

Expert Advice: Renowned Professionals Share Insight and Tips at the YAI/NIPD Network's 29th Annual International Conference

Some of the nation's most prominent experts convened at the YAI/NIPD Network's annual International Conference in Manhattan in May. Families, people with disabilities and professionals attended a keynote address and session by Dr. Temple Grandin, author, educator and one of the most accomplished and well-known adults with autism in the world. Attendees participated in full-day workshops featuring national experts such as Dr. Vincent J. Carbone, and chose from more than 25 sessions and workshops by leaders in the field such as Dr. Lynda Geller. The following is some of the information that they shared.

Temple Grandin, Ph.D., Author, Associate Professor, Colorado State University



According to Dr. Temple Grandin, an author and an Associate Professor at Colorado State University, early intervention and the involvement of family members is an essential part of helping a child with autism develop social and other skills. "Research is very clear that 20 hours or more a week of quality one-to-one interaction with a good teacher is essential," she said. For parents, she added, it is also important to find supports throughout the community to help. "Parents cannot do it all themselves."

Vincent Carbone, Ed.D., Director of the Carbone Clinic



Dr. Vincent Carbone, Director of the Carbone Clinic, highlights the benefits of an Applied Behavior Analysis (ABA) approach to teaching children with autism. "It's important to utilize a language-based program emphasizing expressive language very early on," he said. This distinct approach to programming is fueled by a reliance on B.F. Skinner's behavioral analysis of language. Dr. Carbone makes use of Skinner's analysis, as well as sign language as an alternative form of communication to facilitate the development of vocalization in children who are non-vocal.

Lynda Geller, Ph.D., Clinical Director of the Asperger Institute at the NYU Child Study Center

For Lynda Geller, Ph.D., Clinical Director of the Asperger Institute at the NYU Child Study Center, the key to working successfully with individuals on the autism spectrum is recognizing their individuality. "One of the most important things is that everyone with Aspergers is different, because they have various brain differences which affect their whole developmental profile," she said. Dr. Geller emphasizes the importance of unique visual, verbal and other sensory aspects that may impact an individual's interactions.



For more information on the YAI/NIPD Network's 2008 International Conference, or other YAI conferences addressing autism, please visit yai.org/conference, or contact Tina Sobel at tsobel@yai.org or 212-273-6457. Mark your calendars for next year's International Conference, taking place May 4-8 at the Manhattan Crowne Plaza.

Good Health For Life: Meeting the Medical Needs of People with ASD



by Peter DellaBella, M.D.,
Associate Medical Director and Chief of
Psychiatry, Premier HealthCare

When Devon was small, a visit to the dentist could induce an episode of panic. Having a cavity filled, while unpleasant for anyone, was for him, a nightmare.

But his dentist, **Chrystalla Orthodoxou**, had confidence that Devon, who has an autism spectrum disorder (ASD), could come to terms with a dental checkup — even with having a cavity filled.

As Chief of Dentistry at **Premier HealthCare**, a member of the **YAI/National Institute for People with Disabilities Network**, Dr. Orthodoxou has the training and experience necessary to set patients like Devon at ease. She spent several visits dedicated solely to acclimating Devon to the dental chair and instruments, and to building a trusting relationship with him.

"The staff at Premier HealthCare take the time to understand each patient's specific situation, help them overcome their fear and successfully complete the necessary clinical procedures," Dr. Orthodoxou said.

"For individuals with autism, who may have more difficulty understanding the importance of health care, anxiety can create significant obstacles to physical well-being and overall quality of life," said **David Kaufman, M.D.**, Medical Director at Premier HealthCare.

Cathy, Devon's mother, will never forget the day that Devon was able to calmly have a cavity filled, an event that would have been unthinkable a few months before. "Dr. Orthodoxou called me later that day, saying, 'I knew he could do it! I knew he could do it!'" she recalls.

Today, for Devon, now 16, trips to the dentist are easy and, thanks in part to his regular checkups, he has been cavity-free for years.

Overcoming Barriers to Good Health

For many people on the autism spectrum, routine medical checkups and dental visits often have to be administered under general anesthesia and may even result in trips to the emergency room. This often causes families or caregivers to forgo important preventative checkups and exams.

"People with ASDs can have more complex medical needs than others," said **Stephen E. Freeman**, Associate Executive Director of **YAI/National Institute for People with Disabilities**.

