Advancing Futures *for* Adults with Autism

A NATIONAL CONVERSATION

More than 1,000 people in 16 cities came together to set an agenda for addressing the service needs for adults with autism. The passion and commitment of participants were just as remarkable as the technology's effectiveness in simultaneously connecting people across the country for a day of deliberation and collaborative problem solving.

Currently the Center for Disease Control and Prevention estimates that autism affects 1 in 110 children. These children will soon become adults and will need support. Yet there has never been a national agenda put forward to advocate for these individuals.

"The face of autism is rapidly changing. The AFAA Town Meeting and engagement program created a useful and actionable public policy agenda to ensure we are better prepared to serve autistic people who are transitioning to adulthood."

—Peter Bell, Executive

Vice President for Programs and Services at Autism Speaks

"The America*Speaks* design and planning was wonderful to behold. And what made it special was that it was being done for a client that is going to act upon the information, so participants know that their day will lead to action. That seemed like the perfect purpose for the America*Speaks* Town Meeting model."

—Volunteer Table Facilitator

The Advancing Futures for Adults with Autism (AFAA) National Town Meeting was convened by a diverse consortium of national advocacy organizations concerned about creating a policy agenda to better serve the needs of adults with autism. Utilizing AmericaSpeaks' highly interactive 21st Century Town Meeting® model, adults with autism, family members, advocates, elected officials, service providers and other community members shared their perspectives with others located across the country.

Participants spent the day developing a national policy agenda to address the unique needs of adults living with autism. The result was a set of prioritized strategies for tackling key issues and services for adults with autism, such as housing, employment and community life. Opportunities for action on the local level were also identified, and participants formed connections during the Town Meeting to support this important work

The Issue: Growing Need for Adult Services

When people with autism transition from childhood to adulthood, it places them and their families in financial, programmatic, and personal limbo in a society without adequate resources to meet their needs. Because autism is a lifelong disorder, and there is no cure, it is imperative that infrastructure be developed to support individuals with autism as they age.

The prevalence of autism has significantly increased during the past 10 years, resulting in an estimated 1.5 million individuals in the U.S., and tens of millions worldwide affected Today autism is more common than childhood cancer, juvenile diabetes and pediatric HIV/AIDS combined. With the increase in prevalence has come an increased demand for effective services for adolescents and adults with autism. Unfortunately, the need continues to far exceed the available resources.

Advancing the Future of Adult with Autism Town Meeting: A Nationwide Conversation

To grapple with these pressing issues, the Advancing Futures for Adults with Autism National Town Meeting was convened by a consortium of national advocacy organizations for families living with autism, adults with autism, advocates, elected officials, service providers and other community members. America*Speaks* worked with AFAA to design and host a 21st Century Town Meeting®, featuring a central site in Chicago and webcast live to fifteen participating cities. Seventeen additional cities participated through virtual discussion tables.

Stakeholder Diversity

Organizers of the National Town Meeting made every effort to ensure that participants reflected the many different types of stakeholders who are impacted by autism and autism-related policies. Ten percent of participants were adults living with autism while forty percent were family members and the remaining fifty percent were service providers, policy makers, employers, housing specialists and community members.

Full Participation

Whether they participated in Chicago, at one of the webcast sites or at the virtual tables, everyone took part equally in the national discussion. All participants were an active part of facilitated, small-group discussions. They all submitted their ideas into computers to be themed, and voted on the issues in real-time with the rest of the sites across the country.

Facilitated Deliberation

Over the course of the day-long meeting, participants learned about the issues and deliberated about various policy options for addressing different challenges. Facilitators at each site and online worked with participants to help them listen to and learn from one another. As small groups came to consensus they submitted their ideas to a "theme team" to identify areas of convergence among the national group. Polling keypads then enabled participants to identify collective priorities.

Staying Involved

AFAA Town Meeting participants discussed plans for staying engaged in their communities and are devoted to advancing the futures of adults living with autism. Nine out of ten participants committed to staying involved in the process, and each satellite site identified actions to take on a local level. Autism efforts have been fragmented across the country, but this Town Meeting allowed stakeholders to come together not just for the day but to connect organizations and individuals to continue work as a coalition.

