accept a denial of a preschool setting for their toddler on any basis, as the law protects the provision of a preschool setting even if it is necessary to pay for a private preschool at public expense. In *re: the Educational Assignment of Jonathan S., Special Education Opinion No.1181 (2001), rev'd on other ground sub nom. Delaware County Intermediate Unit v. Jonathan S., 809 A.2d 1051 (Pa. Commonw. Ct 2002)*. Early intervention services in natural environments, including preschool, is not just a guiding principle or suggestion, it is a legal requirement *Bd. of Education of LaGrange Sch. Dist. V Illinois State Bd. of Educ., 29 IDELR 369 (N.D. Ill. 1998)* (a private pre-school is the LRE where no \*10 aspects of the disability of a four old with Downs Syndrome required the "at-risk" program offered by the district which prescreened children for academic or language difficulties); and *Office of Special Education Programs* ruling 16 EHLR 739 (to meet LRE requirement, each preschooler's placement must be consistent with determination of the child's ability to be educated in regular education programs. In the instant case the student's ability to be educated in a typical pre-school program was specific finding of the team).

see IDEA on page 32

## Some Thoughts on Early Diagnosis and Effective Treatment of ASD

By Marion K. Salomon, PhD  
Executive Director  
Marion K. Salomon & Associates, Inc.

**I** am the director of an Early Intervention agency and until recently was its primary Autism Spectrum Disorder (ASD) evaluator. I am a bilingual child psychologist and have been diagnosing and ruling out ASD in children below age three for several decades. We've seen ever-earlier diagnosis (down to age 12 months or less). We no longer label children as mentally retarded, but see increases in the ASD label and its many subcategories. Treatment options and the relative popularity of each continue to be debated. The possibility of curing individual children, the definitions of "cure," and the reasons to use just one treatment vs. a sampling from several are endlessly argued.

I try to be open-minded, but I feel strongly about certain criteria for appropriate evaluation of very young children. First of all, a toddler should be evaluated in a familiar setting (or two settings if the child spends lots of time at daycare or grandma's house as well as at home). Secondly, the appointment time should be chosen to suit the child's needs, not those of the evaluator. The child should be well rested and well fed and should not have spent the previous 90 minutes in a car in stop-and-go traffic. In addition, the professional should spend enough time ob-



Marion K. Salomon, PhD

serving and interacting with the child to convince everyone that a good sample of the child's everyday behavior has been obtained. When working with a young child, the evaluator should use a variety of toys and other items, offering lots of opportunities for the child to initiate and respond to social interaction, make demands, and communicate via eye contact, gestures, and vocalization.

If the parent announces at the beginning of the session that the child has been up all night (uncharacteristically), is getting over an illness, or seems to be developing one, the evaluation should be postponed to a later date. Many times, parents are reluctant to reschedule an evaluation, either because they fear they're inconveniencing the evaluator or because they're so anxious about the procedure that they want it to be over with at all costs. The experienced evaluator should insist on the postponement if the child is not healthy and comfortable. Similarly, if afterward the parent says the child has not behaved as usual, it may be necessary to schedule a second visit.

It does no good for parents to feel that their child's ASD diagnosis is suspect because it resulted from a 10-minute observation in an unfamiliar professional office during the child's usual naptime and after a 45-minute waiting room stay. These circumstances offer too many reasons for a parent to discard the diagnosis and reject appropriate treatment.

Though some people view ASD evaluations of children as young as 12 months as ridiculous, these evaluations do occur, and sometimes they result in legitimate diagnoses. The only one-year-olds I've ever been asked to evaluate all have very knowledgeable parents, some with graduate degrees in psychology, special education or speech pathology, and others with young family members with ASD. Many of the usual evaluation instruments cannot be used with

children who are very young or low-functioning. However, the DSM (Diagnostic and Statistical Manual of the American Psychiatric Association) lists the agreed-upon criteria for a diagnosis of ASD, and ultimately, these criteria can be used with even the youngest children. It is not easy, technically or emotionally, to decide that a 12-month-old has ASD, but sometimes the characteristics are so apparent that a diagnosis is inevitable. Of course, if the evaluator is not sure, the conclusion should be, "Not sure," and a re-evaluation later or a second opinion from another competent professional should be suggested.

The best reason for putting a family through the anguish of having their baby diagnosed with ASD is that the result is treatment, and nowadays we have treatment with proven effectiveness. Parents make all sorts of choices – this treatment vs. that, several treatments vs. just one, evidence-based vs. not. I feel strongly about the following criteria for appropriate treatment. First of all, the professionals and the family should work together. This does not mean that the parents should necessarily take on the role of special education teachers, working with their child just as the providers do. Here's an example. A two-year-old girl had learned to point at desired objects, after many weeks of work on the part of her teachers. On Friday afternoon, the parents agreed to insist on her pointing to make

see Thoughts on page 34

## A Different Kind of Summer Program for Teenagers

By Nancy Phillips, MSED  
Autism Consultant  
Eden II/Genesis Programs

**H**aving just finished our summer, we can say that in its fourth year, the Eden II/Genesis Summer Vocational Preparation Program has had its best summer ever! Headquartered at Hofstra University, in Hempstead, NY, thanks to the cooperation of its Counseling, Research, Special Education and Rehabilitation (CRSR) department, the program's purpose is to afford participants vocational and social opportunities in a community-based environment, to introduce and/or enhance vocational skills, and to develop a social-vocational evaluation to bring into the new school year.

Our participants, who range in age from thirteen to twenty, arrive each morning, meet in a clinic room that becomes part of our "headquarters" for the summer, and set about getting ready for the day. After unpacking, they hang out in the break room and independently find something to do. Some choose to play a group game. Others prefer in individual activity. Staff remain in the adjacent room keeping eyes and ears on the participants but for the most part allowing them to interact without us (observational windows aid us in this endeavor).

Participants attend a daily morning business meeting with the theme "be healthy"



Waiting for the campus bus, right on schedule...

always attached. We exercise to music and discuss our "healthy" journals that include a daily homework assignment to write down a healthy activity and/or food partaken of at home. Participants prepare their agendas for the day. The schedule is written on the whiteboard and each activity that is new is pre-taught. Each student enters his/her schedule in the iPod Touch we've provided for the duration of the summer. These individual iPods are used for budgeting, calendar skills, monitoring of to-do lists, and appropriately managing downtime, such as the use of gaming applications.

Our students are quite independent as the day begins, but this independence comes after some carefully planned introduction and modeling. In preparation, our staff become well-versed in the participants' behavior plans, IEPs, person-centered planning information, and any anecdotal data gathered. The program is staffed by one full-time special education teacher, one supervisor two full-time TAs, two BCBA interns, and occasional interns from Hofstra's graduate Special Ed program. By the time the program begins, we are getting to really know our participants. Two individualized

goals are created for each participant and data are taken throughout the program. And as our students span a broad age and ability range, we must be cognizant of each ones' strengths and how these assets can best be used to help one another.

A significant part of the program – perhaps the most significant – is our internship at Hofstra's Barnes & Noble Bookstore. This on-campus site is housed in the Student Center which in itself offers great value-added for the program. The managers at the bookstore have been consistently welcoming. They recognize that our workforce comes with a range of abilities, and as a result they always have a multi-part job for us to do on the Tuesdays and Fridays we arrive for work. It is so gratifying for the students to know that their work is sought after, and that they really make a difference. This year each worker was given a regular employee ID tag, and at the end of our six weeks, each was given the back-to-school t-shirt that all employees will be wearing as work begins in the fall. How great!!

The college campus offers a multitude of riches. Participants are exposed to the collegiate atmosphere, and they are integrated with typically developing college students. During their Barnes & Noble internship hours, participant eat lunch in the Student Center cafeteria. This provides inclusive opportunities with typical college students, as well as real-life experiences

see Summer on page 34



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### Hispanic from page 4

language other than English) and lower scores on standardized tests of receptive and expressive language. This resulted in lower overall cognitive scores for this group.

"Our results emphasize the importance of considering cultural and other family factors such as multiple language exposure that can affect development when interpreting clinical tests, even when they are conducted in the child's preferred language," said Robin Hansen, chief of developmental-behavioral pediatrics at UC Davis, director of clinical programs with the MIND Institute and a study co-author.

Hansen, the MIND Institute clinical

team and the Center for Excellence in Developmental Disabilities at the MIND Institute have worked hard to provide accurate, current and evidence-based information about developmental disabilities to parents, educators, therapists and health-care specialists through an annual conference, website resources and community outreach.

"That so many children are slipping through the cracks is disheartening," Hansen said. "The differences between developmental disabilities can be subtle but important and involve distinct treatment pathways. We need to make sure that all children are getting routine developmental screening, early diagnosis and intervention so they can achieve their fullest potential."

For information on developmental milestones, visit the Centers for Disease Control and Prevention "Learn the Signs" website, which is available in English and Spanish at [www.cdc.gov/ncbddd/actearly/index.html](http://www.cdc.gov/ncbddd/actearly/index.html). Parents with concerns about their child's development should work with their health-care provider, school district and California Department of Developmental Services regional center to identify appropriate services.

The study, titled "Autism spectrum disorders in Hispanics and non-Hispanics," is available at <http://aut.sagepub.com/content/16/4/381>. The research was funded by the National Institute of Environmental Health Sciences (grants R01-ES015359 and P01-

ES11269), the U.S. Environmental Protection Agency's STAR program (grants R-829388 and R-833292) and the UC Davis MIND Institute.

Based in Sacramento, Calif., the UC Davis MIND Institute is a collaborative international research center committed to the awareness, understanding, prevention, care and cure of neurodevelopmental disorders. Utilizing the advanced biomedical technology and research infrastructure of UC Davis, the institute's scientists and clinicians pursue investigations that will ensure better futures for the one in twenty Americans with neurodevelopmental disorders. For information, visit [www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute).



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

By Carrie Cariello

### Dear Self

A few weeks ago I read an issue of People Magazine that featured one of the Real Housewives of New Jersey and her newly-diagnosed autistic son. The headline bleated something like, "Jersey Housewife Fights to Save Her Son!" When I read this, I felt a surge of outrage.

Save? Save?

After a moment, my sense of indignation subsided, and I thought to myself, "Oh, I remember those days." I remember the days of thinking we had to somehow get Jack to recover from his autism, to heal and to change, to discharge his diagnosis like a snake shedding his skin, leaving us with a beautiful, bright-eyed boy who made eye contact and loved birthday parties.

Now I know better.

My next thought was, "I should write her a letter, telling her to relax, not to worry, it's all going to work out." Luckily before I actually sat myself down to pen such a note, I realized a housewife in New Jersey could probably care less what a housewife in New Hampshire has to say about her situation.

But I thought about what I wished someone had told me when Jack was first diagnosed, what I would've liked to know. And



Two-Year-Old Jack

so I decided instead to write a letter to myself, on the day two-year old Jack was diagnosed by our developmental pediatrician.

