

Today's Advancing Futures for Adults with Autism (AFAA) National Town Hall drew more than 1,200 participants, facilitators and observers in 16 cities to shape a nationwide policy agenda that increases independence, engagement, and quality of life for adults living with autism.

Utilizing the highly interactive 21st Century Town Meeting[®] by AmericaSpeaks, families living with autism, advocates, elected officials, service providers, and other community members shared their perspectives in facilitated table discussions and through keypad polling across the 16 cities via satellite links. The participants discussed and rated strategies for addressing housing, employment, community life, many of which originated at AFAA's January 2009 Think Tank meeting. They then prioritized the top strategies within each of the three topic areas.

With an unprecedented number of children with autism entering adulthood over the next 5-10 years, many participants agreed on why it was important to be here today and offered a few telling perspectives:

- There is an urgent and critical need for transition and adult services.
- Families with autism are concerned about the future, there's a sense of both fear and hope: "So I can sleep at night."
- Individuals with autism "want to share" and "live as independently as possible."
- Service providers wish to influence programs.
- All want to have a voice in shaping a nationwide agenda because "The answers are in this room."

Within two months, a full analysis of today's results will be released in a final report. These conclusions will be presented as the consensus statement from the AFAA Town Hall to members of Congress in 2010 as well as other federal, state and local policymakers. In addition, AFAA Town Hall participants discussed plans for staying engaged in their communities and committed to advancing the futures of adults living with autism.



AFAA Town Hall Sites:

Chicago, Atlanta, Boston, Chapel Hill, Cleveland, Dallas/Ft. Worth, Kansas City, Long Beach, Long Island, Miami, Newark, Philadelphia, Phoenix, Pittsburgh, Sacramento, and Washington, D.C.



Participants at the AFAA National Town Hall deliberated on policies to improve the futures of adults with autism.

Cross-Cutting Strategies

Five-year vision: Adults living with autism will have greater access to the building blocks of a joyful, productive and independent life, which includes housing, employment and community life.

<u>Strategies for the Nationwide Agenda</u>	<u>% rated as essential or important</u>
CC-1: Change existing and establish new funding streams so that the financial assistance follows the person, and can be used in a variety of ways to meet a person's unique and evolving needs.	88%
CC-2: Increase the availability of qualified and motivated personnel who support adults with autism.	91%
CC-3: Ensure adults with autism have access to the supports they need to develop life skills necessary to live safe, independent and successful lives.	87%

Feedback on Cross-Cutting Strategies

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|-------|--|
| CC-1: | <ul style="list-style-type: none"> • Starting point for all other strategies, challenged budgets • Portability for state-to-state moves • Flexibility in choice across lifespan to put "power in the hands" of those who need it – "one size doesn't fit all" • Seamless comprehensive services eliminate "luck of the draw" factor |
| CC-2: | <ul style="list-style-type: none"> • The how—eligibility standards may help access • Our kids won't be successful without qualified providers • Disproportionately high number of people who need support vs. number of qualified staff • With the right personnel, needs are reduced, behaviors improve, independence and quality of life grow • Scarcity of staff means wealthy and well-connected have access to support |
| CC-3: | <ul style="list-style-type: none"> • Funding critical for lifespan entitlement program • Increase awareness, engage community and legislators • Person-centered supports build community integration • Support leads to independence – and long-term cost to society decreases |

Housing Strategies

Five-year vision: Adults living with autism will have an increasing number of housing choices as the necessary underpinnings – financial, educational and political – are put into place.

<u>Strategies for the Nationwide Agenda</u>		<u>*Mean Rating (Scale 1-5)</u>
<i>* Rating scale is based on 5=essential to include, 4=important to include, 3=nice to include, 2=not important to include, 1=do not include</i>		
H-2:	Engage people and institutions that direct capital and influence housing policy by presenting a clear, compelling picture of the substantial demand for housing options for adults with autism.	4.24
H-2:	Increase collaboration and coordination between housing agencies and service agencies at the local, state and federal levels.	3.98
H-3:	Motivate the overall real estate community (including government agencies, developers and others) to create housing options that are transit-oriented and accessible to employment and recreation, as well as increase the opportunities for independence and integration.	3.83
H-4:	Direct support towards residential service models that are person-centered and actively seek to meet the needs and interests of adults with autism.	4.46
H-5:	Expand both public and private funding for residential services for adults with autism.	4.61

