

## Transition, *continued*

your neighborhood. Some may never reach the goal of using public transportation independently, but each step allows for more freedom and opportunity. Explore the NYC District 75 Travel Training Program, available to all NYC Department of Education students with disabilities.

## Day Services & Employment

This is the main focus of most transition planning and a very important part of an individual's future. In searching for the right program, ignore labels. Just because you visited one day habilitation program and didn't like it doesn't mean that day services won't be a good fit for your family member. Each program has a distinct culture based on its location and activities, as well as the age, background and abilities of participants. Visit a variety of programs. Ask questions. How does your family member fit in with other participants? Do the activities match his or her interests? Do people in the program look engaged and happy? Do staff enjoy their jobs? The same goes for employment programs or any other type of service you are considering for your family member.

## Help is Available!

Don't be discouraged. Yes, there is a lot to do and a lot to think about. But help is available. And some things are more urgent than others, depending on your family member's abilities and needs. Feel free to call YAI [LINK](http://www.yai.org) at 212-273-6182 and an experienced and knowledgeable Intake Specialist will provide you with information and resources to help you access the supports you need within and outside of the YAI Network.

## YAI Network Experts Present in Cigna Autism Education Series

This summer, experts from the YAI Network will share their knowledge with parents and professionals through the **Cigna Autism Education Series**. These free telephone seminars will help participants better understand physical, mental and emotional growth in individuals who may display symptoms of autism spectrum disorders.

### Thursday, June 16, 2011, 1:00-2:00 p.m.

#### A Visual Tour of the Social Brain in Autism

Charles Cartwright, M.D., Chief, Premier HealthCare Autism Research and Treatment Institute and Director, YAI Autism Center

### Thursday, July 14, 2011, 1:00-2:00 p.m.

#### Developing Early Communication Skills in Toddlers and Young Children with Autism Spectrum Disorders (ASD) and Limited Language

Moira Lewis, M.S., CCC-SLP, Speech & Language Pathologist, YAI Autism Center

### Thursday, August 11, 2011, 1:00-2:00 p.m.

#### Evidence-Based Practice: What Does It Mean?

Jill Krata, Ph.D., Associate Chief, Premier HealthCare Autism Research and Treatment Institute; Manager of Clinical Services, YAI Autism Center

To listen to a seminar, please call toll-free 1-866-431-5314 on the scheduled date and time. When prompted for a passcode, enter 1150266.



The YAI Network comprises eight 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.

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The YAI Autism Center, Premier HealthCare and NYL are affiliated programs of the Mount Sinai Hospital and The Seaver Autism Center for Research and Treatment at Mount Sinai School of Medicine.



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## Full-Day Autism Conference On Social Thinking

featuring:

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**“Social Thinking Across The Home and School Day: The ILAUGH Model of Social Cognition”**

**Tuesday, October 11, 2011**

**McGraw Hill Auditorium, New York City**

**Limited Seating**

**Register today at [yai.org/autismconference](http://yai.org/autismconference)**

**For more information contact  
Abbe Wittenberg at 212-273-6472  
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**Some Family Scholarships Available**



# Autism Matters

**YAI Network**  
Serving People with Disabilities and their Families

SUMMER/FALL 2011

## Decoding the Spectrum: The Quest of One Researcher and Mother

By **Danny Freedman, George Washington University**

*In a cluttered office tucked away inside a lab, Dr. Valerie Hu, a professor in the Department of Biochemistry and Molecular Biology at George Washington University, is attempting to crack one of biology's most vexing riddles: her son.*

Valerie Hu's son Matthew, 23, has an autism spectrum disorder. And nothing quite brings determination to the case like a mother.

Dr. Hu's office is full of photos of Matthew as a child and through the years leading up to his high school graduation. Her pride is evident, but "it was such a struggle," she recalls.

Dr. Hu and her husband took their son to the doctor in 1989 when he was 2 years old, concerned that he wasn't yet speaking. After six months of testing he was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

The diagnosis offered little relief. It was uncharted territory for her as a parent and as a scientist who was still more than a decade away from diving into autism research.

At the time, she found "virtually nothing" about PDD-NOS in the medical literature. The more she read "the more depressing it was because the prognosis for anyone with autism was pretty bleak."

"From the time he got a diagnosis — your life changes, honestly," she says. "Because all you're thinking about is: What can I do to help my kid?"

For years, those efforts would be outside the lab. Matthew made quick advances in a specialized preschool program but labored the rest of the way through the public school system; too intelligent and high-functioning to be grouped with the learning disabled, too socially impaired to fit in with mainstream classes.

Along the way Dr. Hu helped establish a support group for parents of kids with Asperger's syndrome and high-functioning autism that brought about changes at school, though not in time to impact Matthew.