Strategies for Implementation

By the end of the National Town Meeting, over a thousand people had come together and successfully prioritized eight strategies in the areas of funding, staffing, housing, employment, training and community-life. They also had experienced thousands of practical ideas on how to begin implementation of this nation-wide agenda. Most significantly, participants were able to see themselves as a large action-oriented community. After the Town Meeting they had new strategies and energy to begin educating and transforming how to include adults with autism into society in a more constructive and beneficial way in the future.

Innovations for Bridging Geography

A National Conversation

The challenge of America's vast geography was overcome by hosting 16 in-person webcast-connected meetings and 17 virtual tables on the Internet. In real time, all 1,200 participants discussed the same issues, had their ideas considered and reported back as a whole, and each person voted for their priorities.

Virtual Tables

For who couldn't attend in person, virtual discussion tables engaged people from their home computer using webcasts, online chats, keypad polling and facilitated national discussions via conference call.

Making Connections

Autism efforts have been fragmented across the country, and this Town Meeting brought stakeholders together, not just for the day, but in an ongoing communication between organizations and individuals who continue work as a coalition.

Staying Engaged

Nine out of ten participants of the AFAA Town Meeting committed to stay involved in the process, and each meeting site identified actions to take on a local level.

Being Heard at the Virtual Table

—Sammi Fredenburg, Marysville, WA

"It wasn't until Joey should have been ready to graduate from high school that we finally found out why he was struggling so hard in classes, would shut down inside, and had few close relationships. A psychiatrist finally gave him a solid diagnosis of Asperger's Syndrome, which is a high-functioning form of Autism.

The online autism forum facilitated by America*Speaks* was outstanding; the first of its kind that I am aware of where the forum is not professionals speaking about the current state of affairs, but predominantly focused on mothers like me who are facing the decision to turn their children over to independent living. The broadcasts came through clearly and were inspiring. We were able to instant message one another while also having group conversation through text and speaking on the phone. The real-time participation gave us at the virtual table a chance to be heard.

I feel considerably more empowered since the forum, knowing that other parents are undergoing the same concerns I am with their autistic children coming of adult age. Other parents at my virtual table have invited me to an email group, a regional meeting group, social functions, as well as state lobby days. All this makes me feel connected to an effort that is serious about affecting legislation with and on behalf of our autistic children."

America*Speaks* supported AFAA through a three-phase process:

Phase 1
Featured a January 2009 workshop with leading academics and practitioners in the field.

Phase 2
Created a large National Town meeting for stakeholders in November 2009.

Phase 3
Concluding in July 2010; finalized the priorities from the Town Meeting and presented these to policymakers, including the U.S. Congress' Autism Caucus.

About America*Speaks*:

America*Speaks* gives citizens an authentic voice in local, regional, and national decision-making on the most challenging public issues of the day. Our vision is that the public's business will be conducted differently – that by developing a rich national infrastructure for democratic deliberation we can access the collective wisdom of the American people.

More than 150,000 people have had an impact on their communities through our 21st Century Town Meetings® and multi-faceted citizen engagement strategies. Among other projects, America*Speaks* brought large-scale citizen participation to the redevelopment of the World Trade Center site and post-Katrina New Orleans; to the creation of municipal budgets in Washington, D.C. and San Francisco; to regional planning and economic development efforts in the greater Chicago area and Northeast Ohio; and to setting a framework for brain science research and decision-making for the European Parliament.

Founded in 1995, America*Speaks* is a nonprofit, nonpartisan organization based in Washington, D.C. For more information, please visit us on the web at www.america*speaks*.org

ADVANCING FUTURES
for ADULTS *with* AUTISM

"It was a day that made people smile, laugh, feel deeply and proud. The AFAA community is made up of many subcultures and these groups showed up, paid respect, listened and thought together how to best advocate. The local group committed to a follow-up meeting."

—AFAA Town Meeting Participant