11/3/06

Dear Self,

Today you received Jack's official diagnosis of autism. And although you

expected it all along, you're still reeling from the doctor's softly-spoken words. You listened attentively to his hushed voice saying things like "considerable delay" and "early intervention" as Jack whirled and spun around the tiny exam room. At one point you started to sweat.

It's been a long journey leading up to this day; a long road of, "When will he

talk and why doesn't he recognize me?" A long two years of tantrums, heartache, and the eerie quiet of a toddler who doesn't speak. Months of watching your brown-haired boy through a two-way mirror as a variety of specialists tested his hearing, tested his language, tested the very way he stacked multi-colored blocks.

Autism.

Right now, you're thinking you can fix him, that he will outgrow this. But you can't and he won't. Instead, both you and he will learn to coexist with it, until the beautiful moment when the autism and the boy combine together and you fiercely love them both.

Slowly, you're going to see him for everything is he rather than what he is not. The list of, "He's not talking, when will he point, why doesn't he play with others?" is eventually going to be replaced with, "Look at his smile, I love to hear his voice, tell me again Jack, tell me everything you have to say, tell me!"

He will surprise you every single day.

In the meantime, I won't lie. You have some very long days ahead of you; days full of frustration, of intense outbursts, of whining. Days where you'll go to bed at night hating yourself. But you will always wake in the morning with new resolve and

*see Dear Self on page 34*

## Neighborhood Charter School of Harlem Opens with Integrated Program for Children with High-Functioning Autism

Staff Writer  
Autism Spectrum News

The Neighborhood Charter School of Harlem (NCHS) is a new K-8 charter school with a unique mission: to provide a quality education program for area children that includes a specialized and fully-integrated program for students with high-functioning autism spectrum disorders (ASD) – something no other charter school had ever attempted.

Knowing that low-income children with ASD are often identified later than other students, the founders of NCSH hit the streets with flyers and visits to pre-school programs, looking for neighborhood families who had never had their children evaluated for the disorder. And the school, working with the YAI Autism Center, provided the families with free evaluations.

The school, which currently is serving kindergartners and first-graders, is de-

signed to provide a rigorous, comprehensive program that cultivates the intellectual, social and emotional development of each child. The ASD students are fully integrated into all aspects of the school and also receive specialized supports to help them achieve their full potential.

The YAI Autism Center team evaluated 45 children for the school. The process began in January of 2012 and was completed by July, prior to the school's opening on Aug. 20. The free evaluations were completed by a team of psychologists, a speech and language pathologist, a social worker and a psychiatrist. Assessments included an Autism Diagnostic Observation Schedule (ADOS), a Social Responsiveness Scale (SRS), as well as a psychiatric evaluation.

Once eligibility was determined, the school conducted a public enrollment lottery.

"We were very happy with the team at YAI, all of whom were extremely professional and a pleasure to work with," said Patricia Soussloff, Vice-President of the

Board of Trustees, who also is a former corporate lawyer with experience helping disadvantaged families gain access to special education. "They made the process easy for families and also followed up and provided helpful resources to some families whose children did not qualify for our program."

Of the 49 students in kindergarten, eight have autism; eight of the 57 first-graders are also on the autism spectrum. These students participate in the same grade level academic curriculum as their classmates and are fully included in all aspects of the program.

The classrooms for ASD children are smaller and organized to reduce visual stimulation in order to decrease distraction and sensory overload.

Teachers who work with these students receive training in strategies and supports designed especially for children with autism. Students in the program also participate in special classes taught by a speech pathologist designed to help them with the social understanding and communication

deficits and difficulties with self-regulation that often present challenges for them.

"No charter school had ever created a program that fully integrated children on the spectrum with their typically-developing peers," said Tracy Mazza, Project Manager with YAI LINK, an information and referral department. "Being part of this was not only beneficial for the school, but it also helped us learn more about diagnosing and evaluating children on the spectrum."

"Working in an underserved community, it was enriching for us to meet with the families, work with the children and develop relationships with them and the staff at NCSH," said Jill Krata, Manager of Clinical Services with the YAI Autism Center.

*For more information on the high-functioning autism program at the Neighborhood Charter School of Harlem, visit [ncsharlem.org](http://ncsharlem.org) or call 646-701-7117. For information about the YAI Autism Center, visit [yai.org](http://yai.org) or call 1-866-2-YAI-LINK.*

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**Guide from page 1**

volume and pitch were also painful for Dr. Grandin, “like a dentist’s drill hitting a nerve.” It is no wonder she tried to escape such situations, as do most children with hyper-sensitive sensory systems.

**Suggestions for Parents**

For parents of sensory aversive children, the following suggestions are offered. Firstly, it is important to remember that sensory aversive children require soothing methods to decrease their arousal in order to feel calm. Examples of ways to decrease arousal include brushing, deep pressure, or being wrapped in blankets. For children who are sensitive to loud sounds, wearing earplugs is recommended to reduce auditory input. Speaking calmly to children in order to prepare them for what stimuli may be approaching can also reduce their anxiety and decrease the chances of their being suddenly overwhelmed. Many children are also soothed by classical music.

Children who are sensory seekers benefit from proactive sensory input. This allows them to organize themselves and align their sensory systems before they engage in inappropriate behaviors to meet their sensory needs. Examples of sensory input include carrying a heavy bag, jumping on a trampoline, or doing wall push-ups. Other suggestions include movement breaks to walk or jump in place if a child has been sedentary for a while. Some of these needs can be met in the community to help avoid public tantrums. For example, having sensory seekers be responsible for pushing the cart in the grocery store is

**Sheri Wolnerman-Bardos, MS**

a good way for them to receive the input they need to feel regulated. Also, some toys can help reduce fidgeting during times that demand quiet or focus. Examples of these toys include Koosh balls, small stuffed animals, or stress balls. Sitting on a large inflated ball where sensory seekers can move around while completing tasks can also be helpful as it can provide additional sensory input that is often needed to sustain attention to complete tasks.

As parents gain understanding about their children’s sensory dysregulation, it is essential for them to pay close attention to the specific sensory triggers that unbalance

**Natalia Appenzeller, PhD**

their children. Initially, the triggers may seem arbitrary, but over time parents should be able to identify a pattern. Paying attention to what *triggers* lead to sensory dysregulation in their children, can help parents minimize or prevent negative reactive behaviors. Knowing triggers can also help parents learn to avoid them whenever possible, as well as help to set goals for sensory integration, desensitization, and behavioral programs. Furthermore, it is vital that sensory triggers be taken into account when shopping for clothing or planning excursions. Occupational therapists can assist with this process. Once triggers are identi-

fied they can help create “sensory diets” that parents can follow to help regulate their children throughout the day.

Parents of children with ASDs should also be mindful of *time* in both the long and short term, as their children often require “more time” than their typically developing peers. In the long term, developmental milestones may not arrive until later, making progress toward achieving goals take longer than anticipated. In the short term, allotting more time to complete tasks, for example morning or bedtime routines, can be very helpful as children with sensory processing difficulties can become upset by stimuli in their environment in an inconsistent manner. Thus, something that is not disconcerting to them one day may be another day. Parents who develop patience with these processes will be less frustrated and experience less pressure when working with their children. Furthermore, allowing extra time to complete tasks in the event that there is a behavioral difficulty that will require addressing can reduce the anxiety of time constraints.

Parents may personalize their children’s sensory needs and aversions, despite the fact that they are merely responding to their own sensory systems. This is especially true for parents of children who are aversive to touch, as this is typically a means of bonding between parents and children, especially in the early stages of life. When their children respond negatively, parents often view this as a rejection of them and their affection. For parents of children with sensory processing difficulties, the best way to communicate

*see Guide on page 28*

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**YAI Autism Conference:  
Autism and Bullying Set for Nov. 28**

Staff Writer  
Autism Spectrum News

**L**ee Hirsch the award-winning director of the documentary “Bully” will be the keynote speaker at “Autism and Bullying,” a one-day conference for families and professionals Wednesday, Nov. 28, 2012, at McGraw-Hill.

Dr. Paul Law, Director, Interactive Autism Network, Kennedy Krieger Institute, and Dr. Jed Baker, Director, Social Skills Training Project, will also present at the conference, which is sponsored by YAI.

For more information or to register, visit [yai.org/autismconference](http://yai.org/autismconference) or call Abbe Wittenberg at 212-273-6472. A discount family rate is available.

**Free Conference for New Jersey  
Families on Community Care Waiver**

Staff Writer  
Autism Spectrum News

**A** free conference for New Jersey families on the future of services will be held on Friday, Oct. 12, from 9 a.m. – 1 p.m. at Hackensack University Medical Center’s Hekemian Conference Center, 30 Prospect Ave., in Hackensack.

The conference will focus on the Medicaid Community Care Waiver and its impact on residents with developmental disabilities. Deputy Commissioner Dawn Appar of the

State of New Jersey Department of Human Services, Interim Director of Division of Developmental Disabilities, will be the keynote speaker. Kim Todd, CEO, New Jersey Association of Community Providers, and Ann Martinelli, parent, Advocates for Alternatives, will also present on families and service providers working together.

Pre-registration is required as space is limited. For more information or to make a reservation, contact Abbe Wittenberg at [abbe.wittenberg@yai.org](mailto:abbe.wittenberg@yai.org) or 212-273-6472.

The conference is sponsored by the National Institute for People with Disabilities of New Jersey, a member agency of YAI.



## ROBIN'S VOICE ~ A Resilient Mom's Commentary on Autism

By Robin H. Morris, Freelance Writer

### You've Got a Diagnosis: Early Intervention is Key

The years have not been easy in pursuing a cure for autism. Now we have information that dictates that there may be multiple causes for the autism diagnosis. Depending on the severity of the disorder, there are numerous individuals who have been able to share the gifts that autism has brought into their lives.

Nevertheless, there is pain and suffering for thousands of children and families living with autism. It has been established that early intervention is key. There is no magic format or recipe for success. I would add that an old fashioned notebook and a sturdy pen is vital in this effort. Record your trials and failures/successes. Enlist all parties in this effort. It is quite empowering. Consequently you have a tangible log as a permanent reference. Here is my story:

When I gave birth to quadruplets in 1987, it was big news. Not only was a multiple birth a rarity, our children were in-vitro babies. We were called pioneers nearly 25 years ago. However, our joys were threatened by long hospital stays, respiratory ailments and calculating developmental milestones; like a ticking clock we raced against time.

Our son Paul was the last baby born and

his lung issues spurred a cardiac arrest, six months after his birth. Following subsequent lung surgery, it was a long recovery....but he thrived; at least physically. He started to grow. The minute we realized that Paul had less tangible challenges that were to be reckoned with, I drew from every bit of strength I had learned while pursuing fertility treatment, leaving no stones unturned. It took patience and bravery to investigate what mystery had engulfed my child.