At the end of 2004, she decided to shift into autism research. It was a "no brainer," she says — probably the last easy answer she'll encounter on this journey.

### Personal Journey Inspires Professional Passion

Under the microscope, autism looks like a disorder of a thousand cuts: a cascade of regulatory mishaps that lead to developmental disabilities and the telltale clutch of social and communication deficits, repetitive behaviors, and the risk of epilepsy and other disorders.

Dr. Hu's approach is to pan back, to take in a broad view of the body's biological systems and identify where things have run amok. These systems operate like a network of connected highways: a rush-hour wreck in one lane can foul an entire route and spread to the roads around it. By getting a sense of how molecular traffic moves, Dr. Hu's hope is that her research will lead to fixes that keep traffic running smoothly, even if the ultimate roots of a problem remain unknown.

In order to do this, her work involves better understanding individual genes — sections of DNA that are turned on and off, producing proteins that help build and regulate cells in the body — as well as the function of genes along the complete set of DNA, called the genome.

She's also exploring the epigenome, which scientists are only beginning to fully grasp. The epigenome can control the on-off

switch of genes using natural and manmade chemicals.

Recently, her research has added insights that are bringing scientists closer to the day when medicine might have a better shot at relieving, or even reversing, individual features of autism.

For example, last year a pair of small studies from her lab found that two elements of epigenetics — chemical tags, called DNA methylation, and microRNAs — may have a hand in hundreds of the abnormally expressed genes that turned up in the lab's studies.

Drugs to reverse methylation already are used in cancer patients, Dr. Hu says, and levels of microRNA also can be controlled. Much work remains, though, in parlaying those strategies to the treatment of autism. "We're not there yet, for sure," she says. "But there's a possibility."

Her research, however, may be closing-in on the next best thing: screening for autism with a blood test, or even a cheek swab.

Dr. Hu's lab has identified both differences in gene expression and in the building blocks of a person's DNA that could provide hallmarks needed for screening. A diagnostic test built around this work, Dr. Hu says, could identify not only a person's risk of developing autism, but also specific types of autism based on behavior, such as severe language deficits or savant qualities.

In the meantime, she's also learned to leverage her experience as a mother.

"It's nothing but an advantage for me because I think it helps me see autism in a different light," she says. "I think it also makes me better able to talk about our research with parents because I know what their concerns are; I know where they're coming from, and they know where I'm coming from."

*A version of this story originally appeared in the GW Magazine, where Danny is an associate editor.*



Dr. Valerie Hu



**Autism Matters is made possible by the  
New York City Council's Autism Initiative**



The YAI Network is a proud partner of the New York City Council in its Autism Initiative. The initiative, which began in 2007, provides funding to agencies city-wide who serve individuals with autism spectrum disorders and their families. Through the Autism Initiative, the YAI Network has provided families and professionals with free training and support through a variety of programs, workshops and conferences in English, Spanish, Mandarin and Cantonese. Special thanks to Council Member Mark Weprin for his continued support and dedication to the renewal of the Autism Initiative.

**For more information on YAI Network services, call 1-866-2-YAI-LINK or visit [www.yai.org](http://www.yai.org)**



## Psychiatric Disorders Associated With Autism Spectrum Disorders By Charles Cartwright, M.D. and Victoria Bein, M.A., M.S.

Clinical and community studies indicate that up to 70 percent of people with autism spectrum disorders (ASD) meet diagnostic criteria for at least one emotional or behavioral disorder. The presence of co-existing disorders can have a dramatic impact on the lives of individuals with autism and their families. It is important for clinicians and families to watch for emotional and behavioral changes that may indicate a disorder.

### Emotional Dysregulation

Emotional dysregulation is a commonly used term to describe emotional and behavioral issues in those diagnosed with ASD. Symptoms and behaviors can include irritability, temper tantrums, hyperactivity and self-injurious behaviors. It is important to understand whether these symptoms reflect underlying mood, anxiety, impulse control and psychotic disorders, or if they are part of the autism spectrum.

### Diagnosing Co-Existing Disorders

In order to develop effective treatments targeting emotional and behavioral issues, clinicians should be rigorous in their efforts to accurately diagnose the mental health issues that pose challenges for people with ASD. A comprehensive psychiatric evaluation should be performed by a professional with expertise in the assessment and diagnosis of ASD with co-occurring psychiatric disorders.

### Vignettes of Common Co-morbid Diagnoses

**Attention Deficit Hyperactivity Disorder** (affects 20-35% of individuals with ASD): Brian is a 4-year-old with a history of language delay. He started using single words at age 3 and a year later began repeating what others said to him. He is unable to sit still. When in an enclosed space, he pushes over furniture, throws things, runs around or attempts to dart out of the room. He becomes easily frustrated and has tantrums when limits are set. He also appears to be oppositional and defiant, which may reflect his frustration with his inability to communicate.

