



ADVANCING FUTURES
for ADULTS *with* AUTISM

National Town Hall

Executive Summary



“The face of autism is rapidly changing with a generation of children who will be entering adulthood over the next 5 to 10 years. As a society, we are ill prepared to deal with what will be a boom in demand for housing, employment and other critical services needed to appropriately serve adults living with autism. The AFAA initiative is an effort to create, with the input of a wide range of stakeholders, a useful and actionable public policy agenda.”

–Peter Bell, Executive Vice President of Programs and Services, Autism Speaks

“If you’ve met one person with autism, you’ve met one person with autism. The heterogeneity of autism is evident in the broad range of severity, abilities, challenges and extraordinary talents.”

Stephen M. Shore, Ed.D
Associate Professor of
Education
Adelphi University

What is autism?

Autism is a developmental disability that by definition begins before the age of three and most often lasts throughout a person’s lifetime. Individuals with autism experience challenges in the areas of social interaction and communication. Many individuals with autism have repetitive behaviors or intensely focused interests. The severity of symptoms vary widely among individuals and run the spectrum from those who do not develop spoken language and require extensive support to ensure their wellbeing to individuals who are highly intelligent but socially awkward.

Individuals with autism are unique. Each person has strengths and areas of need. The following are a few common characteristics that can be considered challenges or strengths depending on their severity:

- Difficulty understanding language and social cues
- Excessive or minimal speech
- Concrete thinker, often has difficulty with abstract concepts
- Difficulty relating to others
- Social awkwardness
- Intense interests or concentration
- Repetitive behaviors such as pacing, rocking or hand flapping
- Sensitivity to light, sound, smell or other sensory issues
- Anxiety or abnormal fears
- Complex and in some cases challenging behaviors
- Difficulty managing transitions or changes in routine
- Strong visual skills
- Excellent memory for facts and statistics
- Adheres to rules and honesty sometimes to a fault
- Musical, mathematical, technological, artistic ability or interest

***Autism is an umbrella term for a class of disabilities called “pervasive developmental disorders” that include Asperger Syndrome, Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Rhetts Syndrome, and Childhood Disintegrative Disorder. For this document, we refer to the entire class of disorders as “autism.”*

Why is there an urgent and critical need for adult services?

On December 18, 2009, the U.S. Centers for Disease Control and Prevention announced that autism now reportedly affects 1 in 110 children, including 1 in 70 boys. This represents a staggering 57 percent increase from 2002 to 2006 and a 600 percent increase in just the past 20 years. These children will soon be entering adulthood.

With this increase in prevalence has come an increase in the need for effective services for adults with autism. The need continues to far exceed the available resources leaving a generation of people with autism and their families in a programmatic, financial and personal limbo. In order for adults with autism to have the services they need, resources must be available and policy needs to be amended in order to ensure that these individuals have access to resources to meet their needs.

What are some examples of the need for adult services?

Housing, employment and community life opportunities are limited for adults living with autism. Limited resources restrict their abilities from achieving more productive and independent lives. The following are examples of adults with autism who face everyday life challenges that cannot be resolved with the current state of services.

Dan: Dan, age 45, lives at home with his mother who is 78 years old. He's been on a waiting list for three years for appropriate residential support which could be a group home or additional in-home support. His mother is anxious about what will happen to Dan when she can no longer care for him. Dan would benefit from access to supported housing opportunities for adults with autism.

Charlie: Charlie, age 28, has a master's degree in engineering and had a job he enjoyed. He performed well and was praised for his work. However, he lost his job because of difficulty interacting with his co-workers. He is depressed because he was unable to keep a job. Charlie would benefit from a job counselor who could help him manage and navigate interactions with others that he finds difficult. Charlie's employer and fellow co-workers would benefit from awareness and sensitivity training.

Stacey: Stacey, age 21, has received appropriate educational support since she was diagnosed with autism at the age of three. She is still in school and enjoys her full day of school and after-school activities. However, within the year, she will age out of the educational system and lose all support. There are few programs to assist Stacey once she leaves school, and those programs have very long waiting lists. Stacey would benefit from vocational and supported employment programs to help her develop job skills and find an appropriate job.

Bill: Bill, age 33, loves books and has been volunteering at his local library for the past year. He has been offered a full-time paid position at a library two towns away. Unfortunately, he's not able to accept the job, because he does not know how to navigate the public transportation system and has no other form of private transportation. Bill would benefit from transportation support that allows him to become gainfully employed.





These individuals represent just a handful of adults living with autism who need extra support and care. Resources currently available are inadequate and the demand for them will only continue to rise as the number of children with autism reach adulthood. Changes and an expansion of employment supports, housing, and transportation options could make a big difference.

What is AFAA?

Advancing Futures for Adults with Autism (AFAA) is a national consortium of organizations working together, promoting a collaborative spirit and developing the public and private sector support needed to improving the lives of adults with autism. The ultimate goal of AFAA is to develop a national policy agenda that addresses the unique needs of adults living with autism.

Organization Chairs

Autism Speaks – National
New York Center for Autism – New York, NY

Honorary Chair

Global Communities of Support – Princeton, NJ

Partners

Alpine Learning Group – Paramus, NJ
The Autism Program of Illinois – Springfield, IL
The Daniel Jordan Fiddle Foundation – Paramus, NJ
The Hope Institute – Springfield, IL
Easter Seals – National
Hallmark Community Solutions – San Francisco, CA
Organization for Autism Research – National
Rethink Autism – National
Southwest Autism Research & Resource Center – Phoenix, AZ
Trinity Services, Inc. – Joliet, IL
University of Miami/Nova Southeastern University Center for Autism and Related Disabilities – Miami, FL

To date, AFAA has carried out two thought-provoking forums for discussion and consensus building to prioritize the needs of adults living with autism and advance the conversation with local, state and federal government, private sector interests and local communities. The first initiative was the AFAA Think Tank held on January 23-24, 2009 in New York City. The Think Tank was made up of affected families and individuals, program directors, university professors, public policy authorities and specialists from both the public and private sectors. The three main areas of focus were housing, employment and community integration. The participants identified gaps in current services and strategies for filling them. The group discussed how to effectively address these areas. Refer to www.afa-us.org for the summary report and addendum.