Hearing tests multiplied, and developmental evaluations explored our two-year-old baby boy. An electroencephalogram was performed while he slept. While that test showed no seizure or abnormal brain activity, the consensus was that Paul had "atypical developmental disorder," which, in those days was a catch-all phrase. I took a deep breath and drew on that resilience. "I don't care what you call it," I said. "What are we going to do about it?"

Early intervention was my answer. I became my own contractor:

- I learned that brushing my son with corn husking brushes might "awaken" his sensory issues (to no avail)
- I became a Dr. Stanley Greenspan disciple and practiced *Floortime Therapy* as I followed Paul's actions on his level
- I employed Speech, Occupational and Play therapists

- I tried Auditory Training (benign intervention, but not substantiated)
- I tried a gluten free diet (to no avail)
- I stopped at invasive treatments
- I followed my gut

Initially, our Paulie seemed very content in his world. He did not tantrum or cry unless he was hurt. However, I never allowed him to perseverate or dwell on rigid ritualistic behavior. I remember sabotaging his obsessive design of salt, pepper and napkins that were grouped in a line on our kitchen table. Every time he tried, I went in there and messed it up. I was operating on gut feeling, and somehow fighting an unknown opponent. My resilience and tenacity were my militia.

I am reminded of all of the trials and patience that we, as families living with autism have endured. Add it to the list, I thought, and a silly analogy popped into my head. I call it the autism jingle, hardly "My Favorite Things." Sometimes I have to cut myself some slack, find humor in adversity and simply brush myself off and move forward with hope.

Years ago, I sang and skipped to the lyrics in *A Sound of Music*:

*Raindrops on roses and whiskers on kittens  
Bright copper kettles and warm woolen mittens  
Brown paper packages tied up with strings  
These are a few of my favorite things....*

After 25 years of miss steps in the autism dance, I chronicle our personal song of interventions, and so it goes...

*Corn husking brushes and auditory training  
Hours and hours of waxing and waning  
Hyperbaric oxygen & warnings about vaccines  
These aren't a few of my favorite things  
Searching and begging and years of frustration  
Said no to secretin and vetoed chelation  
Then looked at that face and how hard he tried  
My favorite thing is this child and I cry  
When reality bites  
When the bullies sting  
When I'm feeling sad  
I simply remember my boy/my hero  
And then I don't feel so bad*

It is a good thing to look at where we started and where we are now. We are vulnerable yet strong. The best mantra is to keep our eyes on the prize, our children, and move forward with purpose and hope.

Note - The choice to employ alternative treatments is not a statement of scientific or proven intervention. Whatever choices we made, were based on personal decisions.

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### Emotion from page 20

whom we work who have a highly limited emotional skills set, even starting with matching emotions in pictures. And yet, much of the published research on emotions and ASDs has been limited to emotion recognition in facial expressions. What about the rest of an emotions skill set? Mayer and Salovey (1997) argue that there are four components to a fully developed emotions skill set. These include:

1. *Perceiving Emotions* - detecting and deciphering emotions of both self and others across a wide range of stimuli (e.g., pictures, voices, sculpture). Perception is the foundation on which emotional intelligence is built, and is therefore a key skill to learn in early intervention.
2. *Using Emotions* - being able to harness our emotions to facilitate cognitive activities such as thinking and problem solving.
3. *Understanding Emotions* - comprehend an emotional vocabulary and understand the complex relationships amongst emotions (e.g., a girl going to her first day of camp is feeling both nervous and excited).
4. *Managing Emotions* - this facilitates emotion regulation in ourselves.

Emotional skills are an essential target of intervention as they are highly

connected to communication abilities, behavior, self-awareness and self-monitoring, social skills, well-being, mental health, and self-esteem. Data has shown that girls with ASDs as young as 2 years of age present with more sleep difficulties and depressive and anxious affect. By adolescence, many youth have full-blown depression and anxiety, and present with *internalizing* symptoms. Youth with ASDs, like Hilary, generally have difficulty regulating their emotions, and they frequently have a limited repertoire of coping skills. If emotional skills are a target of intervention during the EI years, it is possible that we may be able to prevent some of the challenges that emerge during childhood, and continue on into adulthood. A comprehensive EI emotions program would incorporate the following skills:

- *Labeling* primary (happy, mad, sad, scared) and secondary (surprised, disgusted, embarrassed) emotions across a wide range of stimuli to incorporate multisensory learning (e.g., puppets, music, drawing, acting, mirrors)
- Identifying a *range* of emotions (e.g., happy-----ecstatic)
- Identifying what causes emotions in favorite characters in books or on television or in movies (e.g., why is Sponge Bob crying?)
- Identifying whether a display of emotion matches the severity of a situa-

tion (e.g., having a meltdown because a video game has to be put down at dinner time)

- Identifying the causes of their own emotions
- Beginning to identify their own emotion-based behavior in certain situations (e.g., runs away when angry)
- Being able to identify what goes on in their body when they feel a certain emotion (e.g., jittery stomach when anxious)

From here, you can begin to work on self-monitoring and the development of simple, concrete coping skills (e.g., breathing, counting, visualization, mantras), in addition to the more sophisticated skill of identifying thoughts, and linking those thoughts to feelings, situations, and behavior (early stages of cognitive behavioral therapy).

A recent study demonstrated that many youth and teens with ASDs (approximately 70%) develop a co-occurring psychiatric disorder, such as an anxiety disorder, or depression. Other youth present with sub-threshold symptoms, and difficulties with "life management" (poor coping skills, low frustration tolerance, self-regulatory difficulties, anger, poor problem-solving skills, and deficits in executive function: Gjevick et al., 2011).

If we are able to incorporate substantive skill-building in the area of emotions when kids are young, we are essentially facilitating strong *emotion regula-*

*tion skills* as kids get older. Both *external* and *internal* supports are available in teaching emotion regulation. Early learners typically start with having external support (e.g., consistency in routine, scheduled breaks, clear calm communication, visuals, choice and control). As skills are taught, *internal* supports develop and more independence emerges (e.g., social skills, asking for help, problem-solving skills, relaxation and coping skills, being able to engage in cognitive restructuring).

The basics of identifying emotions creates the first step in the ladder towards independent self-regulation. Youth can't self-regulate if they don't know what they are feeling, if they don't know what they do and how their body experiences a particular feeling, and if they don't know what situations cause them to feel certain ways. By incorporating emotion skills as an essential component of a comprehensive EI treatment plan, providers are building the stage for self-esteem and self-efficacy, the ability to self-monitor, and ultimately the ability to regulate behavior and emotions. Youth as young as five years old have come to our clinic for emotion assessments and interventions in order to get ready to participate in cognitive behavioral therapy. Remember, it all starts with feelings.

*For more information about our therapy program at ASPIRE, please call 631-923-0923, visit our website at [www.aspirecenterforlearning.com](http://www.aspirecenterforlearning.com) or email us at [aspirecenterforlearning@gmail.com](mailto:aspirecenterforlearning@gmail.com).*

**Ten Questions from page 8**

only competent, but also inspires your trust and confidence. The best financial professionals are good listeners who seek to fully understand your circumstances and financial objectives before proposing possible solutions. They should have access to product solutions from many fine companies, should clearly explain how they get paid for their services, and should provide references upon request. Make sure your financial professional has a solid support network behind them since those affiliated with a strong, reputable firm will likely have access to better resources to support your changing needs.

7. How do I pick the right financial services company?

Based on your specific needs, your financial professional should present product solutions from companies that they highly regard and with which they have had positive experience. Just as you will want to align

yourself with a strong, reputable financial professional, you will want to do the same with regard to financial services companies. In many cases, products will be used to address financial needs and objectives that last for decades, if not a lifetime. To help ensure that your financial product providers will be there when you (or loved ones) need them, work with strong, stable companies that have received high marks from independent ratings agencies such as A.M. Best, Standard & Poor's, Moody's and Fitch.

8. What if I already have a plan?

Even the best financial strategies should be revisited and updated regularly, generally at least once a year. Common life events such as marriage, having children, changing jobs, or even moving, can affect your existing approach. So, too, can just having another birthday – particularly if it means you have reached a financial milestone, such as the year you can begin collecting Social Security, re-

ceiving Medicare benefits, or taking distributions from your retirement accounts. An experienced financial professional should regularly review your strategy with you, to help ensure that it remains aligned with your objectives and appropriate for your circumstances.

9. What is the downside of putting this off?

Developing a financial strategy is a critically important activity that should not be rushed; however, there is a fine line between not rushing the process and not focusing on it at all. By putting this off, we expose ourselves and our families to unnecessary risks and lost opportunities – be it by not safeguarding our lifestyle from unexpected events, by not insuring our livelihood and legacy while in a position of health and strength, or by not capitalizing on even one extra day to build and protect our retirement nest egg. By actively focusing on this process, you can help protect your interests and shape your future.

10. What am I waiting for?

You should now know what to consider as you develop your financial strategy and how to secure the best resources to turn that strategy into a reality. Perhaps most importantly, you should now understand how to avoid common pitfalls that lead some to take what may be the greatest risk of all – the risk of doing nothing. Take the next step by doing additional research on your own or seeking guidance from an experienced financial professional.

*This article is provided by Stuart Flaum, a financial representative with MassMutual Westchester, a MassMutual Agency; courtesy of Massachusetts Mutual Life Insurance Company (MassMutual). Stuart may be reached at [sflaum@financialguide.com](mailto:sflaum@financialguide.com).*

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education department at the preschool level. An Individualized Education Plan (IEP) is the document developed for your child and outlines, among other things, your child's needs and how these needs will be met. Like the IFSP, the IEP is required to adequately describe your child's strengths and weaknesses, set appropriate goals and objectives and provide specific information and plans as to how your child's needs will be met. It is often helpful for parents to bring along another parent, a family member, or a member of your child's E.I. team.

When determining the appropriate educational program and placement for your child – including preschoolers – the school district must recommend a program and placement in your child's least restrictive environment (LRE) and must educate your child with children without disabilities to the maximum extent appropriate. Your school district and IEP team should also consider if your child requires an extended school day (after-school services) or an extended school year (summer) services.

When a preschool placement is recommended you need to visit the proposed

placement ASAP and meet with the school staff and therapists. You should encourage your IEP team to develop a transition plan to effectively transition your child from the E.I. model to the preschool model. This transition plan could be as simple as introducing your child to the new school building on one day, and the gradually introducing just a few new students or teachers at a time over a few days. As parents, you should try to meet with other parents and share your concerns, if possible, as this often leads to valuable information gathering.

**Tips for Ongoing Success**

1) Forge an alliance. At both the E.I. and school-based level, it is essential for you and your family to endeavor to develop a strong partnership with your child's E.I. agencies and school district. This will enhance the transition process for children who will attend the school district's program.

2) Don't get hung up on the "six month transition period." Every child presents with individual needs and this can look very different from one child to another. It may take your child one month to transi-

tion from E.I. to preschool, or it may take one year. Think of the entire preschool phase as a transition period.