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Living with Autism: What Every Parent Should Know



by Bernice Polinsky

As the mother of an adult diagnosed with autism and as an effective parent advocate, Bernice Polinsky has learned a lot on her journey to access services and supports to enhance the quality of life for her entire family. Bernice, whose son receives services through the YAI/NIPD Network, graciously shared the following tips to help other families find information, support and greater peace of mind. Bernice is a board member of the AHA Association/Asperger Syndrome and High Functioning Autism Association.

1. Join a support group.

By meeting and talking with other individuals whose loved ones have autism, you will receive support, information and networking opportunities that can help you and your family. You may learn from others how to organize your records, navigate the system, cope and solve problems. Encourage your family members to join a support group. This is a great opportunity to connect with others and realize that you are not alone.

2. Learn as much as you can.

You and your loved one with autism know best what you need. Ask for help when you are unsure. Get a second opinion if you are not happy and comfortable with the professionals in your life. When possible, attend conferences and workshops. Stick with scientific and evidence based information. It will be the safest in the long run and you won't spend unnecessary funds on methods that won't work and in some cases could be harmful. Join an e-list such as www.ahaNY.org or Autism_NY_News@yahoo.com.

3. Advocate: Be a squeaky wheel.

Know your rights: you are your child's best advocate. Learn as much as you can about special education law, ADA, civil rights law, 504, etc. Remember: If you don't know your rights, then you don't have any. Find a good service coordinator or education consultant (depending on age and services) to help you navigate the system. Don't give up when the system seems to be giving you a hard time.

Good Health For Life, *continued from cover*

"They also have specific health concerns that need to be addressed. They often require more time and patience to treat than the general population, so it can be very difficult to find doctors, dentists and mental health professionals who have the knowledge and willingness to work with them."

In fact, a 2002 study conducted by researchers from the **Heller School for Social Policy and Management at Brandeis University** found that more than a third of children with autism encountered obstacles in obtaining necessary care from medical specialists over a 12-month time span. The reason? An inability to find referrals and providers with appropriate training (Krauss, Gulley, Sciegaj & Wells, 2002).

While health care services for people with autism have begun to improve, much needs to be accomplished in providing access to services and educating health care professionals about patients with autism spectrum disorders.

Health Concerns Specific to Autism

In addition to being aware of the social and psychological needs of individuals with autism, health care providers should also be aware of certain medical issues that arise more frequently in these patients.

As a condition that affects many areas of brain and behavioral development, autism — whatever its causes are — can also affect other parts of the body. For example, up to a quarter of people with an ASD also have epilepsy.

People with autism tend to be more susceptible to gastrointestinal

4. Keep organized medical and educational records.

When you apply for services, it is much easier if you have the documents required to show that the developmental disability is a long-standing condition that affected the person before age 22. If your loved one with autism is taking any medication, keep a list of what he or she is taking and log how he or she is responding. This is important information to share with doctors and useful for the individual's medical history for other service providers in the future.

5. Plan for the future.

Be sure to plan early when to meet the future needs of your family member. Being realistic is very important. Seek the services of a professional who has experience with special needs planning. If your family member is receiving services, involve your other family members to be sure they are knowledgeable and informed. Transition to adulthood, particularly, is a complex, multi-faceted process. There are excellent workshops and Web sites for transition and it's important to understand the process inside and out, including SSI, guardianship, OMRDD services, college and vocational programs.

6. Take care of yourself.

This will be a long road and you must take care of yourself in order to take care of others. Take advantage of respite care when you can. Reach out to family and friends, and don't be afraid to ask for help. If you don't have anyone to reach out to, think about counseling for yourself to get the support you need.

7. Help your family members feel good about themselves.

Emphasize the positives in your family member with autism and focus on his or her strengths. Give your loved one with autism as much information as he or she can understand about his or her diagnosis as early as possible. Insight into themselves and a high self-esteem are valuable to enable them to advocate for themselves and be the best they can be.

For recommended sources of additional information, please see our resource list on the back cover.

disturbances, immune and inflammatory conditions and sleep disorders. Autism has also been associated with genetic and congenital conditions such as fragile X syndrome, tuberous sclerosis and congenital rubella syndrome.

There are a number of general considerations to keep in mind when working with people who have autism. When patients with limited verbal skills experience discomfort or are in pain, they may express their distress by acting out, through self-injurious behaviors or by withdrawing. What, to untrained staff may at first appear to be a behavioral issue, could actually be a sign of a serious health concern.

People with autism are typically hypersensitive to many types of sensory stimuli, which rarely affect the general population. Because many people with an ASD often cope with anxiety by rocking, hand-flapping, jumping and pacing, providers can use these behaviors to assess the patient's level of stress.

Those of us who work with and care for people with autism spectrum disorders must understand our obligation to explain medical procedures to them in a way that diminishes fear, enhances their understanding of their health and empowers them to make healthful choices.