The purpose of the AFAA Think Tank was to establish the building blocks for the AFAA National Town Hall meeting agenda, which included the formulation of five-year vision statements in the areas of housing, employment and community life as well as identification of service gaps and mitigating strategies. These topics were explored in detail at the AFAA National Town Hall meeting.

What happened at the AFAA National Town Hall Meeting?

The AFAA National Town Hall meeting hosted on November 13, 2009 involved participants from 16 locations throughout the U.S.. Chicago served as the hub with nearly 400 people; approximately 750 people participated at the satellite sites. Additionally, about 60 stakeholders who were not at one of the 16 locations participated via the internet in a virtual town hall.

Satellite Site Partners

Atlanta:	Marcus Autism Center
Boston:	Doug Flutie, Jr. Foundation for Autism Matthew and Eve Megarel Melmark New England Nashoba Learning Group The New England Center for Children
Chapel Hill:	Autism Society of North Carolina Division of TEACCH Extraordinary Ventures, Inc.
Cleveland:	Children's Hospital Cleveland Clinic Cleveland Foundation Rainbow Babies and Children's Hospital: Monarch Center for Autism
Dallas/Ft Worth:	Easter Seals
Kansas City:	University of Kansas Lifespan Institute Children's Mercy Hospitals and Clinics
Long Beach:	Easter Seals
Long Island:	Asperger's Syndrome and High Functioning Autism Association (AHA) The Cody Center Developmental Disabilities Institute Eden II Programs Elija Foundation Nassau Suffolk Services for Autism
Miami:	Autism Society Miami-Dade Chapter Easter Seals University of Miami/ Nova Southeastern University CARD The Victory Center
Newark:	Alpine Learning Group The Daniel Jordan Fiddle Foundation
Philadelphia:	Autism Delaware The Children's Hospital of Philadelphia Drexel University, School of Public Health Whitesell



*Mayor and Mrs. Daley
opening the National
Town Hall in Chicago*

- Phoenix:** Southwest Autism Research & Resource Center (SARRC)
- Pittsburgh:** Milestones Achievement Center of America, Inc. (MAC)
- Sacramento:** Hallmark Community Solutions
- Washington, DC:** Madison House Foundation
Organization for Autism Research (OAR)
- Virtual Town Hall:** Rethink Autism

The AFAA National Town Hall was designed and facilitated by AmericaSpeaks (www.americaspeaks.org) an organization that has conducted these kinds of interactive sessions on some of the most important public policy issues in the nation and in other countries.

Overall, approximately 1200 participants shared their perspectives in facilitated table discussions and through integrated keypad polling across the cities. Strategies discussed focused on improving the lives of and services for adults with autism in the areas of employment, housing and community life. Cross-cutting strategies that affect all areas of life were also addressed.

The goals of the Town Hall were to engage a broad community of people who are committed to addressing the needs of adults living with autism; generate shared agreement on the most important strategies to be pursued at federal, state and local level, and brainstorm empowering actions that participants can initiate and support at all levels.

The data and comments collected from participants of the AFAA National Town Hall have been analyzed and dominant themes are presented in this final report.

Who attended the Town Hall Meeting?

Approximately 1200 participants attended the Town Hall, almost 400 in Chicago and 790 scattered around the 15 satellite sites in Atlanta, Boston, Chapel Hill, Cleveland, Dallas/Fort Worth, Kansas City, Long Beach, Long Island, Miami, Newark, Philadelphia, Phoenix, Pittsburgh, Sacramento, Washington, DC, as well as an online site. Demographics were taken based on key pad responses from each of the participants. For demographic information and rankings of priorities, please refer to Addendum 1.

The dynamic keypad technology afforded AFAA the opportunity to look at the feedback of various stakeholder groups and gain additional perspectives on their priorities and needs. Although there was a large degree of consensus, differences in priorities were identified by location level and among the different stakeholder groups. For more in-depth information about the input received from Town Hall participants on Housing, Employment and Community Life, please refer to Addendum 2.

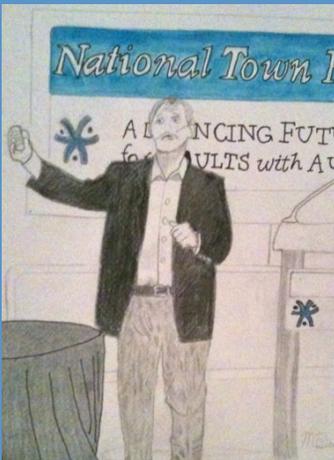


Illustration by Matt Bianci: Matt is a talented artist living with autism, he worked on the above drawing during the Town Hall meeting in Chicago, IL.



“Flexible funding provides empowerment to persons with autism.”
- Philadelphia Participant

“A program is only as good as the people delivering it.”
- Chapel Hill Participant

Cross-Cutting Strategies

Five-year Vision: Adults living with autism will have access to the building blocks for fulfilling, productive and independent lives which include housing, employment and community life.

Strategy #1: Change existing systems to ensure funding streams follow the person, and can be used in a variety of ways to meet a person’s unique and evolving needs.

Arguably, one of the most important strategies, as well as the biggest hurdles, is to increase the funding and alter the policies regarding how funding can be used for adults with autism. Funding must be increased in order to provide adults with the resources and services they need to live successful, independent lives. Funding must be allocated in a way that allows individuals to meet their unique needs. These needs vary greatly among individuals and throughout the lifespan. Funding must be flexible. Decisions about services utilized should be left up to the individual with autism and their family. The strategies should be cost effective and allow cross-state portability and uniformity. In addition, it is critical to secure other types of funding in addition to public money to carry out this priority.