3) Set realistic expectations and establish roles. Use the transition period as a time to formulate your "game plan." Does everyone on your child's team (including parents and family members) have a clear picture as to how this transition period should look?

4) Consider the importance of individualized parent counseling and training and home visits. Under federal law, parents of students with autism are entitled to receive individualized parent counseling and training and a related service on their child's IEP. During E.I., home visits and parent training and counseling provide parents with extensive support to help "carry over" their child's program. At the preschool stage, home visits similarly give teachers and parents an opportunity to maintain consistent effective communication, provides the teacher with additional information about the student, and provides the parents with addition support and advice within the home environment.

5) Never stop advocating for your child. If you feel as though a proposed program or placement is not appropriate for your child, there are ways for you to disagree without being disagreeable. First, you can consider requesting or securing an independent evaluation (preferably at school district expense) to determine what your child needs and to support your contention that the proposed program/placement is not appropriate. You may be able to negotiate with your school district, or you may need to file for due process (impartial hearing) to secure appropriate and effective services for your child.

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click on calendar). Also for more information on Combating Autism grants in all states, see <http://mchb.hrsa.gov/programs/>

[autism/statedempolicy.html](http://autism/statedempolicy.html).

Families need to be aware that early intervention will allow their child with a developmental disability to reach their personal best potential. For more infor-

mation, go to [www.spannj.org/cyshcn/index.html](http://www.spannj.org/cyshcn/index.html).

*Lauren Agoratus is the parent of a child with autism/kidney disease. She is*

*the NJ Coordinator of Family Voices, the national network that advocates on behalf of children with special healthcare needs. Families can find free help in their state at [www.familyvoices.org/states](http://www.familyvoices.org/states).*

**Guide from page 26**

love is to speak the children's "sensory language." For example, if a child is a sensory seeker, parents can show affection by giving a deep massage, bear hug or vibrating pillow. If a child is sensory aversive, holding up a sign that says "I love you," giving a high five, or giving them time in a quiet environment can be means of showing affection. Many parents find it helpful to discuss their feelings in individual therapy or in a support group with other parents who are also experiencing similar challenges.

Over time, as parents become more knowledgeable about how to address their children's sensory needs and triggers, they will observe children with improved behavioral regulation and ultimately, they will experience more mutually gratifying relationships. Identifying whether their children are sensory seekers or sensory aversive and adapting to those needs within various environments, as well as working with professionals to create appropriate sensory integration, desensitization, and behavioral programs are key components to ameliorating difficult behaviors. It can also be helpful for parents

to have their own outlet of support in individual or group therapy. The more empowered parents feel and the more tools they have to address their children's sensory processing difficulties, the more positive the interactions will be and the more bonded the relationships with their children will become.

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*The Fay J. Lindner Center for Autism, an affiliate of the North Shore-LIJ Health System, was formed to meet the needs of children and adults with autism and related developmental disabilities and their families. The Center is located in a state-of-the-art facility on AHRC Nassau's Brookville campus. The Center offers a wide range of programs, clinical services, professional training, community education, specialized program consultation and research, to individuals, families and schools. Visit us online at [www.FayJLindnerCenter.org](http://www.FayJLindnerCenter.org).*

## A Family's Story of Their Early Intervention Journey

By Sandra Natale  
Parent

Looking back, there were definitely signs and red flags of something amiss with my son's behavior, but I just didn't recognize them since Luca was my first born. He was a sweet and quiet boy that could self-entertain, which made everything easier for me, I thought. He caused no trouble and never had tantrums. The only thing he did that bothered me was repeatedly opening and closing doors. He also did not play with toys, even if they were given directly to him. But Luca is now 5 years old and a "graduate" of Early Intervention (EI). I am sharing our story about our family's journey within the world of EI because I can attest to the life changing differences it made into my son's life.

At 18 months of age, Luca had no words but I was not worried too much about him not talking because he was hearing two languages, and people told me that bilingual kids begin to talk later than children who hear only one language. But I did think that he should at least be saying "mamma" or his name. I was longing to hear either, or at least "dada" for my husband.



Luca Natale

So I started asking other family members when their children began speaking. I got the usual response of, "He's a boy and they talk much later than girls," or "By two he will start." Well, luckily for Luca, baby number two was coming and I figured that, since I would be on a maternity leave and home with him, it was a good time to get

some speech therapy started, if needed. I got the phone number for EI from my pediatrician and called. They took my information and said I would get a call back from the EI office in my county. I will say that the turnaround time was quick, it was a matter of days. Someone was sent to my home to get all the information and help me select an evaluator. Days later, we got an appointment and he was evaluated for his speech and play skills. The evaluators noticed the "red flags" immediately, such as restricted play and no eye contact or verbal communication. Afterwards, they said it looked like he would qualify for services, but they would have to score the tests. I once again got a quick call back letting me know that his scores qualified him and a meeting would take place to determine services. They also recommended we do a psychological evaluation. In my mind, I pictured Luca on a couch unable to answer any questions. I dismissed their suggestion.

When the time came for our meeting with the Department of Health (DOH), they outlined his services for speech (which is all I really wanted), and special instruction. The evaluators once again suggested I do a psychological evaluation, and my husband and I declined.

Luckily again for my son, his sister, Sofia, was born at that time. A friend of mine who is a speech pathologist came to visit the baby and I caught her up on all that had gone on with Luca. After her visit, she called me and said I should go ahead and do the psychological evaluation because sometimes it could lead to more services. I had a feeling that she was skirting around something. Her input convinced me to move forward with the psychological evaluation.

Thanks to the wonderful Service Coordinator we had selected, a psychologist soon came to our home to meet with Luca. She asked me if I understood that he was being evaluated for an autism diagnosis based on how he performed during his initial evaluation. I quickly envisioned Dustin Hoffman in *Rain Man* and figured she was nuts. My son was not like that at all. He always let me hug him, even if he never looked at my face. But memories of that movie were all the knowledge I had about autism at that time. I observed the evaluation, and along the way, she would tell me what kind of responses or reactions a typically developing child of his age would give. Luca was not responding as such. But still, I needed convincing.

see *Journey on page 34*

### Linked from page 6

This recent study explored the relationship between anxiety (a part of the arousal continuum) and sleep problems in ASD. The CAR researchers conducted an in-depth assessment of anxiety using anxiety questionnaires and the ADIS-C/P. Sleep was characterized by seven nights of actigraphy (a micro-computer worn at night during sleep to monitor movements), sleep diaries, sleep questionnaires, and a comprehensive medical interview by Dr. Souders, an assistant professor and pediatric nurse practitioner.

To date, (new data is still being analyzed), thirty-five individuals, ages 6-17, have been compared to eight individuals with typical development. Fifty-one percent of the individuals with ASD were diagnosed with an anxiety disorder. One of the typically developing individuals had a spe-

cific phobia. Insomnia was identified in 54% of the children and adolescents with ASD. No individuals with typical development had insomnia. However, four children with ASD had medical conditions causing insomnia. One child had severe allergies and one child had nocturnal reflux that resulted in frequent coughing at night. They were referred to their primary physician. One child had symptoms of obstructive sleep apnea and one child had symptoms of restless leg syndrome. They were referred to a sleep center. These cases were removed from the analysis. The first phase of the preliminary analysis included summary statistics and cross-tabulations, followed by a formal statistical assessment using Fisher's Exact test. We found a significant association between anxiety (Anxiety Diagnosis and No-Anxiety Diagnosis) and insomnia in individuals with ASD. The second phase included Pearson correlations

between anxiety and the continuous sleep variables. Sleep latency (the time it takes to fall asleep), sleep efficiency (the amount of time in bed asleep over the time in bed) and wake in minutes were all significant. These preliminary results suggest that anxiety and insomnia in ASD are linked. The clinical conduct of this study is complete and we are in the process of doing a full analysis. These findings may have important implications for treatment of sleep problems and anxiety symptoms in individuals with ASD.

Our next steps are to explore an innovative treatment for individuals with ASD and anxiety and insomnia. Based on the idea that a subset of individuals with ASD has anxiety and a hyper-aroused state, we developed a Tailored Behavioral Intervention that addresses the internal and external factors that threaten sleep. The Tailored Behavioral Intervention includes positive routines, calming module (developed to decrease

arousal levels) and faded bedtime protocol. The Tailored Behavioral Intervention is novel in that it includes a detailed calming module with 12 soothing and relaxing activities to choose from in order to help an individual fall asleep. If the Tailored Behavioral Intervention is effective and acceptable to caregivers and individuals with ASD, we hope it will be incorporated into the Sleep Tool Kit available to families from the Autism Treatment Network ([www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit](http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit)). The Sleep Tool Kit developed by Dr. Beth Malow and colleagues from Vanderbilt University provides sleep education and behavioral strategies to improve sleep in children with ASD with external sleep problems. Our future research will continue to focus on internal factors related to insomnia in individuals with ASD, namely anxiety and arousal dysregulation.

### Training from page 21

**Phase 2 - Phone Call:** When parents contact ALG, they immediately speak to a clinician who describes the Parent Training and Education Program. Following that initial contact, parents and caregivers are enrolled into the PTEP.

**Phase 3 - Workshop:** Once parents are enrolled in the program, they are scheduled to attend a workshop provided by a Board Certified Behavior Analyst®. This workshop provides parents with the opportunity to interact with an expert clinician who can answer questions, as well as meet other parents who have newly diagnosed children. During the workshop, the clinician provides parents with an overview of specific teaching procedures based on Applied Behavior Analysis (e.g., how to shape early learning behavior, how to reinforce responses, how to prompt responses, how to increase play

skills, etc.) so that they may begin the process of facilitating skills in their young child with autism. Addressing challenging behaviors is also reviewed with the parents during the training. At the end of the workshop, parents are asked to complete a form that lists some of the skills that they would like to teach or challenging behaviors they would like to address with their children in the home-based training sessions.

**Phase 4 - Training at Home:** Following the workshop, eight hours of in-home structured teaching sessions are conducted by a clinician trained in Applied Behavior Analysis. The goal of these sessions is to empower parents by providing them with the tools necessary to increase the skills of their youngster with autism and to learn the skills necessary to manage problem behavior.

To facilitate the in-home training sessions, parents generally select three target adaptive skills to teach their children during

the training program (e.g., establishing eye contact, requesting items, and following simple instructions). The PTEP clinician will then provide a skill-based, hands-on training that includes four components: (1) *instructions*: the trainer verbally describes each component of the teaching procedure; (2) *in-vivo modeling*: the trainer interacts with the child and models the skills for teaching the first skill targeted for increase; (3) *behavioral rehearsal*: the parent implements the teaching procedure with the child; (4) *feedback*: the clinician provides the parents descriptive feedback immediately following their performance, including positive comments on teaching skills performed correctly and corrective feedback on components performed incorrectly. This parent training procedure is repeated with all three target skills selected by the parents.

In addition to the 3 skills targeted for increase, the clinician will identify other areas of skill development or identify

challenging behaviors to decrease that will assist the parents in their everyday interactions with their child (e.g., clinicians will create and help train and implement communication systems, help teach parents to ignore attention seeking behaviors and reinforce appropriate behavior).