*For more information on medical services for children and adults with autism spectrum disorders and other disabilities, please contact YAI **LINK** at 1-866-2-YAI-LINK; TDD: 212-290-2787, link@yai.org or visit www.yai.org.*

Early Detection Makes a Lifetime of Difference!



by **Dr. Bernadette Flynn, Director**
New York League for Early Learning

At 15 months old, **James** had not yet begun to speak. His mother, **Michelle**, was not particularly worried, but she decided to do the prudent thing and have him evaluated for a speech delay.

When the speech therapist recommended a second, more comprehensive evaluation, “I said, ‘Sure, go ahead!’” Michelle recalls. “Our speech therapist kept saying it was behavioral, but I really wasn’t sure what that meant.”

Months later, James was diagnosed as being on the autism spectrum. Autism is a neurologically based developmental disability that according to the **Centers for Disease Control and Prevention** affects one in 150 children in the United States.

James was lucky. Because he was diagnosed before the age of 2, he was able to begin receiving crucial early intervention services that, for many children, can change the course of their lives. According to the **New York State Department of Health Early Intervention Program**, intensive behavioral approaches, when started at an early age, can significantly improve outcomes for children with autism.

In fact, this explains why the American Academy for Pediatrics adopted a new guideline that all children be screened for autism spectrum disorders twice by age 2 — once at 18 months and once at 24 months — as part of well baby checkups. It also recommends that treatment for autism be started when autism spectrum disorder is suspected, rather than when a formal diagnosis is made.

Unfortunately, parents sometimes ignore the signs of autism. They may attribute their children’s lack of speech to being a “late bloomer.” Early identification of an autism spectrum disorder is essential, but can only occur if parents, caregivers, doctors and other professionals know what to look for.

Parents are advised to consult a physician if their child exhibits any of the following tendencies:

- No response to name
- Repetitive and excessive use of words, phrases, mannerisms or gestures
- Little or no eye contact
- Lack of interest in making friends
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

Carol Stein-Schulman, M.S.Ed., BCABA, Assistant Director of Education and Training for the **New York League for Early Learning**, a member of the YAI/NIPD Network, explains that parents sometimes miss crucial indicators for autism because their children appear to be good, easy babies, who play in their cribs without fussing.

“Parents need to see whether their children are understanding language,” Carol said. “You want to make sure that by approximately 12- to 18-months-old, they are interacting with their primary caretaker. If all they want to do is sit in the corner and arrange their cars or play with the string on the rug, it might be a red flag.”

Carol advises parents to watch for certain behaviors that can vary with each child’s development: By about six months, babies should be smiling and expressing warmth and joy; by around nine

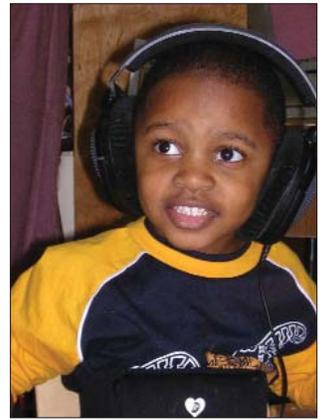
months, they should be engaging in reciprocity of sounds, smiles and other facial expressions; by approximately 12 months, they should be babbling; and by about 16-18 months, they should be able to form at least some words.

And anytime there is a regression in speech or social skills, parents are advised to consult a pediatrician or developmental pediatrician for an evaluation.

“The good news is that early intervention is here,” Carol said.

“We didn’t have it 30 years ago. If there’s a delay, early intervention gives the child a good start on the right path to learning how to communicate and interact appropriately.”

For more information on evaluations and services for children and adults with autism spectrum disorders, please contact YAI LINK at 1-866-2-YAI-LINK, TDD: 212-290-2787, link@tyai.org or visit www.yai.org.



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Early Detection Quick Tips

Pediatricians should screen all children for ASDs at 18 and 24 months. They should also listen carefully to parents about their child’s development.

Remember: Parents are the most reliable sources of information about their children!

If a child exhibits any of the following tendencies, he or she should see a pediatrician.

- No response to name.
- Lack of or delay in speaking.
- Repetitive and excessive use of words, phrases, mannerisms or gestures.
- Little or no eye contact.
- Persistent fixation on parts of objects

Research has shown that early intervention is critical to maximizing the development of a child with an ASD. Pediatricians and other qualified clinicians can help obtain an early diagnosis and make referrals for appropriate services and interventions.