**Obsessive Compulsive Disorder** (affects 10-25% of people with ASD): Maria is a 13-year-old who abruptly insisted that her family's home be arranged a certain way: with chairs in the exact same position, all TVs on and all doors closed. She has an intense need to watch the same TV show episode repeatedly. If this routine is disrupted, she becomes extremely upset. These ritualistic behaviors were not present six months earlier, before Maria and her family moved to a new neighborhood and she was placed in a new school.

**Social anxiety** (affects 10-20% of people with ASD): Elijah is a socially isolated 16-year-old diagnosed with Asperger's syndrome. Over the past three months, he has found it progressively harder to be with unfamiliar people without becoming anxious. He now avoids social situations, even gatherings of family and close friends. Making eye contact upsets him. He finds relief looking down or past people.

**Mood disorder** (affects 5-15% of individuals with ASD): At 15, Nigel presented with a sudden onset of irritability, which lasted more than a month. He began having difficulty sleeping. His irritability alternated with periods of giddy happiness or brief, intense periods of sadness, with no apparent reason for the sudden shift. Nigel's symptoms are consistent with a mood disorder, possibly of a bipolar type.

**Tic disorders** (affects 5-10% of individuals with ASD): Jenny is a 9-year-old with a two-year history of an increasing frequency of throat clearing sounds. She has a six-month history of jerking movements of fluctuating intensity and frequency of her head and neck. More recently, they have been accompanied by obsessive compulsive behaviors.

### Treatment

Professional treatment, including cognitive-behavioral and behavioral interventions and the careful use of psychotropic medication, can significantly reduce the severity of these issues and improve the quality of life of the individual with ASD, as well as his or her family or caregiver.

*Charles Cartwright, M.D., is Director of the YAI Autism Center and Chief of the Premier HealthCare Autism Research and Treatment Institute. Victoria Bein, M.A., M.S., is Coordinator at the Premier HealthCare Autism Research and Treatment Institute. Premier HealthCare is a member of the YAI Network.*

### Enhanced Communication & Functional Skills

Video modeling and self-modeling can lead to substantial increases in verbal requests and responses in children with autism. The success of these interventions in promoting conversation skills for children and adolescents with autism has been well documented. Video modeling is effective in teaching conversational skills to children, who can transfer them to other settings, such as school and home.

Research also supports the effectiveness of these interventions in helping children and adolescents on the spectrum acquire and maintain skills in activities of daily living. They are a highly effective method for teaching functional skills such as brushing teeth, tying shoes, shopping in a store, or doing laundry.

Video modeling is just one of many evidence-based practices that is easily available to parents and professionals. Having a repertoire of different strategies and interventions that focus on the child's individual needs will lead to the most beneficial outcomes and positive results for children with ASD and their families.

*Jill Krata, Ph.D., is Associate Chief of the Premier HealthCare Autism Research and Treatment Institute, and Manager of Clinical Services at the YAI Autism Center.*



## Using Video Modeling with Individuals with Autism Spectrum Disorders by Jill Krata, Ph.D.

New research indicates that video modeling is effective in enhancing social communication and functional skills in children and adolescents with autism spectrum disorders (ASD).

Video modeling entails watching a video of a desired behavior and then imitating that behavior. A similar intervention, video self-modeling, allows the individual to imitate targeted behaviors by observing him or herself successfully performing a behavior on video.

### Easing Anxiety, Promoting New Skills

Video modeling and video self-modeling, which have met evidenced-based practice standards, help individuals with autism learn and maintain new skills by eliminating social distractions and anxiety. For many individuals, watching a video creates less anxiety than interacting with a person, and is more likely to promote learning. Research indicates that positive gains from this intervention, including, new skills and desired behaviors, are maintained months after. This is particularly important for children and adolescents with autism who have difficulty transferring skills from one setting to another.

Video modeling and self modeling integrate a visually-cued instruction. This is especially helpful for children and adolescents with ASD who prefer visual learning because they help them literally see that they can accomplish tasks being modeled.

## Beyond Daytime Activity: A Comprehensive Approach to the Transition to Adulthood By Jennifer Shaoul, M.P.A., Sr. Coordinator, YAI LINK Department



*When people with autism, their families and professionals discuss "transition planning," the focus is generally on day programs, employment or advanced education. The transition from Department of Education (DOE) services to adult services, however, requires important but frequently overlooked steps to promote the continued growth of your family member on the spectrum.*

### Exploring Eligibility for OPWDD Services

Families of individuals with autism spectrum disorders (ASD) often bypass this step, thinking their child won't be eligible, or that appropriate services are not available. Some families don't realize that an individual can be high-functioning and still be eligible for services if the person has difficulty functioning in his or her environment. The earlier you establish eligibility for services through the NYS Office for People with Developmental Disabilities (OPWDD), the earlier your family member can access supports to promote success as they age. It is best to establish eligibility by age 22, as it is sometimes more difficult later. It's helpful to have a knowledgeable and experienced professional in the field of developmental disabilities to help you prepare your packet for eligibility. Learn more about services and training for individuals with ASD, parents and caregivers from your local Developmental Disabilities Service Office (DDSO). Visit [www.opwdd.ny.gov](http://www.opwdd.ny.gov) to find your local office. Don't be disappointed if your family member with autism doesn't obtain eligibility – this may actually be a sign of how high-functioning he or she is. Also, there are sometimes other funding streams or private pay options for certain necessary services.