Who Should I Contact to  
Get More Information?

If you are a parent of a newly diagnosed child with autism, and you would like more information about the program, please contact Angela Pagliaro at the Alpine Learning Group at 201-612-7800 x 17.

Angela Pagliaro MA, BCBA, is Director of Outreach Services, Jaime A. De Quinzio, PhD, BCBA-D, is a Behavior Consultant, and Bridget A. Taylor, PsyD, BCBA-D is Executive Director at Alpine Learning Group.

**Identification from page 10**

with other assessment information, results from the ASRS helps guide diagnostic decisions, treatment planning and ongoing monitoring of response to intervention. The ASRS can also be used to evaluate the effectiveness of a treatment plan for a young child with ASD.

A separate version of the ASRS has been created for preschool children, age two to five years. A comprehensive review of current theory and literature on the assessment of ASD is the DSM-IV and the ICD-10 diagnostic criteria as well as the authors' clinical and research experiences were used to determine the preliminary content structure. This structure guided item generalization and multiple items were developed to capture key components of each construct. For young children, key content areas included socialization (with children and adults), stereotypes, behavioral rigidity, sensory sensitivity, language and attention.

**Fifty from page 17**

As people within the fields of child education and Autism Spectrum Disorder realized that increasing numbers of preschool children were being referred to foster care due to their parent's inability to manage the children's behavior, New York City's Department of Mental Health contacted AMAC to run a preschool, which would provide early intervention, guide through ABA and educate parents and caregivers.

**The Value of Positive Reinforcement**

AMAC's goal is to move individuals towards independence in all settings. In addition to individualized behavior management programs, there are intensive and immediate positive reinforcement systems in place in all of our programs.

The Reward Store is an institution at AMAC. This is a token economy that features a wide range of offerings that reaches each student. Reward carts "travel" to reinforce a child's behavior or children can visit our general store which is appointed with everything from ice cream to the latest magazines. At regularly scheduled intervals during the day, students receive various forms of tokens which can be ex-

**Dear Self from page 25**

determination, because deep down you know he needs your strength.

You're going to question your decision to continue working and sending him to daycare three days a week. Don't. The time you spend away from him will fuel your time together; it is essential to have a mental and emotional break. Otherwise autism will consume you altogether.

In the summer of 2007 you'll spend most of your meals chasing him around the kitchen and planting him back in his chair, over and over and over again. You'll wonder if it's worth it. I assure you it is; by the time he's six Jack will be a pleasure at the dinner table.

At times you are going to marvel at his progress, his giant leaps in communication and social behavior. And then for a while, nothing. His development will level off and you'll fight a rising panic that he'll never move forward again. Don't worry, like the steps on a staircase, his pattern will be to

In the normative standardization, 640 two to five-year-old normal children were rated by parents and teacher/child care providers. These samples included ratings of forty males and forty females at each age and are representative of the U.S. population across several demographic variables. Clinical samples included nearly 700 ratings of youth diagnosed with ASD and over 500 ratings of youth diagnosed with other clinical disorders, including delayed cognitive development, delayed communication and language development, ADHD, anxiety disorders, and depression.

In order to exam the underlying factor structure of the ASRS items, data from both normative and clinical samples were used in exploratory factor analyses. Results of these analyses suggested that a two factor model was most suitable for parent and teacher ASRS forms for two to five-year-olds, whereas a three factor model was most suitable for the parent and teacher ASRS for older children. These factor de-

changed for rewards. Determining when to save and when to buy teaches decision-making and money management and increases a child's independence.

**An Emphasis on Early Intervention**

A majority of research has underscored the importance of early intervention in enhancing the global functioning in preschool children. AMAC's success with the children enrolled in its nationally-accredited special education pre-kindergarten program reflects these results as well.

Each year, AMAC celebrates the graduation of its preschoolers. In fact, the parents and teachers couldn't be prouder if the students from this aren't staying for elementary school. There is a sense of triumph when students "graduate" to a less restrictive environment within a variety of public and private schools...however, sometimes parents harbor mixed feelings.

According to Felicia Richgat, principal of both the Children's House and AMAC's Elementary School, "When graduation is on the horizon, parents are thrilled. Yet, as the ceremonies approach, many parents realize that this is a chapter closing, and their child is leaving the haven of AMAC."

Mrs. Richgat continues, "AMAC has

jump up and then stand still for a while.

You are going to meet some extraordinary people in the next few years, and your idea of a hero is going to change dramatically. A hero is going to be a bubbly blonde preschool teacher who patiently coaxes sentences from Jack lips, and a rail-thin painter from Texas who good-naturedly lets your son play country music on his radio while he paints the front porch. It will be a man who sits beside his dog in a hotel lobby and ever so gently persuades Jack to come closer, closer, *closer Jack we're waiting for you*, until Jack reaches out a tentative hand and breaks down a phobia with a quick stroke of soft gray fur.

Your biggest hero will be the dark-haired man you married.

You will find new ways to channel your stress, things like running and writing and yoga. Maybe you'll even run a marathon. In learning to manage the endless demands of autism and a family, you will also learn to take care of yourself.

He's going to latch onto subjects,

rived scales were labeled the ASRS Scales and for young children included Social/Communication and Unusual Behaviors. The accuracy of the ASRS to identify young children with ASD is over 90% with a very low false positive rate.

The ASRS is designed such that once the instrument is scored, a profile of strengths and weaknesses can be generated, leading to the development of treatment plans in clinical settings and Individualized Education Plans as per the Individuals with Disabilities Education Improvement Act and/or 504 Plans under the Americans for Disabilities Act. The ASRS has been constructed and designed to allow treating providers to evaluate specific behaviors over multiple periods of time in an effort to determine if treatment has yielded clinically significant results.

The assessment of ASD, especially in young children, is complex, requiring a reasoned and reasonable appreciation of diagnostic criteria, assessment tools and

been such a supportive resource to these families that they are often skeptical that their children can continue to thrive in the outside world." Her response? "Give it time. Your children will flourish and blossom more than you could ever have imagined."

**A Place for Research**

Our school keeps pace with the most current research based treatment in the field and successfully educates and empowers individuals with Autism Spectrum Disorder so that they may lead fulfilling, successful lives. The planning for each child's program is based upon well-founded research.

At AMAC, both day-to-day decisions, as well as the long-term direction of our programs, are based upon the research literature. Staff training sessions include examinations of particular articles and research projects that guide our interventions. In fact, just this afternoon, staff completed a training module that emphasized the programs of the famed UCLA Young Autism Project (the "Lovaas Project"). Particular teaching techniques, as well as a general approach based on the findings of the literature were emphasized.

No interventions are implemented at AMAC until they have been deemed ef-

fective in peer-reviewed studies. We help to participate in these studies on occasion as well. In this manner, we ensure that student time is not wasted with ineffective treatments nor harmful ones, and learning time is maximized.

AMAC now serves children from infancy (in the Early Intervention program and evaluation site) through elementary and high school into adulthood. Day Habilitation, remedial and vocational services are available to adults. Sleep away summer camp allows AMAC to work intensively with its students even when school is closed. Research and recreational programming are also part of AMAC's mission. The agency has grown from its early years as a social service agency to the full service full life span agency using an ethical and best practice models.

Throughout our fifty years and into the foreseeable future, AMAC will strive to assist participants to develop and maintain the skills required to lead fulfilling and engaged lives.

Frederica Blausten, MA, MS, is the Executive Director, Association for Metroarea Autistic Children, Inc. (AMAC). She can be contacted via [Rica@AMAC.org](mailto:Rica@AMAC.org).

that you can't save Jack, you will never, ever give up on this dazzling boy. And here's the best secret of all: at some point you're going to realize you're glad he has autism. Not glad for him; certainly his life would be easier without it. But glad for you, glad you are privy to the miracle of his extraordinary mind.

He's eight now, and I can't wait for you to meet him.

Oh, and one more thing. If you think today was crazy, you might want to brace yourself. Because tomorrow you're going to find out you're pregnant.

Love,  
Me

P.S. It's a girl.

Carrie Cariello lives in New Hampshire with her husband and five children. You can read her weekly blog and learn more about her online at [www.WhatColorIsMonday.com](http://www.WhatColorIsMonday.com)

And although you'll start to understand

**Empower from page 14**

parents what I know or to give them a cookie-cutter list of resources. My role is to individualize information to their specific situation, so I start every meeting with families by asking, "Do you have any questions about what your child's doctor just told you?" I gain so much knowledge about their understanding of the diagnosis and what they are supposed to do next by their response, even if they reply, "I don't have any questions." This can often mean they are so overwhelmed that they don't even know what to ask, so a few simple questions can help me figure that out.

I also ask them if they have services in place, and what they think about the agencies/people providing those services. If they are already connected with an Early Intervention agency but feel that their concerns are not understood, I can coach them in ways to ensure their voice is heard. If they are thrilled with their child's teacher but not the IEP Team leader, I will discuss approaches or resources that can make a difference in the future. If they are not connected to any services, I know I have to start with the basics.

In addition, I ask about the support they have in their lives. Many parents are dealing with the challenges and worry of having a child who is not developing as expected and who might have difficult behaviors, while at the same time coping with a spouse or extended family members who don't understand, friends and a community who are judgmental or non-welcoming, and sometimes even a pediatrician who is dismissive of their concerns.

Other parents are completely alone, new to this country or this area, or just don't have anyone they can lean on. Learning about their support system enables me to further tailor my resources to meet their needs.

*Explaining the doctor's recommendations is the next step.* Clinicians have limited time with families and have to focus on evaluation results and the diagnostic formulation, and can usually provide just an overview of their recommendations. However, knowledge is power. If parents have a comprehensive understanding of the services recommended for their child, how the services will work, how to get the services, and the importance of acting immediately and being assertive, they are much more likely to pursue them. Telling a family that their child will be going from a few hours a week of therapy to 15 or 20 hours seems impossible and can even be off-putting, but once they understand how the service will actually work, why they need to move quickly, and where to go for the services, I see a fire light in their eyes. "I can do this!"

*The final step is providing the resources.* A recent study (Mulligan, *et al.*, 2010) analyzing a resource given to parents of children after their child received an autism diagnosis found that what families want is "concrete guidance regarding existing services; and specifically which services should be sought, in what order, and in how to navigate the various tiers of service."

With that in mind, the most important resource I provide to parents is a simple To

do list, prioritized by importance. Each step includes the name of the program/service/person that provides the services the child needs, the phone number, the website, what they are supposed to say when they call or email, and what to do if nobody gets back to them. I often put the steps into sections such as "Do Tomorrow," "Do Next Week," and "Do Next Month" so they don't feel inundated and will recognize that not everything must be completed immediately. I make a copy of the list and assure them that when we talk again, we will go through the list to make sure everything gets done.