Strategy #2: Increase the availability of qualified and motivated personnel who support adults with autism.

Staff members play an integral role in the life development of adults with autism. Quality staff can assist, guide and support adults with autism in ways that lead to increased independence and empowerment. Qualified caregivers also play a key role in family support. If the parents have confidence in the care provider, the family’s stress is reduced. Service providers act as role models, and with the right personnel, needs are reduced, behaviors improve and quality of life increases. Bolstering the availability of qualified and motivated personnel is a difficult task. Support staff caring for individuals with autism are not well paid, and their job responsibilities are extensive. As a result, high quality staff is difficult to recruit and retain. Training programs must be created to teach direct-care staff how to effectively work with adults with autism. Funding must be increased to attract qualified and caring personnel to the field. Further, rewarding career paths for those working in the field must be created.

Strategy #3: Ensure that adults with autism have access to the supports they need to develop the life skills necessary to live safe, independent and productive lives.

Adults with autism need life skills training to learn how to maximize independence to the greatest degree possible and achieve their goals. Greater independence increases the quality of life for individuals with autism and their families. Life skills training should be incorporated into the school system along with transition programs that enable individuals to gain the skills necessary for adult life. There should be a national mandate for lifetime access to these supports. Life skills training should be a right not a privilege.

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.

"It is important to show the people who can actually make it happen how to do it and why it needs to be done."

- Philadelphia Participant

Strategy #1: Engage leaders and institutions that direct capital and influence housing policy by presenting a clear, compelling picture of the substantial demand for housing options for adults living with autism.

We must provide a compelling case to those who control funding, clearly demonstrate the consequences of inaction and articulate the benefits of action. The cost of not creating housing options is staggering and far greater in the long term. There is also significant opportunity to involve private and public resources. Housing options have two major components: the house itself and the services offered within the home. We must address the capital needs for developing and maintaining the home as well as the ongoing funding needed to provide services and supports for daily living. Both are critical to ensure successful outcomes. Funding for the home (e.g. a house, group home, apartment, etc.) and the services should remain separate so that a person's change in services does not result in a person having to relocate. We must also recognize the importance of creating alignment with the broader adult disability community while acknowledging the important differences for adults living with autism. It's critical we reach out to significant numbers of people within the public, private and nonprofit sectors to influence capital and policy. This also requires unifying the voice of the autism community to support cohesive plans that respect the heterogeneity of the disorder and allow for greater choices by individuals and families. If there is agreement on the "case" then many voices can make progress in the same direction.

Strategy #2: Increase collaboration and coordination among housing and service agencies at the local, state and federal levels.

Interagency collaboration and coordination will increase the efficiency and cost-effectiveness of the housing system. The current system is disjointed, which often leads to inefficiencies and sacrifices in quality. Interagency strategies and well integrated plans can improve and expand the system and make it easier for families to navigate the system. Individual needs vary widely across ages and spectrums, and more collaborative dialogue will allow for better responses that accommodate a broad range of needs. The introduction of government tax incentives could increase collaboration and community participation and further engage the private sector. Autism-specific, nationalized waivers that are portable and utilize specific programs, should be considered. These waivers plus collaboration between agencies will lead to vast improvements in the housing system for adults living with autism.

"Housing is the easy part. The support and services received is the most difficult part – coordination is critical."

- Phoenix Participant

“Housing options must create more opportunities for independent access, opportunities for individuals on the spectrum to be active, contributing members of their community.”

- Chicago Participant

“This strategy is imperative. One size does not fit all. Housing is the link to life, work and happiness. There needs to be access to the outside world through person-centered supports.”

- Chicago Participant

Strategy #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, and increase opportunities for independence and integration.

To actively engage public and private sector real estate interests in addressing the housing concerns for adults with autism, incentives must be in place in the form of tax breaks, credits, fee reductions, etc. Awareness of market demand, special requirements and risks/rewards are key components to motivating those in control of creating housing options. Public opinion must be shifted to rid communities of the “not in my backyard” or “NIMBY” concept that often surfaces. We must motivate developers to create housing options that promote community integration for adults living with autism. Transit-oriented housing is critical for providing access to jobs, community involvement, etc., while promoting greater independence. The goals of the autism community overlap with trends in green building and sustainable development in this regard, so efforts are aligned. Rural, suburban and urban options, along with a mix of housing designs and amenities, should be presented to the real estate community, demonstrating that one size does not fit the needs and interests of this diverse population of current and future residents. As a result, there are many different ways the real estate community can engage to address the demand.

Strategy #4: Direct support toward residential service models that are person-centered and actively seek to meet the needs and interests of adults living with autism.

The vast majority of existing housing options do not properly support many adults with autism. Flexibility in housing design and supports are critical in meeting the needs of individuals throughout their lifetimes and providing for greater efficiencies, quality of life and desired impact. Some adults may live in a fully supervised group home with other adults who have similar or complementary skill sets. Others might choose to live independently while requiring periodic visits from support staff that help with a variety of skills like balancing a checkbook, nutritious menu planning, food preparation, etc. Some adults may elect to continue living at home with parents or siblings and also require additional supports. The participation of family members in the decision-making process is essential. Quality of life options should be evaluated based on the interests and abilities of the resident, not just on the amount and types of services provided. Residential services and housing providers should be separate. There should be best practice models for others to follow. Residential services should not just take care of adults; they should strive to maximize independence to the greatest degree possible. We must also imbed procedural safeguards that protect the rights of individuals in residential facilities.

“Public and private interests must come together to expand the capacity of available housing and provide individuals with more choices.”

- Chapel Hill Participant

Strategy #5: Expand both public and private funding for residential services for adults with autism.

