

# AFAA Conference Thanks 516Ads



Pat Schissel, LMSW  
President, AHA  
December 2009

Dear 516Ads – AHA was one of 6 agencies in NYS, 16 satellite locations across the country, over 1000 in all, who took part in this fabulous day devoted to the needs of the ever-growing population of adults on the autism spectrum. I am still exhilarated and proud of our part in what will be an ongoing initiative to work towards a better future for our family members. The information is below. All the best – Pat (and thank you always for giving us the opportunity to raise awareness through 516ADS – Happy Holiday!!!)

## **1,003 PARTICIPATE IN UNPRECEDENTED NATIONAL TOWN HALL MEETING TO HELP DEVELOP NATIONAL POLICY AGENDA FOR ADDRESSING THE NEEDS OF ADULTS WITH AUTISM**

**ADULTS WITH AUTISM, FAMILY MEMBERS, SERVICE PROVIDERS, ELECTED OFFICIALS, AND COMMUNITY MEMBERS GATHERED AT 16 SITES NATIONWIDE, INCLUDING PLAINVIEW, LONG ISLAND**

We are ill prepared for the socio-economic tsunami approaching the shores of our country, despite decades of warning. In the late 1980's, the prevalence of autism among children in this country was 1 in 10,000, in the late 1990's, 1 in 500, and today the Centers for Disease Control estimate a catastrophic prevalence of 1 in 100. Our society has yet to address how the need for services, jobs, housing and other opportunities will be met as more than 800,000 children identified with Autism Spectrum Disorders (ASD) approach adulthood, and greater numbers of children with ASD grow behind them. Such was the impetus for the creation of Advancing Futures for Adults with Autism (AFAA), a consortium of leading autism advocacy organizations and service providers focused on

meeting this nationally unmet demand for effective services for adolescents and adults.

On November 13th, AFAA held a National Town Hall meeting at sixteen sites across the country, with the goal of developing an actionable national policy agenda for life-long living and learning with autism. The Long Island Satellite site was housed at the Four Points Sheraton in Plainview. Other satellite locations included Atlanta, Boston, Chapel Hill, Cleveland, Dallas/ Ft.Worth, Kansas City, Long Beach, Miami, Newark, Philadelphia, Phoenix, Pittsburgh, Sacramento and Washington D.C. At each site, working groups - including adults with autism, family members, community members, neighbors, employers, service providers, representatives of funding and support agencies, elected officials and others - worked to establish priorities for meeting the needs of adults with autism in several key areas, including employment, housing, safety, recreation, transportation and social opportunities.

Each of the fifty participants at the Plainview site were hand-picked in recognition of their past contributions to the lives of adults with autism. They included such leaders as Mark Roithmayer, President of Autism Speaks, Dr. John Pomeroy, Founding Director of the Cody Center for Autism and Developmental Disabilities, Sandra Gumerove, Esq., long-standing advocate for and counsel to children and adults with autism, and Pat Schissel and Bernice Polinsky of the Asperger Syndrome and High Functioning Autism Association. Kathy Mannion, Associate Executive Director of Nassau Suffolk Services for Autism and mother of four young men, two with autism, served as the Long Island Satellite Coordinator, and linked scores of passionate Long Islanders with more than one thousand participants from coast to coast, via live webcast with a central Chicago hub.

The meeting infused state-of-the-art technology, such as video conferencing, networked computers, and wireless keypad technologies, to transform individual discussions into synthesized recommendations representative of more than 1,000 voices across our great nation. AFAA will now build on the outcomes of the National Town Hall to create an implementation plan for presentation at an Autism Congress set to be held in Washington D.C., 2010.

The host agencies for the Long Island Satellite site were Nassau Suffolk Services for Autism, Eden II Programs, The Cody Center, Asperger Syndrome and High Functioning Autism Association (AHA), The Elija Foundation and Developmental Disabilities Institute. Autism Speaks, the nation's largest autism science and advocacy organization, and the New York Center for Autism are the AFAA organization chairs. The AFAA partners are Global Communities of Support, Alpine Learning Group, The Autism Program of Illinois, The Daniel Jordan Fiddle Foundation, Easter Seals, Hallmark Community Solutions, Organization for Autism Research, Southwest Autism Research & Resource Center, and the University of Miami-Nova Southeastern University Center for Autism and Related Disabilities.

With the cataclysmic tenfold increase in the prevalence of autism across the United States comes a tremendous demand for effective services for these children as they grow to become adults, a need that continues to exceed available resources. Some states have responded to this need, but the result is a tangle of underfunded and often confusing state-by-state initiatives. The Town Hall meeting was the first step in developing a national policy to address these issues.

For more information about the AFAA National

Town Hall, please visit [www.affaa-us.org](http://www.affaa-us.org)  
<<http://www.affaa-us.org>>.

### **About Autism**

Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships, and is often accompanied by behavioral challenges. Autism spectrum disorders are diagnosed in 1 in 100 children in the United States, affecting four times as many boys as girls. The Centers for Disease Control and Prevention have called autism a national public health crisis whose cause and cure remain unknown.

### **About AFAA**

Advancing Futures for Adults with Autism (AFAA) is a national consortium seeking to create meaningful futures for adults with autism that include homes, jobs, recreation, friends and supportive communities. This unique national consortium has united to set national priorities for adults on the autism spectrum and to transform public policy and programming for teens and adults with autism ASD's.

### **LONG ISLAND SATELLITE INFORMATION:**

Friday, November 13, 2009 - Time: 10:30am-5:30pm  
Location: Four Points Sheraton, Plainview, NY, 333 South Service Road.

Contacts: Kathy Mannion, Long Island Satellite Coordinator, NSSA, 631-462-0386,  
[kmannion@nssa.net](mailto:kmannion@nssa.net).

Terri Manzione, Esq., Media Spokes person for LI Satellite Site, NSSA, 631-462-0386,  
[tmanzione@nssa.net](mailto:tmanzione@nssa.net)

### **Patricia R. Schissel, LMSW, President, AHA**

Asperger Syndrome and HFA Assoc.  
PO Box 916  
Bethpage, NY 11714  
888.918.9198  
[www.ahany.org](http://www.ahany.org) email: [pats@ahany.org](mailto:pats@ahany.org)