In addition, I give each family a copy of the American Academy of Pediatrics booklet "Understanding Autism Spectrum Disorders," along with the Autism Consortium's Parent Information Packet (PIP). The PIP is downloadable (see Resources at the end of this article), available in five languages (English, Spanish, Vietnamese, Chinese, and Haitian-Creole), and provides easy-to-understand answers to parents' most-often-asked questions about autism.

I also go through the PIP with the parents and mark sections that align with their needs and questions so they know exactly where to look and don't get distracted by information they don't need to know now. Finally, I provide them with the link to the Autism Consortium's extensive database so if they have access to a computer, they can look up resources themselves instead of calling me, further empowering them.

We all know the importance of getting intervention for children after an autism

diagnosis as quickly as possible. By following the above steps and using appropriate and individualized resources, you can help make that happen for the children in your clinic as well.

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**Resources**

Autism Consortium Resource Database. Available at [www.autismconsortium.org/resources-and-events/database/](http://www.autismconsortium.org/resources-and-events/database/)

J. Mulligan, L. Steel, R. MacColloch, and D. Nicholas, "Evaluation of an Information Resource for Parents of Children with Autism Spectrum Disorder," *The National Autistic Society*. Vol. 14(2) 113-126; 342570 1362-3613(2010).

Parent Information Packet. Autism Consortium. Available in five languages at [www.autismconsortium.org/take-action/become-a-family-partner/](http://www.autismconsortium.org/take-action/become-a-family-partner/)

"Understanding Autism Spectrum Disorders." American Academy of Pediatrics. Available at [https://www.nfaap.org/netFORUM/eWeb/DynamicPage.aspx?webcode=aapbks\\_productdetail&key=5852d055-e054-4262-a79b-57a8b839b0c8](https://www.nfaap.org/netFORUM/eWeb/DynamicPage.aspx?webcode=aapbks_productdetail&key=5852d055-e054-4262-a79b-57a8b839b0c8)

**Toddlers from page 15**

sight. Children with ASD may overreact to certain sounds by covering their ears. They may also avoid certain textures of food or find certain types of tactile input aversive. Sometimes children with ASD will engage in self-stimulatory behavior and hold items close to their eyes, or move their hands in an unusual manner to get sensory input. Occupational therapists can help children with ASD in the area of sensory integration by systematically providing sensory input and working on tolerating various sensory stimuli, making these behaviors less disruptive.

Physical therapy focuses on strengthening the gross motor skills and coordination of a child. Some, but not all, children with ASD may be delayed in obtaining their gross motor milestones. Some children may also have low muscle tone. Physical therapists can help children learn to walk, run, jump, climb, safely navigate stairs, and pedal a tricycle.

Most children with ASD have different learning styles than typically developing children. Your child may have difficulty learning language, play, and social skills naturally from the environment. S/he may need a more structured environment to maximize his or her learning. Applied Behavior Analysis (ABA) sets up the environment optimally to help your child learn. This type of therapy uses behavioral principles which assist children with ASD in acquiring the prerequisites to learning. All tasks are broken down into the smallest possible components and taught systematically using behavioral principals to ensure success. Family training is also a common component of an ABA program.

During periodic family meetings with the team leader, you will gain a comprehensive understanding of the therapy goals and be given specific strategies to use with your child to promote their social, communicative and cognitive development.

Some parents of children with ASD who enrolled their child in a parent and me class for typically developing children reported that their toddler refuses to follow the structure, sit during story time, eat snack, etc. This often creates parental and child stress and anxiety during an activity which should be pleasurable. Early intervention parent and me classes are run by certified special educators where the activities are developmentally appropriate and interesting to the child with ASD. These classes will allow parents to get out into the community, be involved in fun activities with their child and meet other parents.

Many families are surprised at the recommendation that their toddler begin a center-based program or classroom. Early Intervention classrooms are instructed by certified early childhood special education teachers and provide a rich and stimulating milieu which promotes the social, communicative and cognitive development of children. Not all children are ready for a classroom experience; however, many children can benefit from the structure and social opportunities provided in such a setting. Your child may receive some of his or her additional therapies at the school or within the home.

Parents may find it difficult to imagine their baby, still in diapers, receiving such an intensive program of therapies. Therapists working in Early Intervention are specially trained in understanding the

nuances of working with such young children. Most therapists will begin by establishing rapport with your child and spend the first several sessions playing and pairing themselves with pleasurable activities. Early Intervention therapists understand that toddlers have short attention spans, can be naturally defiant and sometimes have separation anxiety. All of these factors are not atypical, and will certainly be considered in the therapy.

Many families struggle with the revolving door of therapists entering and exiting their homes on a daily basis. It is natural to feel as if your privacy is being compromised. This certainly takes some getting used to and once a routine is set the stress typically decreases. While having numerous people in your home on a daily basis can be difficult, the majority of therapies after a child reaches three years are provided outside of the home. Your child may experience some anxiety and agitation once services begin. It may be difficult for you to hear your child upset, but remember to give him or her some time to work it through. This is most likely one of the first times in your child's life that increased demands are being placed on him or her. If you feel that after a reasonable period of time any therapist is not developing a rapport with your child, it is perfectly acceptable to discuss your concerns with the therapist or the your Early Intervention coordinator.

It is essential that while your family focuses intensely on your child's development, the other needs of the family do not get overlooked. Perhaps one of the most therapeutic interventions is that of the family support group. Typically run by a social worker or psychologist, these groups meet

weekly and address the struggles and triumphs of raising a child with ASD. Having a group experience decreases feelings of isolation and provides a therapeutic environment to address a multitude of issues specific to families of children with ASD. Similarly, sibling groups are often available where the brothers and sisters of children with ASD can discuss what it is like to have a sibling with ASD. The naturally intense focus placed upon a child with ASD sometimes triggers various emotions in a sibling and a group is an excellent place to address these feelings. Siblings also learn that they are not alone and meet other children with similar experiences.

Many people sadly capitalize on the vulnerability of parents facing an ASD diagnosis. Beware of interventions which promise miraculous results and those which are extremely costly. Research any intervention before beginning to be sure it is both safe and evidence based (the research demonstrates that it is effective). There are many safe and effective interventions available for toddlers on the Autism Spectrum. Consult with your Early Intervention team to access these services. By educating yourself about the most current and efficacious interventions, you have taken the first step in helping your child reach his or her fullest potential.

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**Drug from page 4**

of pediatrics, neurological sciences and biochemistry at Rush University Medical Center.

"This study will help to signal the beginning of a new era of targeted treatments for genetic disorders that have historically been regarded as beyond the reach of pharmacotherapy," Berry-Kravis said. "It will be a model for treatment of autism, intellectual disability and developmental brain disorders based on understanding of dysfunction in brain pathways, as opposed to empiric treatment of symptoms. We hope mechanistically based treatments like STX209 ultimately will be shown to improve cognitive functioning in longer-term trials."

Studies in mice genetically engineered to exhibit features of fragile X, including social impairment, have suggested that the behavioral abnormalities in fragile X result from deficiencies in the neurotransmitter gamma-amino butyric acid (GABA). Decreased GABA has been observed in a mouse model of fragile X in many areas of the brain, including the hippocampus, and has been hypothesized to be a basis of the social anxiety and avoidance characteristic of fragile X sufferers, the study says.

Arbaclofen is an agonist for gamma-amino butyric acid type B, or GABA-B, receptors. An agonist is a chemical that effectively combines with a receptor on a synapse to effect a physiologic reaction

typical of a naturally occurring substance. Anxiety-driven repetitive behavior and social avoidance have been reduced in fragile X-engineered mice treated with arbaclofen. The current, first-of-its-kind study investigated whether arbaclofen would produce similar results in human subjects.

The double-blind, placebo-controlled clinical trial initially recruited 63 male and female subjects at 12 sites across the United States for the research, conducted between December 2008 and March 2010. The participants ranged in age from 6 to 39 years. Of the initial participants, 56 completed the clinical trial. There were no withdrawals related to drug tolerability. The majority of the subjects were treated with what was assessed as the optimum tolerated dosage of the study drug, 10 milligrams twice a day in younger patients and three times a day in adults. Compliance was monitored by patient guardians, who filled out a dosing form on a daily basis.

The study subjects returned for evaluations at two- and four-week intervals after beginning the six-week-long treatment. The drug then was tapered down over a one- to two-week period. After a week, the subjects entered a second treatment period.

The effects of the medication were scored on variables of the Aberrant Behavior Checklist (ABC), a behavior-rating scale for the assessment of drug-treatment effects. The checklist includes variables for irritability, lethargy/withdrawal, stereotypic (repetitive) behavior and hy-

peractivity, among other factors.

The study found improvement for the full study population on the social-avoidance subscale, an analysis validated by secondary ratings from parent observation of improvement in subjects' three most problematic behaviors. It found that the medication was the same as placebo, however, on the subscale for irritability.

The study is one of several at the MIND Institute aiming to help improve behavior and cognition for individuals with fragile X syndrome and autism spectrum disorder. Hagerman currently is leading larger controlled trials of STX 209 at UC Davis that also are carried out at multiple centers and are enrolling individuals with fragile X syndrome from ages 5 to 50. Individuals interested in enrolling may contact Lindsey Partington at 916-703-0471 or via e-mail at [lindsey.partington@ucdmc.ucdavis.edu](mailto:lindsey.partington@ucdmc.ucdavis.edu). Details of the study also can be found at ClinicalTrials.gov, an online resource for people interested in learning more about advanced clinical studies in a variety of different therapeutic areas.

"We are looking forward to further studies utilizing STX 209 in both autism and fragile X syndrome because the fragile X mouse studies demonstrate long-term strengthening of synaptic connections with continued use of this medication," Hagerman said.

Other study authors include David R. Hessl, Yi Mu and Danh V. Nguyen of UC Davis; Barbara Rathmell, Peter Zarevics,

Maryann Cherubini, Karen Walton-Bowen, Paul P. Wang and Randall L. Carpenter of Seaside Therapeutics; Joseph Gonzalez-Heydrich of Boston Children's Hospital; and Mark F. Bear of the Massachusetts Institute of Technology.

*The study was funded by Seaside Therapeutics.*

*Rush is a not-for-profit academic medical center in Chicago comprising Rush University Medical Center, Rush University, Rush Oak Park Hospital and Rush Health. Rush University is a private, health sciences university offering more than 30 unique degree or certificate options in medicine, nursing, allied health and biomedical research. Rush University is comprised of Rush Medical College, the College of Nursing, the College of Health Sciences, and the Graduate College.*

*At the UC Davis MIND Institute, world-renowned scientists engage in research to find improved treatments as well as the causes and cures for autism, attention-deficit/hyperactivity disorder, fragile X syndrome, Tourette syndrome and other neurodevelopmental disorders. Advances in neuroscience, molecular biology, genetics, pharmacology and behavioral sciences are making inroads into a better understanding of brain function. The UC Davis MIND Institute draws from these and other disciplines to conduct collaborative, multidisciplinary research. For more information, visit <http://mindinstitute.ucdavis.edu>.*

**IDEA from page 23**

A vast body of research demonstrates that the behavioral, social and communication needs of the student as identified by the evaluations and the team and the interventions and supports engineered to address them are inextricably interwoven with and dependent upon the stimuli, naturally occurring cues, and naturalistic teaching opportunities occurring within the environment where services are delivered (e.g., Hart & Risley, 1975; Ingersoll & Schreibman, 2006; Pierce & Schreibman, 1995). Particularly with respect to the pervasive nature of the core deficits common to the diagnosis of autism, and most importantly with respect to the social skills interventions necessary to the future success of young children with this diagnosis, it is not possible to parse the "service" from the framework in which they are provided. The provision of supportive services, particularly during the critical window of opportunity during early intervention, should not be viewed in a vacuum<sup>1</sup>.