** Top priorities based on voting noted in bold.

Feedback on Housing

- H-1:
- Show there's a need: "facing a tidal wave"
 - Different options to meet individual needs
 - Inclusiveness promotes "community" rather than institutions
 - Better housing options critical: "We need to think beyond group homes"
- H-2:
- "Collaboration is necessary to simplify the system" and "allows for better use of money"
 - When regulations vary across the system difficulties and confusion arise
 - Broadening housing providers creates more flexibility and individual choice
 - "Creates a community of support"
- H-3:
- Without nearby transportation, options to access everyday activities are limited
 - Incentives to create housing options needed
 - Motivate housing and transportation to work together
 - Reintegrates people into society
- H-4:
- "People with autism are like fingerprints; all are different, with different needs."
 - Helps individuals with autism to be independent
 - Reward model programs to serve as examples for others
 - "I want to live how I want to live, not how others think I should."

Employment Strategies

Five-year vision: Adults living with autism will have an increasing number of housing choices as the necessary underpinnings – financial, educational and political – are put into place.

<u>Strategies for the Nationwide Agenda</u>		<u>*Mean Rating (Scale 1-5)</u>
E-1:	Demonstrate to employers the benefits of employing adults with autism.	4.05
E-2:	Increase and expand the number of successful programs that match adults with autism with meaningful jobs.	4.41
E-3:	Ensure ongoing accessibility to employment supports (including both technical and social dimensions) for adults with autism.	4.59
E-4:	Work with employers to develop model programs that adapt the work environment to help ensure success of adults with autism.	3.99
E-5:	Create and expand career development and vocational skills training programs for individuals with autism while they are still in school.	4.66
E-6:	Create meaningful alternatives to traditional employment (volunteering, entrepreneurial and self ownership opportunities).	4.01

Feedback on Employment

- E-1:
- Helps break down barriers, eliminate stereotyping
 - Educates employers about successful results from other business leaders
 - Focus on abilities, not disabilities; leverage strengths
 - People with autism are reliable and focused, "we are the best workers ever"
 - Enact tax incentives
- E-2:
- Creates more choices, improves quality of life, and increases the "possibilities beyond food, filth, flowers or folding."
 - "When we match people correctly the retention rate can be as high as 90 percent."
 - Need more ways to connect employers with potential employees
- E-3:
- Job coaching and social supports key
 - "Without ongoing job support, cost of failure of the human spirit is a price too high to pay"
 - Employers need education; recognition for efforts that work
- E-4:
- "Everyone knows someone with autism except those in HR."
 - Benefits bottom-line to buy from autism friendly companies
 - Need financial incentives
 - Include business and educational community in development of a national model with state implementation templates

Feedback on Housing, cont.

- H-5:
 - National model providing continuity of services
 - Collaboration between public and private partners leverages resources and increases community inclusion
 - Housing not the primary challenge -- it's the ongoing operating budget; need financial incentives to encourage development
 - More housing options: "big demand with no supply"; supported living, community group homes are more fiscally responsible



Long Beach participants think through strategies for community life.



Participants at the AFAA satellite site in Cleveland celebrate a day of insightful discussions and meaningful work for adults living with autism.

Community Life Strategies

Five-year vision: Adults living with autism will have the opportunity to be valued, contributing members of their communities based on their unique strengths, differences and challenges.

Strategies for the Nationwide Agenda

***Mean Rating (Scale 1-5)**

** Rating scale is based on 5=essential to include, 4=important to include, 3=nice to include, 2=not important to include, 1=do not include*

CL- 1:	Create a comprehensive public awareness campaign that enables the general public to better understand, engage and support adults with autism and their families.	4.09
CL- 2:	Educate local recreation organizations as well as the community about the positive benefits of including adults with autism in their programs.	3.43
CL- 3:	Educate first responders about the challenging behavior that might arise in dangerous situations involving adults with autism so that they are prepared to handle these occasions in the safest and most effective manner.	4.56
CL- 4:	Assist adults with autism to access public and private transportation that makes it possible for them to live, work and recreate where they choose, including providing training for transportation service providers that teaches them to respond to the needs of adults with autism.	4.06
CL- 5:	Create programs to support individuals to create meaningful interpersonal relationships, healthy sexuality and personal safety.	4.05