### Health Care: From Pediatrics to Adult Medicine

Many families wait too long to make this transition. It's hard to leave a trusted pediatrician, but unless that practitioner has expertise in adult medicine, you are doing your family member a disservice. There are many doctors and specialists in the NY metropolitan area with expertise in treating adults with ASD. Some patients are sensitive to essential services such as dentistry, gynecology and blood work. Do not avoid treatment! Lack of care often leads to more serious challenges. Work with health care professionals who utilize desensitization techniques to overcome fear.

### Socialization

Friendship is an important part of life. People with ASD often have trouble making and keeping friends. There are opportunities for socialization and social skills training within and outside of the OPWDD service system. Many people with disabilities have an interest in dating and sexuality. It is important for families and professionals to gauge an individual's interest and activity level and to ensure that they have the skills and knowledge to make appropriate and safe decisions.

### Behavior

Behaviors that were tolerated or even cute when your family member was younger may prove to be detrimental or dangerous as he or she grows older. These behaviors may limit the programs available to them, friendships and relationships. Identifying inappropriate behaviors and working with an expert to develop a plan to eliminate them is critical.

### Case Management – To Have or Have Not

You do not need Medicaid to have a case manager, though most are funded through Medicaid and obtained via the OPWDD system. Some families expect that a case manager or Medicaid Service Coordinator (MSC) will take care of obtaining all these services for them. It's important to understand that the role of the MSC is evolving. While many MSCs are great resources, the

increased demand for the service and the turnover rate means that many MSCs may be bright and motivated, but not necessarily knowledgeable and experienced. Your best approach is to ask: Is he/she motivated? What kind of training will the agency provide? Does the supervisor have a lot of knowledge and experience? If the answer to any of these questions is negative, ask for another case manager or try another agency. If the person you get is willing to do research with and for you, he or she can be a real asset.

### Benefits, Guardianship and Future Care Planning

As individuals with autism reach adulthood, they can be eligible for Supplemental Security Income and Medicaid, even if they still live at home with their families. Medicaid funds many services for people with ASD and other developmental disabilities.

When any child turns 18, parents no longer have legal guardianship. For many high-functioning and independent individuals, this won't make a difference. But for individuals who can't manage themselves or their finances, families should obtain legal guardianship. There are supports available to assist with this process. A lawyer is not always required.

If your family member will require benefits such as Medicaid to support services for the foreseeable future, it's important to ensure that any inherited money or current assets be secured in a Special Needs Trust. You will need specialized legal services to create this trust. We recommend downloading the "Planning for your Future" guide at [ddpc.ny.gov](http://ddpc.ny.gov).

### Independent Living and Residential Life

Some individuals with autism will require full-time support to live in the community, while others will require very little. There exists a broad continuum of options, but the waiting list for residential opportunities is daunting. You may expect me to say "get on the waiting list right away." I'm not. OPWDD and most agencies don't want you on the waiting list until you and your family member are really ready for placement. The important thing, in the early stages, is to prepare your family member for community living.

### Overnight Stays

Spending the night away from home is an important rite of passage. There are many ways to accomplish this for your family member with ASD. The first time away from home should be positive, planned and brief. Don't wait for an emergency. Have the individual spend the night at a relative's or friend's home. Use OPWDD-funded overnight respite programs and build up the experience gradually. Often, this separation is more difficult for parents. In most cases, the individual with ASD adapts quickly. If not, all the more reason to keep trying under controlled and positive circumstances. Then, in an emergency, you have options and your child has skills and experience.

### Independent Living Skills

We all struggle with aspects of independent living, but through trial and error, we learn what we need to do to manage successfully. People with ASD are no different. We can help them become successful if we prepare them. Individual or group training programs are available to help your family member learn skills such as budgeting, food preparation, doing laundry, accommodating a roommate and responding to emergencies.

### Travel Training

Travel is an integral part of independence. When a person is travel trained for a fixed route or for general travel, the door opens to an array of opportunities. For example, most employment training programs require travel training skills. Start with basic skills like finding a room within a building. Graduate to crossing a street safely, then navigating