One way to determine that a preschool setting is the appropriate framework within which to deliver early intervention services is to analyze the purpose of each goal decided upon by the early intervention team in the IFSP. If the fundamental core of each goal promulgated by the team requires, as a necessary component, the availability of peers and activities promoting interaction with those peers, an inclusive preschool environment is necessary. The need for adult supervision and facilitation (teachers) and a "place" to conduct these activities (classroom) is obvious. Taken together, these core components equate to a pre-school setting. If the county does not operate a public preschool<sup>2</sup>, the county must fund the tuition for a private school. See, e.g., *Office of Special Educa-*

*tion Programs* ruling 22 IDELR 630, 663 (1995) (if placement team determines, based on child's IEP, that preschooler needs interaction with non-disabled peers, public agency is responsible for making available appropriate program in the least restrict environment at no cost to parents); The dilemma is that public policy has not kept pace with our cultural norms. Publically funded pre-school is not widely embraced<sup>3</sup>. In the Commonwealth of Pennsylvania, for example, provision of publically funded pre-school services are available in connection with Head Start services only and there exists a perceived confusion regarding placement vs. services. Preschool placements are often seen as requests for social skills and "social skills" is not a service. In fact, the Pennsylvania Department of Education has explicitly stated "that there is currently no universal pre-school in the Commonwealth of Pennsylvania" (*BEC Early Intervention and Private Schools* 11 P.S. 875-304 (Jul. 1, 2003; also see *Allyson B. v. Montgomery County Intermediate Unit*, U.S. Dist. LEXIS 32159, \*41-\*42 (E.D. Pa 2010)). However, there is no Federal mandate forcing the creation of publically funded pre-schools. Public agencies (such as a School District or Departments of Mental Health and Intellectual Disabilities) are not required, under the law, to create public pre-schools to satisfy the requirements regarding placement (*Board of Educ. of LaGrange Sch. Dist. No. 105 v. Illinois State Board of Educ.*, 30 IDELR 891, 184 F.3d 912 (7th Cir. 1999)). For public agencies without publically funded preschool opportunities, some alternative methods for meeting the requirements include: (1) providing opportunities for participation (even part time) of preschool children with disabilities in other preschool programs operated by public

agencies (such as Head Start); (2) placing children with disabilities in private school programs for nondisabled preschool children or private preschool programs that integrate children with disabilities and nondisabled children; and (3) locating classes for preschool children with disabilities in regular elementary schools (*See also Letter to Anonymous*, 50 IDELR 229 (OSEP 2008); see also *Letter to Neveldine*, 22 IDELR 630 (OSEP 1995)).

It is expected that with the advent of and concentration on early intervention services and the continued development of these programs as well as the increasing the wealth of positive outcome research now available regarding the indicia of success preschool experiences have for young children, the debate regarding preschool as a part of public responsibility vs. parent responsibility should diminish and publically available options for preschool services increase. In the meantime, failure to provide a pre-school setting, where determined necessary by a team, is a failure of FAPE.

*Gloria M. Satriale, Esq., BCABA is Executive Director of Preparing Adolescents and Adults for Life (PAAL). Thomas L. Zane, PhD, BCBA-D is Interim Clinical Director of PAAL, and is Professor of Education and Director of the Applied Behavior Analysis Online Program at Endicott College. For more information about PAAL, please visit [www.mecaautism.org/paal.html](http://www.mecaautism.org/paal.html).*

**Footnotes**

1. It is reasonable and, in fact, quite common for certain services for a child to be clinic based only and delivered in segregated "pull out" settings such as physical

therapy, however for most supportive services (e.g. speech and language, occupational therapy), best practice is for the delivery of services in an integrated, consultative manner (e.g. Schopler & Mesibov, 1984).

2. Some states do offer publically funded preschool programs for disadvantaged children identified "at risk" (e.g. Head Start Preschool Programs).

3. The fact that "pre-school" is currently offered in many forms (c.f. Montessori systems) rather than a uniform system which would adhere to the usually envisioned structure of what constitutes public education complicates this issue – particularly as it may relate to an analysis of appropriateness.

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**ASD in 3D from page 16**

With this 3-dimensional graph in hand, we are now in a position to plot the progress of individuals with ASD over time, taking into account three variables at once: degree of atypicality, IQ, and age (Figure 2B). Thinking about ASD this way leads to useful insights and projections regarding prognosis and future needs.

Therapies follow a general sequence from adult-directed behavior shaping (“bottom-up”) learning, to a partnership model between the adult and child, and eventually, a child-driven (“top-down”) learning model) that requires active problem-solving by the child. This can also be displayed graphically, with degree of atypicality on the X axis, and cognitive orientation of therapy (rather than IQ) on the Y axis.

Although some of the highest functioning children eventually “outgrow” ASD criteria, they remain at risk for anxiety, depression, and social isolation as adults. Although we do not have hard data, it has been our impression that the higher the child’s IQ, the greater the risk that he or she will experience anxiety and/or depression, due to heightened awareness of social issues, and struggles around “fitting in,” compared to persons with significant Intellectual Disability. Self-reports by adults with Asperger Syndrome or High-Functioning Autism (IAN 2009) indicate a prevalence of anxiety or depression of approximately 70%.

In summary, we have synthesized two well-established pieces of “old knowledge” – (1) ASD has a natural history, with a predictable succession of changes in symptoms over time, and (2) IQ is an im-

portant driver of outcome - into a new, 3 dimensional schema that facilitates a more informed discussion of diagnosis, intervention, and prognosis for persons with ASD. By looking simultaneously at atypicality, age, and IQ, we can make better decisions in the present, and have a clearer expectation of long-term issues. This 3-dimensional schema has the potential to become even more useful as a way of anchoring the discussion of a given individual’s strengths and service needs, if and when current DSM labels (autism, PDD-NOS, Asperger Syndrome) are discarded.

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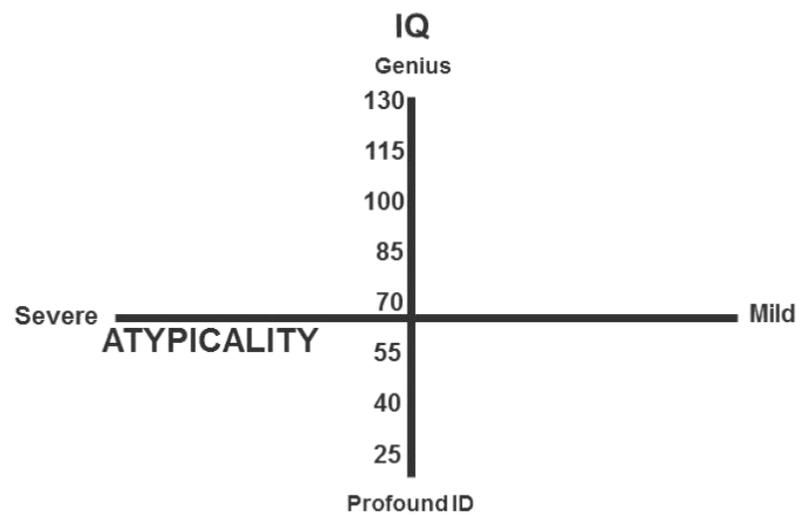
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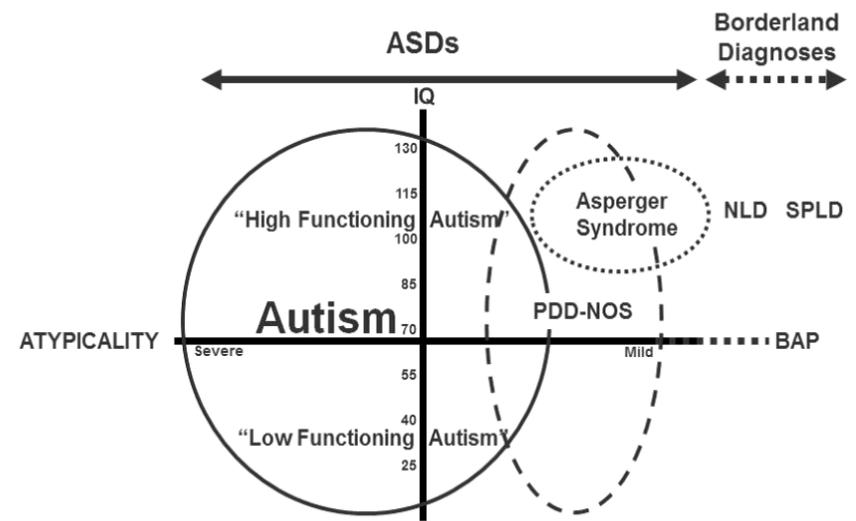
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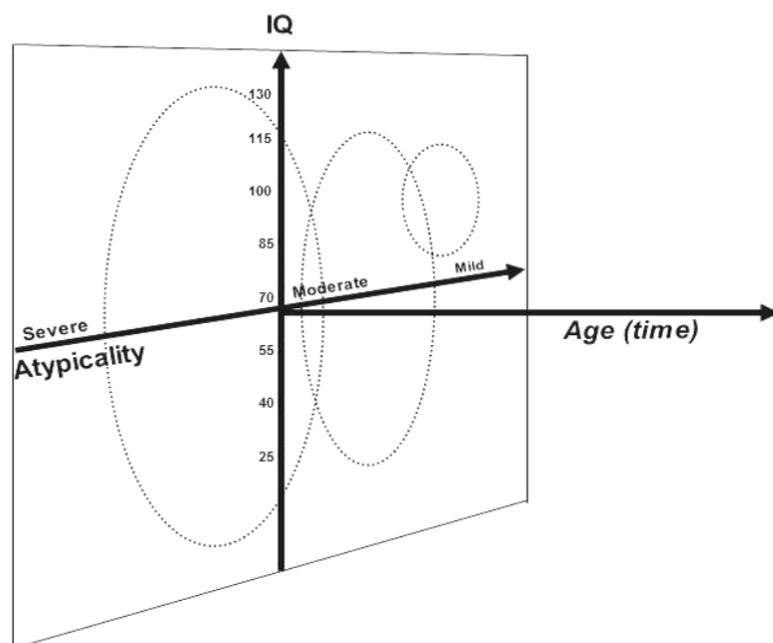
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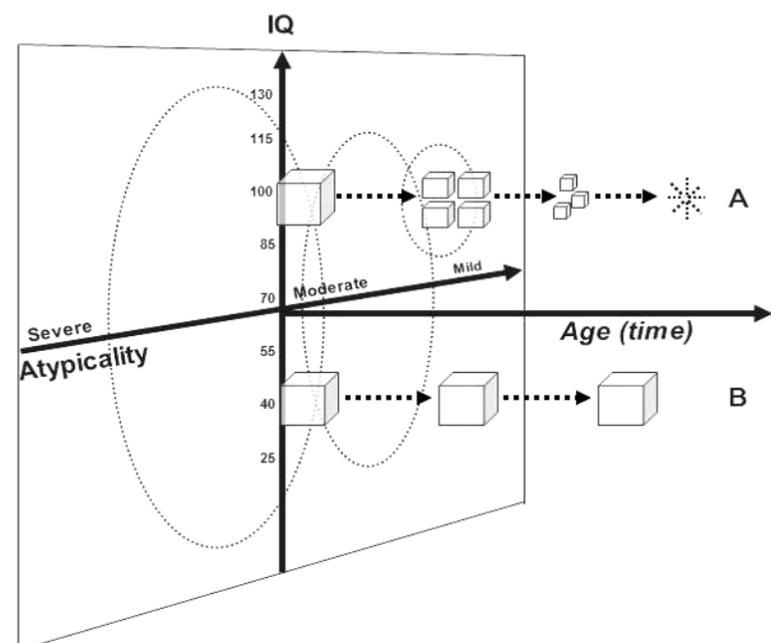
**Figure 1A** - Relationship between Atypicality and IQ: any degree of atypicality can be accompanied by any level of general intelligence. Intelligence tests are all set to have an average score of 100. Any degree of atypicality from severe to mild can co-exist with any level of IQ, from Genius, to profound Intellectual Disability. Figure 1A gives us a way of thinking about each person’s unique combination of intelligence and atypicality.