Limited residential options are currently available and the demand far exceeds supply. Improved funding streams for new housing options are needed, and the balance between public and private funding to improve outcomes must be addressed. The current housing system places significant financial responsibility on the families. Adults with autism should have access to housing regardless of their family's financial situation. More funding provides a greater number of housing options and allows for a continuum of services throughout their lifetimes. Private funding is a necessary component of achieving this goal and allows for increased efficiency, competition and continuity of housing. Public, private and nonprofit sector collaborations are needed to ensure housing stock is available along with reliable resources and services. It is also important to address the bias of institutional funding as institutions are not the best options for the majority of adults with autism. A system must be in place that allows private and public funding to come together and achieve the highest quality and most efficient and effective outcomes.



“Show employers the wide spectrum of autism and how easy some modifications are to implement, and the added benefit of a highly motivated workforce.”
- Pittsburgh Participant

“We must create the opportunities at a much younger age. Why wait until 22?”
- Sacramento Participant

Employment Strategies

Five-year Vision: Adults living with autism will have a measurable increase in job opportunities paired with ongoing training and support that enables them to be successful in the workplace.

Strategy #1: Engage employers by presenting a clear and compelling picture of the benefits of employing adults with autism.

Present a compelling case to those who control jobs about the benefits of employing adults with autism. Demonstrate that in some circumstances, an adult with autism may be best suited for a position. Many adults with autism are consistent in their job performance, enjoy routine, have lower turnover rates, focus well on repetitive tasks, are detail oriented, have a serious work ethic and are extremely honest. Fear of the unknown and common misconceptions about autism can be addressed by sharing information and success stories. Employers should be educated through best-practice models and all forms of media should be used to get the word out and demonstrate to employers the value of hiring adults with autism. Clear information is a necessary component of a successful campaign to interest employers. Successful models such as Walgreen’s, Clark Manufacturing, Glaxo Smith Kline, Specialisterne in Denmark, Outback Steakhouse and CVS Pharmacy present market-based reasons that demonstrate why employing adults with autism is good for business. Employers require information and training that lead to successful outcomes. Workplace adjustments may be needed so adults with autism are able to do the same job as neuro-typical employees. Incentives like tax breaks, awards and free advertisements for companies who support adults with autism may increase the hiring rate. Adults with autism should be offered volunteer or internship positions so employers may see firsthand how these individuals work, and increase the likelihood of employment offers. Hiring adults with autism can be good for business.

Strategy #2: Increase and expand the number of successful programs that match adults with autism with meaningful jobs.

Jobs that allow individuals with autism to thrive and succeed are far more valuable because they lead to increased motivation, which translates into productivity, commitment and loyalty. Meaningful jobs, not just any job, should be found. Commonly, adults with autism are underemployed and their potential to benefit the employer is not realized. Individuals with autism have far greater potential than is utilized in many of the jobs currently available to them. Creative matching of skills and interests with available jobs maximizes the potential of the adult with autism and benefits the employer by delivering an employee highly qualified to fulfill the job functions. An excellent example is Specialisterne in Denmark. (<http://specialisterne.com/index.html> and Aspiritech in the United States <http://www.aspiritech.org/>). The adult with autism and their family should be consulted to obtain a better understanding of the strengths, needs and wants of each individual. Many families have limited information or support. Agencies and professionals

“Consistency keeps them from digressing. Support helps present their best potential. More support leads to more independence.”
- Cleveland Participant

“Employers who may want to hire persons with disabilities aren’t sure how to make adaptations and accommodations and often have concerns about safety. Employers need models that can be sustained when other supports disappear.”
- Miami Participant

are needed for facilitate employment and career opportunities. Best practice models, as well as successful job coaching and job matching programs, should be expanded. Consider incentives, such as tax breaks for employers. Matching skills and interests with jobs that capitalize on individual strengths increases successful outcomes for individuals and employers.

Strategy #3: Ensure ongoing accessibility to employment supports (including both technical and social dimensions) for adults with autism.

Once adults with autism have a job, continued employment supports are critical for ongoing success in the workplace. Job environments constantly change; tasks are modified; managers and co-workers leave their positions and are replaced by new employees. This presents unique challenges for individuals with autism because they often have difficulty making transitions to new people and expectations. Individuals with autism have a core deficit in communication and self advocacy skills are generally weak. As a result, continued support is necessary for adults with autism to remain successful and employed over time. It is commonly understood that job coaches, mentors and liaisons are necessary to ensure that individuals with autism understand their jobs and employers and co-workers understand the unique needs of their colleague with autism. Individuals with autism have social difficulties, which serve as a frequent barrier to employment. Therefore, social aspects of the working relationship are an important factor for the job coaches and mentors to address. Support must be tailored to the individual. Each adult with autism has different skills and challenges to overcome in the workplace. Eligibility for employment supports should be expanded through legislation. Supports must be available to adults with autism regardless of their place on the autism spectrum. Currently, most vocational rehabilitation programs do not include adequate supports. Workplace training must start at a young age; internships, job shadowing, volunteer positions should be available to high school students with autism so individuals are better prepared for the workplace and require fewer ongoing supports. Adults with autism are a valuable sector of the workforce and with support can be very productive and valued employees.

Strategy #4: Encourage employers to develop model programs that adapt the work environment to help adults living with autism be productive and successful employees.

Modifications in the job process or job environment may enable individuals with autism to successfully complete job tasks. Model programs (e.g., Walgreens, Glaxo Smith Kline, Clark Manufacturing, Specialisterne, Outback Steakhouse and CVS Pharmacy) should be developed and information disseminated so employers can learn about the benefits of such accommodations. Managers and co-workers should be educated about common challenges faced by individuals with autism so they may better understand and work together. Managers and co-workers should be made aware of common strategies and information on model programs through the dissemination of videos, tool kits and readily accessible sources. Public vocational rehabilitation agencies should serve as a clearinghouse for such information and engage relevant community organizations to assist.