Feedback on Community Life

- CL- 1:
 - Adults with autism are left out of current campaigns, their needs aren't well known
 - Must increase this awareness to gain the public's support
 - Awareness opens doors, helps with access to services, reduces stigma and eliminates misconceptions
- CL- 2:
 - "We all just want to belong."
 - Education is key to dispel myths and encourage inclusion
 - Recreation is critical to quality of life, improves overall health and socialization
 - Local recreation programs need to know how to include adults with autism
- CL- 3:
 - Misinterpretation of behavior creates vulnerability to danger and suspicion
 - Training will help address wrongful incarceration, physical harm, lawsuits – provide first responders with tools they need to respond appropriately
 - "The times I most need help are often the times I am least able to ask for help."
- CL- 4:
 - National challenge - requiring national policy and national funding – should include rural options
 - Foundational to inclusion and independence
 - Travel training for individuals with autism
 - Educate transportation providers
 - "If you can't get to work, how will it work?"

** Top priorities based on voting noted in bold.

Participant Demographics	
Age	Participants
Under 20	1%
20-34	17%
35-44	19%
45-54	36%
55-64	22%
65 or better	5%
Race/Ethnicity	
Asian American	2%
Black/African-American	6%
Latino	6%
Native American/Indian	0%
White/Caucasian	83%
Other	3%
Household Income	
Less than \$20,000	5%
\$20,000-\$39,999	10%
\$40,000-\$59,999	11%
\$60,000-\$74,999	16%
Over \$75,000	51%
Other	7%
Relationship to Autism	
Adults with autism	7%
Family member	35%
Program or service provider	32%
Policy maker	6%
Employer	5%
Realtor or housing specialist	3%
Community member	12%
Level of Support for Family Member with Autism	
None	2%
Minimal	10%
Moderate	23%
Extensive	32%
Not Applicable	33%

Overall Priorities

Cross-Cutting Strategies

Change existing and establish new funding streams so that the financial assistance follows the person, and can be used in a variety of ways to meet a person's unique and evolving needs.

Increase the availability of qualified and motivated personnel who support adults with autism.

Ensure adults with autism have access to the supports they need to develop life skills necessary to live safe, independent and successful lives.

Housing Strategies

Direct support towards residential service models that are person-centered and actively seek to meet the needs and interests of adults with autism.

Expand both public and private funding for residential services for adults with autism.

Employment Strategies

Create and expand career development and vocational skills training programs for individuals with autism while they are still in school.

Ensure ongoing accessibility to employment supports (including both technical and social dimensions) for adults with autism.

Community-Life Strategies

Educate first responders about the challenging behavior that might arise in dangerous situations involving adults with autism so that they are prepared to handle these occasions in the safest and most effective manner.



Advancing Futures for Adults with Autism (AFAA) (www.afa-us.org) is a national consortium seeking to create meaningful futures for adults with autism that include homes, jobs, recreation, friends and supportive communities. It includes members from Autism Speaks, Alpine Learning Group, The Autism Program Service Network, The Daniel Jordan Fiddle Foundation, Easter Seals, Global Communities of Support, Hallmark Community Solutions, New York Center for Autism, Organization for Autism Research, Southwest Autism Research and Resource Center, and University of Miami/Nova Southeastern University Center for Autism & Related Disabilities. The support of our 44 satellite hosts, committee members, table facilitators, theme team members, other volunteers and AmericaSpeaks made today's summit possible.



Based in Washington, DC, AmericaSpeaks (www.americaspeaks.org) is a nonprofit organization that engages citizens in important public decisions that impact their lives. More than 150,000 people have had an impact on their communities through this 21st Century Town Meetings® and multi-faceted citizen engagement strategies. Since 1997, AmericaSpeaks has conducted 21st Century Town Meetings® across the country and on the redevelopment of the World Trade Center after 9/11, statewide health care plans in California and Maine, regional economic development in Ohio, childhood obesity, and the Washington D.C. municipal budget.