**Figure 1B** - Current diagnostic categories, mapped onto 2D graph. Persons with moderate to severe atypicality have “autism.” If their IQ is 70 or above, it is deemed “high functioning” autism. Persons with normal IQ, mild-moderate atypicality, and pedantic, hyperverbal speech have Asperger Syndrome (AS). In between autism and AS lies PDD-NOS. To the right of these “spectrum diagnoses” lie children and adults with “borderland” diagnoses: Nonverbal Learning Disability (NLD), Semantic-Pragmatic Language Disorder (SPLD), and BAP (“Broad Autism Phenotype” – a term commonly used in the adult literature). As the figure makes clear, each of these diagnoses overlaps the adjacent conditions on the graph, leading to endless (and largely pointless) discussion about what is the “correct” diagnosis.



**Figure 2A** - Three-dimensional diagnostic “space” in which we can simultaneously display the key variables relevant to clinical status and prognosis: degree of atypicality, level of general intelligence, and age. Degree of atypicality runs from left (severe) to right (mild) on the X axis. IQ runs from top (Genius) to bottom (Profound Intellectual Disability) on the Y axis. The point where the X and Y axes cross represents moderate atypicality and an IQ of 70 (the cutoff for Intellectual Disability). The Z axis begins at birth, and extends to the right (increasing age).



**Figure 2B** - Here we depict two children, with similar degrees of atypicality, but different levels of general intelligence. Atypical features fade dramatically in the child with normal IQ (A), but persist nearly unchanged in the child with low IQ (B). Low IQ thus constitutes a double burden: not only is a low IQ problematic in and of itself; the lower the IQ, the more persistent the atypical features will remain over time. Thus, we return full circle to the observations of Kanner, Bartak, and Rutter. See Coplan, 2010 for list of outcome studies.

**Thoughts from page 23**

requests, though the little girl had done so only for her teachers until then. That weekend was emotionally wrenching for the whole family; the child resisted in every way she could, but her parents held their ground, and finally, by Sunday night, that child was pointing consistently to ask for things. The parents did not teach pointing the way the teachers did, but they did insist on their daughter's using what she had learned.

The other treatment criteria I endorse are that the underlying philosophy and methods

should make logical sense and that they should be supported by research evidence. There is so much evidence favoring applied behavior analysis (ABA) that it is clearly the first option to be considered. Goals are broken down into small steps and the child gets positive feedback for correct responses. Slower learners need more repetition, and faster learners need less, but each child moves to the next step after showing mastery of earlier steps. Objective data, available for inspection, indicate where there has been progress and where more work is needed. Generalization is built into the pro-

gram; the child works with a variety of materials, in a variety of settings, and even with a variety of teachers. I do not know if ABA is always the best approach to use with every child, but I have seen wonderful progress with this approach.

I urge parents who are worried about their young children's development to seek evaluation, rather than waiting and seeing. If your child is doing fine, you will be told so, and you can then relax. If your child has significant delays, treatment will be offered to help the child reach his or her potential. In either case,

you and your child will be better off than if you simply listen to the reassurances of well-meaning friends and family and do nothing while your anxiety increases.

*Marion K. Salomon & Associates, Inc. serves parents and their children birth to 35 months through Early Intervention (EI), preschoolers through each school district's Committee on Preschool Special Education (CPSE), and school-age children through each district's Committee on Special Education (CSE). For more information, please visit [www.mksalomon.com](http://www.mksalomon.com).*

**Summer from page 24**

such as deciding what to eat, ordering lunch independently, and paying for lunch using their own money, including asking cashiers questions and waiting for their change. The students sit together at their lunch table, with staff nearby but not hovering.

Our off-campus internship takes place at a local gardening center. The managers there are always welcoming, and the students work on maintaining the skills learned from the previous summer, including weeding, fertilizing, watering and planting. However, that's not all that we work on. Appropriate manners, requesting, introductions and other interpersonal skills are developed and maintained as well.

We often make use of the computer lab in our Hofstra building so participants are able to write letters of thanks to Hofstra staff and to email friends. The students use Microsoft Office (Word and Power-

point) to create presentations and develop resumes. And because Smartboard technology is available to us, teachers and students are able to use a multimedia approach to teaching and learning.

Recreational activities abound on-campus and off. A soccer clinic created by a middle school gym teacher who was on our staff was a big hit. Hofstra's regulation-sized soccer field offers quite a workout. Off-campus, we utilize a village swimming pool and the Atlantic Ocean, where we wade, swim, and picnic on the beach. We visit museums on Long Island and take notes in our journals. The local Museum of Aviation and IMAX theater makes for quite a fun and informative trip. Amusement parks, indoor arcades, miniature golf and bowling round out our fun. A visit to the market to buy the ingredients from the list we prepared in order to do our cooking lesson provides its own unique learning. Even a trip to the mall is not just a trip to the mall, but another summer highlight of

which we can be proud. Our participants each picked a store at which they might like to work one day, and interviewed the manager at that store about the business, daily responsibilities and their likes and dislikes of their jobs. What a multi-layered activity. And each of our students were awesome.

Travel training is another important piece of the program. Staff members teach participants how to use the university shuttle for navigating the campus, allocating appropriate travel time, and using a map and timetable. Sometimes we missed the bus and had to come up with reasonable alternatives. That's life!

Typical peers are included in the program. Teens join us on recreational days when our students can engage in social activities with these peers. It is a fun experience for both our students and the teen volunteers. Student interns who join the program intermittently enhance the flexibility of our participants and afford them opportunities to work on interpersonal

communication with novel people.

We are pleased to have once again achieved the three program goals set forth in our mission to provide social skills training, vocational opportunities and generate a summative evaluation. What makes this program special is the integration of our participants with typical peers in a semi-structured setting and into the broader college community. Our kids felt loved, safe and most of all appreciated. We saw the kids take personal risks on all levels. And because of our great success, we will continue with our expansion into an after-school program. In addition to the summer program, we now run the program at Hofstra during the academic year in 10-week cycles.

We hope that by sharing the success of our program, we will inspire other innovative clinicians and families to follow suit and initiate creative, out-of-the-box pilot programs addressing critical needs in clinical populations.

**Journey from page 29**

Shortly after the psychological evaluation, my Service Coordinator met with me to begin my education about autism. She pointed me to resources, explained that it is a spectrum disorder and what kind of EI services were available. She said starting early with more intensive therapy would make a big difference for Luca.

So once again, my husband and I met with the Service Coordinator, Psychologist, and a representative of the DOH to outline new EI services. Inside, I was still not convinced and a bit resistant, but I still had not heard "mama" after what now was about three months of speech therapy. So I agreed to all of their sugges-

tions and very soon after, we had therapists in our home daily, sometimes multiple times per day because he was getting Applied Behavioral Analysis (something I never heard of before), Occupational Therapy, and Speech Therapy. He would also be starting a toddler program in the fall geared towards working with children like my son.

Even with all of this support, it still took two months before we heard Luca's first word, which was not "mama," but "go." I ran with it! I don't know how many times I said "ready, set..." just to hear his "go." From then on, Luca's world opened up. Like his two younger siblings (baby number three, Genna, came along during this time also), Luca is like a

sponge and talks so much that I actually catch myself saying "stop talking for a minute" sometimes. His imagination in his play has emerged, and he seeks the company of his sisters constantly.

Luca is starting kindergarten this fall, in an integrated class at his neighborhood school. His classmates will include those who are typically developing as well as other students with special learning needs. He is no longer receiving EI services because he now has an Individual Education Plan (IEP) through the school district. Even though Luca still has a long road ahead of him, the progress he has made has been outstanding. There is no doubt in my mind that had it not been for EI services, he would not be where he is today.

Without the guidance I received through the EI process, I am sure I would have floundered trying to figure out what to do and he would not have received the level of high quality therapy that he did. I do not take for granted the EI process that was in place for us! The efficient Service Coordinator that was good at her job found us amazing therapists and the therapists themselves had their hearts into helping him. EI helped level the playing field for Luca and drew him out of his cocoon, giving him a shot at a bright and hopeful future. I hope our story has inspired anyone who has any inkling about their child's development to pick up the phone and call EI. Getting started early has been key for Luca – and our family.

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For more information, visit our website [www.FAAHFA.com](http://www.FAAHFA.com) or contact the facilitators:

Bonnie Kaplan - [Parenttalk@gmail.com](mailto:Parenttalk@gmail.com) | Judith Omidvaran - [Judyomid@aol.com](mailto:Judyomid@aol.com)

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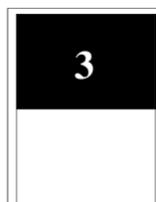
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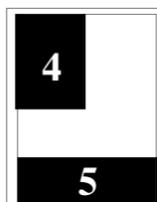
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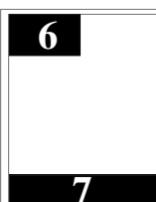
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