Two additional strategies were added during the Town Hall based on feedback from participants:

Strategy #5: Create and expand career development and vocational skills training programs while individuals with autism are still in the educational system.

Despite the requirements of the IDEA, most individuals with autism do not have adequate skills to obtain and retain a job when they leave the school system. Better pre-employment and employment supports should be offered while a student is still in school. Such supports include vocational skills as well as social skills training. Such training cannot wait until an individual with autism reaches adulthood. Volunteer positions and internships should be encouraged while the student is still in school to help build their skills and resumes.

Strategy #6: Create meaningful alternatives to traditional employment, such as volunteering, entrepreneurial and self ownership opportunities.

Non-traditional employment opportunities must be considered for adults with autism. For some individuals with autism, volunteer or internship positions might be optimal. For others, entrepreneurial or self ownership opportunities may provide the right environment in which a person with autism may make productive use of his time. Innovative employment options must be explored to find productive positions for individuals that capitalize on their interests, strengths and growth opportunities.



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.

“The face of autism is not the adult with autism.”

- Long Beach Participant

Strategy #1: Create a comprehensive public awareness campaign that enables the general public to better understand, engage and support adults with autism and their families.

Public awareness is critical for engaging public support at the individual, local and federal levels. Increased understanding about the challenges facing an adult with autism each day is the first step towards greater acceptance and support by the public. Public awareness can happen through many channels: television, movies, social media, internet, PSAs, school education, etc. A strong and unified autism community implementation of a coordinated, national public awareness strategy will lead to greater success. An important component of this coordinated effort will be that the content and messaging reflect the wide spectrum of autism so people can see the whole picture. A successful campaign will be comprehensive and celebrate differences. Government grants for these campaigns will be a smart investment - essentially leveraging government dollars to increase the public's engagement and support at the citizen and community level. Not only does an effective public awareness strategy make community integration more possible, it can help reach families with little exposure to autism spot the symptoms in their child, leading to earlier diagnosis and earlier, more effective intervention. Additionally, as the average age of a person with autism increases, so must the age of a person with autism portrayed in the media. Currently, the media primarily depicts high-functioning children with exceptional talents when featuring a person with autism. It is now time for a shift in the media to also include adults and individuals with autism that need more supports. To be most effective, awareness campaigns must start at a very young age, teaching young children about autism in school curriculums and through compelling, age-appropriate mediums so children understand autism early in life. With the right exposure and experiences, fears can be greatly reduced or eliminated, and acceptance and compassion can grow in its place. The broader the reach of such campaigns, the brighter the future of adults with autism.

Strategy #2: Educate local recreation organizations as well as the community about the positive benefits of including adults with autism in their programs.

Many participants felt that recreation is a key ingredient to successful community integration, overall health, self-esteem and social skills. All of these factors are necessary to live a full and independent life. Currently, there are far more recreation activities for children with autism than for adults. Many children age out of these programs at 18 or 21 years old. Given the dramatic increase of teens transitioning

“This has to be included. Our children are at risk. Adults are at risk. It's a life safety issue.”

- Miami Participant

into adulthood, it is critical to extend these programs into adulthood - essentially allowing these programs to age with their participants. We can look to seed autism integration programs in large organizations like the YMCA or JCC, creating a best practice and paving the way for other public and private organizations to follow. These programs can play a substantial role in better integrating adults into the community. Education for such programs should be two-fold. There needs to be autism education for the staff of the recreational organizations, as well as education for the individuals with autism so that all are better prepared for positive interactions. Just like for any "typical" adult recreational opportunities, choices should extend beyond sports and games. Parks, libraries, theaters, churches and coffee shops are all forms of recreation that provide people with a rich quality of life and should be accessible to adults with autism.

"Recreation and community integration promotes awareness of autism. The more we include, the more acceptance there will be. It decreases the feelings of isolation of families and increases compassion."
- Chicago Participant

Strategy #3: Educate first responders about the challenging behavior that might arise in dangerous situations involving adults with autism so they are prepared to handle these occasions in the safest and most effective manner.

Educating first responders about autism is a priority. First responders must be prepared to handle occasions involving adults with autism in a safe and effective manner. National standards and mandated trainings are fundamental for the safety and protection of adults with autism. In many cases, first responders are not prepared to deal with an adult with autism and may improperly or inaccurately interpret the adult's reaction to an emergency situation. A survey of individuals with autism and their families indicated that 23% have had interactions with first responders because of wandering (Autism Information for Law Enforcement and Other First Responders, Autism Society of America Report). The development of a national autism safety kit for first responders may be an appropriate way to increase awareness of how to best support an adult with autism during emergency situations. The training should be expanded to include emergency room personnel, judges, mall security guards and other individuals in the public domain. There is some uncertainty as to whether this initiative should be handled at a national or local level. Different communities may have varying degrees of difficulty with this issue. In turn, individuals with autism also need to be educated about emergency situations and first responders. Understanding that first responders are there to help them and keep them safe will decrease the likelihood of a person with autism behaving in a manner that could result in harm. In order to reduce the number of incidents, relationships between the autism community and police and fire departments must be built. Education of the first responder, the person with autism and their family is critical for improving this aspect of community life.

"Transportation impacts everything else. We have an obligation to give adults what they need to be independent."

- Virtual Town Hall Participant

Strategy #4: Assist adults with autism to access public and private transportation making it possible for them to live, work and recreate where they choose, including providing training for transportation service providers enabling them to be more responsive.