To learn more about YAI/NIPD Network programs and services for infants, children and adults with autism spectrum disorders, please contact YAI LINK at 1-866-2-YAI-LINK, TDD: 212-290-2787, link@yai.org or visit www.yai.org.



Premier HealthCare and YAI/NIPD are affiliates of The Mount Sinai Hospital and The Seaver and New York Autism Center of Excellence of The Mount Sinai School of Medicine.

This resource box has been adapted from information available on the Web sites of The American Academy of Pediatrics and The Centers for Disease Control and Prevention, and was made possible in part by a grant from the New York City Council’s Autism Awareness Initiative.

Autism Resources

For more information on research, training, education, services and family support for people with autism spectrum disorders, their families and professionals, please visit the following Web sites.

- YAI/National Institute for People with Disabilities Network www.yai.org
- New York State Office of Mental Retardation and Developmental Disabilities www.omr.state.ny.us
- Autism Speaks www.autismspeaks.org
- The Cody Center at Stony Brook Medical Center www.stonybrookmedicalcenter.org/codycenter
- Autism and PDD Support Network www.autism-pdd.net
- The Global and Regional Asperger Syndrome Partnership www.grasp.org
- The Carbone Clinic www.carboneclinic.com
- The Elija Foundation www.elija.org
- Aspen Asperger Syndrome Education Network www.aspenj.org
- The Autism Foundation of New York - Autism Advocacy Outreach Group www.aaog.org
- The Asperger Syndrome and High Functioning Autism Association www.ahany.org
- The Autistic Self Advocacy Network www.autisticadvocacy.com
- The Seaver and New York Autism Center of Excellence at the Mount Sinai School of Medicine www.mssm.edu/psychiatry/autism
- The Yale Child Study Center at the Yale School of Medicine childstudycenter.yale.edu
- New York University Child Study Center www.aboutourkids.org
- American Academy of Pediatrics www.aap.org
- Centers for Disease Control and Prevention www.cdc.gov/ncbddd/autism/actearly

Families & Professionals Advocate for Crucial NYC Autism Funding

When it comes to ensuring that individuals with autism receive the services they need to lead the most independent, fulfilling lives, advocacy is crucial. As part of YAI/NIPD's ongoing advocacy efforts, YAI consumers, families and staff joined representatives from UJA, Lifespire, QSAC, Resources for Children with Special Needs, and other agencies at City Hall on June 18 to advocate for the continuation of funding in 2009 of the New York City Council's "1 in 150" initiative.

Funded through 2008, the "1 in 150" initiative aims to elevate the quality of life for families living with autism through after-school and summer programs, a public-awareness campaign, and educational and training seminars.

"Autism and related communication disorders have reached epidemic proportions, as evidenced by the recent federal report by the Centers for Disease Control, which stated that 1 in 150 children are now born with autism," said Council Member David Weprin. "With this initiative, the Council has filled an important gap in services."

Children, teachers, direct service professionals and individuals with autism spoke from the heart about why the funding should be continued in 2009.

"My job coach has helped me with applications and helped me find jobs," said Debra, a YAI consumer. "Without this program, I wouldn't know where to go."

"Individuals who receive services, family members and professionals are the most powerful advocates in educating legislators about the importance of programs such as the '1 in 150' initiative," said Marco Damiani, Director of YAI/NIPD's Clinical and Family Services Department.

For information on how you can help, please contact Joshua Rubin, YAI/NIPD's Senior Management Fellow, at jrubin@yai.org or 212-273-6413.

ABOUT



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The YAI/National Institute for People with Disabilities Network is comprised of seven independent, award-winning, not-for-profit, 501(c)3 health and human service agencies serving more than 20,000 infants, children, adolescents and adults with developmental and learning delays and disabilities and their families. The foundation of our success is the partnerships we form with the consumers of our services and their families, staff, government, corporations, supporters and volunteers. By working together, we fulfill our common goal of building brighter futures for people with disabilities and their families.

The YAI/NIPD Network's Autism Advisory Council

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The YAI/NIPD Network is a proud partner of the New York City Council in its "1 in 150" Autism Initiative. The Autism Initiative offers wraparound services for children in after-school and summer programs in every City Council district and allows for a public-awareness campaign, including educational and training seminars in every City Council district. The goal of the initiative, which began in 2007 under the leadership of Council Member David I. Weprin, chair of the New York City Council Finance Committee; and Council Member Hiram Monserrate, chair of the Council's Veterans Committee, and the UJA-Federation of New York; is to positively alter the lives of families who deal with autism and autism spectrum disorders on a daily basis.

For more information call 1-866-2-YAI-LINK or visit www.yai.org