Access to safe and effective transportation is a key ingredient to community integration, opening up employment, housing and recreation opportunities. The right transportation gives an adult with autism greater choice and control over where they live, work and play, which in turn increases self-esteem, empowerment and a sense of belonging. Currently, transportation is a major roadblock to other services and is very often the single most restricting factor. While there are some transportation solutions that can be handled by local officials and service providers, there are larger accessibility issues which are national in scope. Much like the training needed with first responders, we must teach transportation employees how to interact with adults with autism and to handle situations involving adults with autism. In turn, it is important to teach adults with autism from an early age how to use the public transportation system. Transportation education should be part of transition programs and taught at younger ages. Public transportation is everywhere in big cities, but we need to make sure people outside cities have access to transportation services to access their housing, jobs and communities. In areas where public services are lacking, we need to expand private services so there is sufficient coverage. There must be policy changes and increased funding to improve transportation.

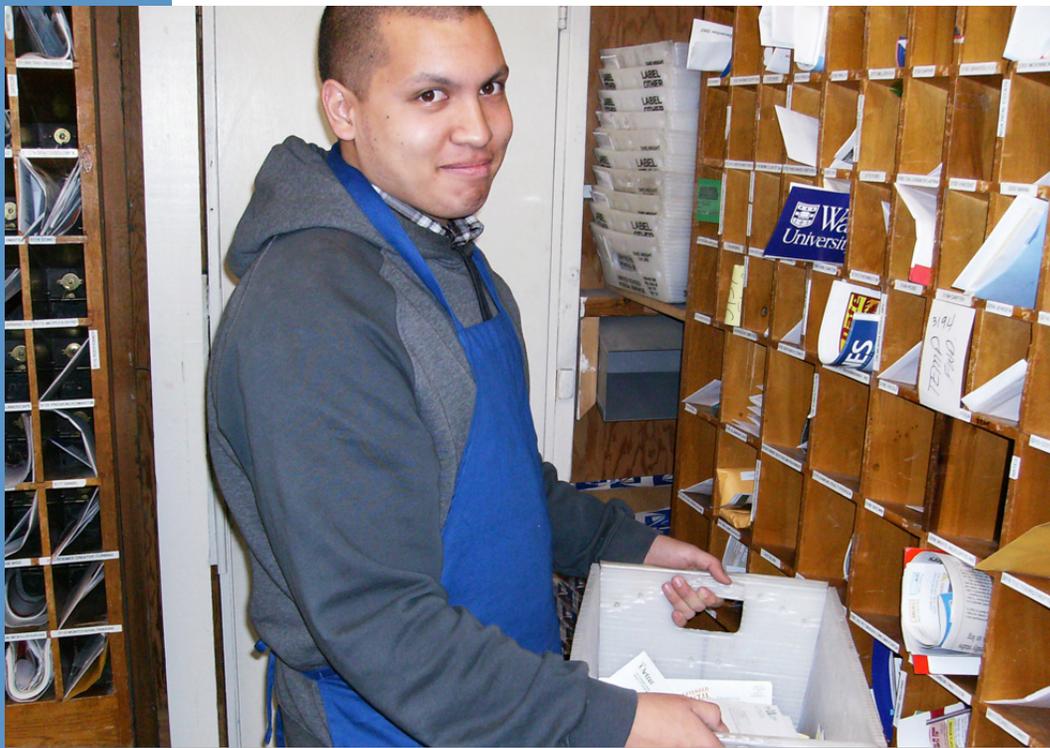




What's Next?

The priorities set forth in this document represent the starting point for bringing these issues to the forefront. The third phase of AFAA's major initiatives is a Congressional Briefing (Autism Congress) that will take place in July 2010. The briefing will include information about autism, background on AFAA and a presentation of the issues identified through the AFAA Think Tank and AFAA National Town Hall. The goal of the Congressional Briefing is to bring together federal legislators, national policymakers and advocates for adults with autism to develop cost-effective, evidence-based solutions to the challenges.

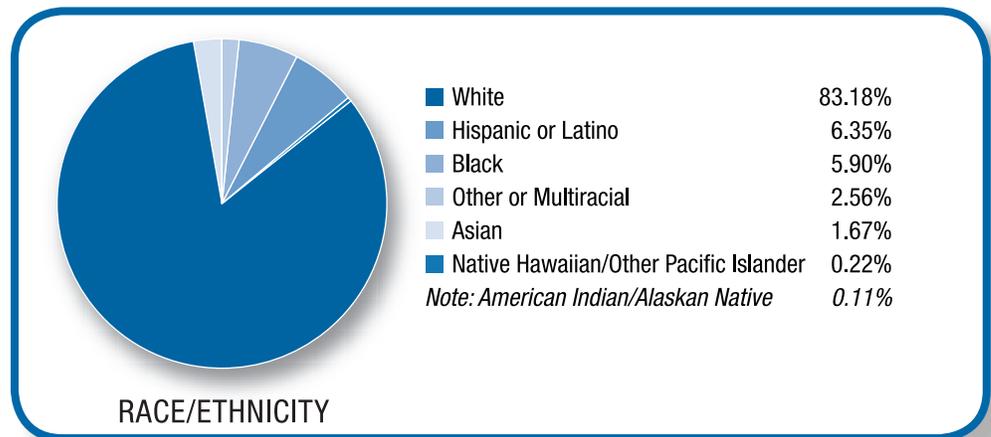
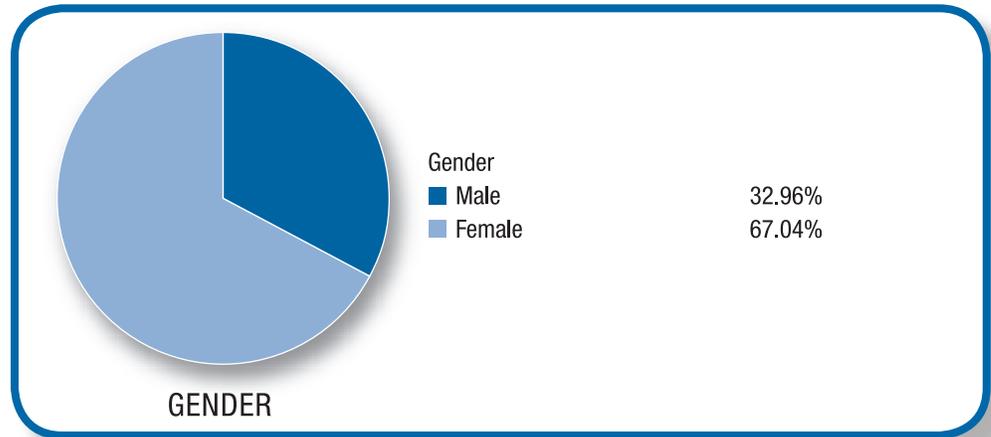
It should be noted that not all of the strategies developed will be effectuated at the federal legislative level. There are many opportunities for collaborations between public, private and nonprofit organizations. To this end, several of the AFAA satellite hosts continue to meet and engage their local participants on the issues outlined during the National Town Hall. They are working collectively on a local level to better meet the needs of adults with autism. Their efforts will be communicated through the AFAA website (www.afa-us.org), so other communities can learn from and replicate the promising programs and strategies now underway. It is through the collective efforts of the public, private and nonprofit sectors that we will be able to advance the futures for those living with autism.



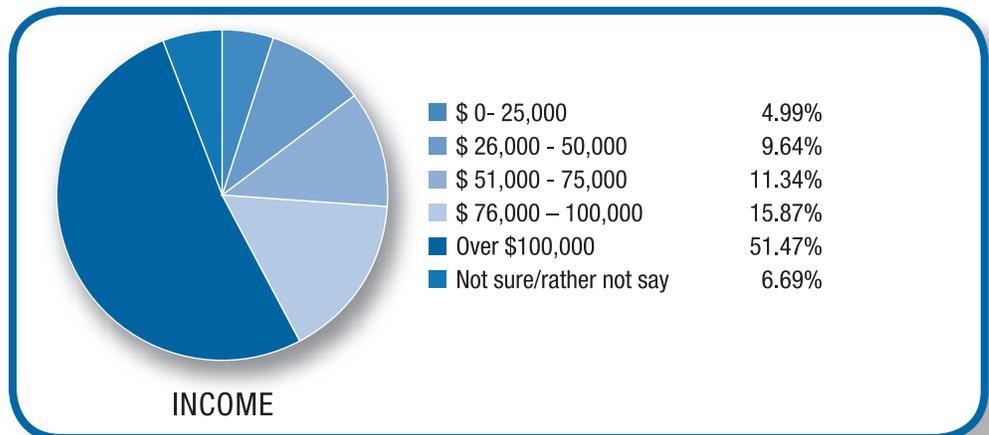
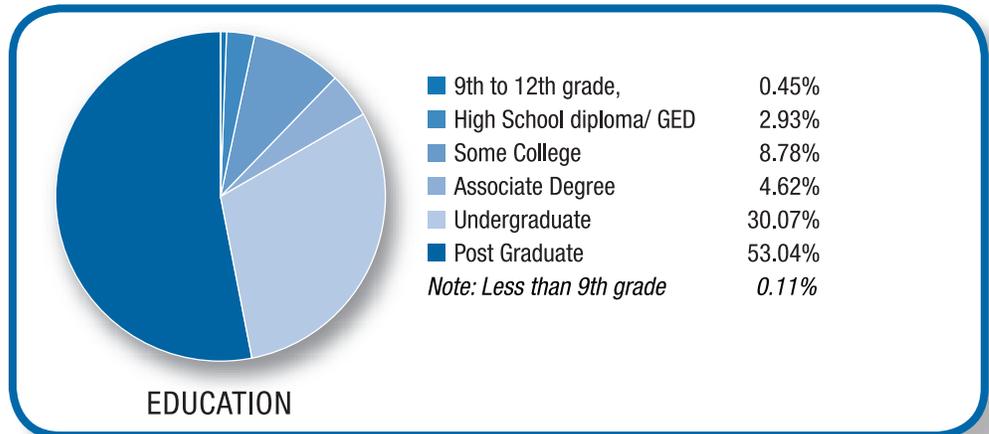
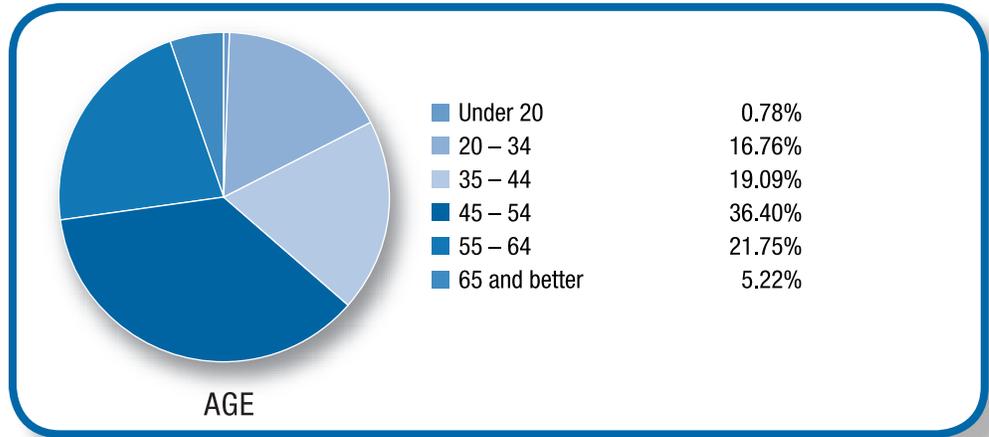
Addendum 1

Approximately 1200 participants attended the National Town Hall. The following graphs provide demographic information about the participants. All information was collected using electronic key pads.

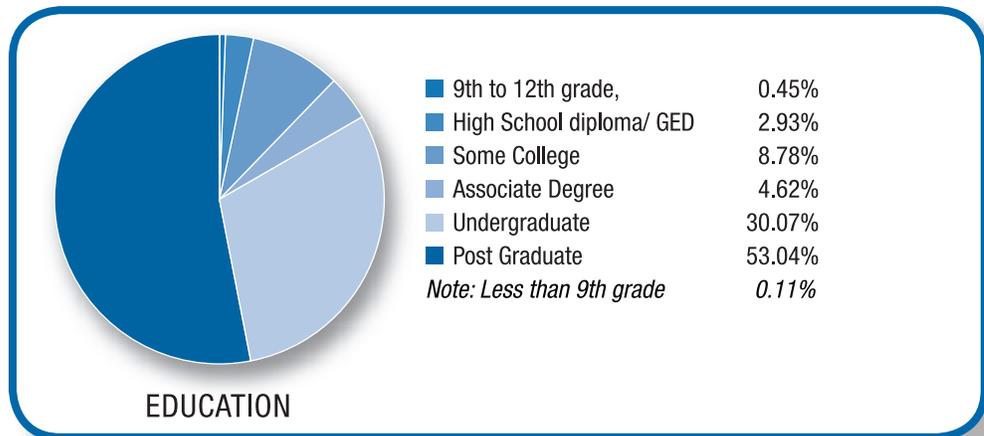
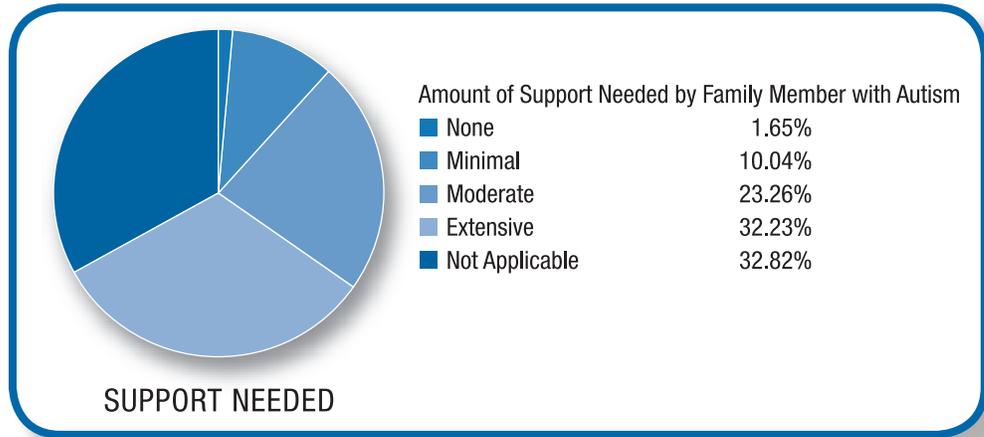
The following demographic information about the participants of the AFAA National Town Hall was collected using electronic keypads.



Addendum 1 (cont.)



Addendum 1 (cont.)



Addendum 2

There was a large degree of consensus on many of the issues addressed during the AFAA National Town Hall, however there were also some differences by location and stakeholder group. The following charts identifies the differences by stakeholder group and by location.

HOUSING PRIORITIES *(page 22)*

1. Present a compelling picture of the demand for housing options.
2. Increase collaboration and coordination between housing agencies & service agencies.
3. Motivate the overall real estate community to create housing options.
4. Support residential service models that are person-centered.
5. Expand funding for residential services.

EMPLOYMENT PRIORITIES *(page 23)*

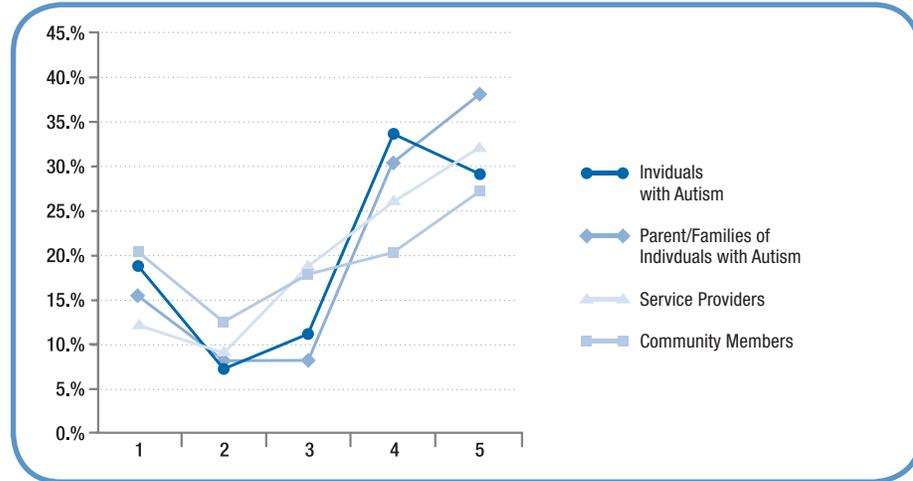
1. Demonstrate the benefits of employing adults with autism.
2. Increase/expand the number of programs for meaningful jobs.
3. Ensure ongoing accessibility to employment supports.
4. Work with employers to develop model programs that adapt the work environment.
5. Create and expand career development and vocational skills training programs while individuals with autism are still in the educational system.
6. Create meaningful alternatives to traditional employment.

COMMUNITY LIFE PRIORITIES *(page 24)*

1. Create a comprehensive public awareness campaign.
2. Educate local recreation organizations and community about the positive benefits of including adults with autism in their programs.
3. Educate first responders about the challenging behavior that might arise in dangerous situations.
4. Assist adults with autism to access transportation.
5. Create programs to support individuals to create meaningful interpersonal relationships, healthy sexuality and personal safety.

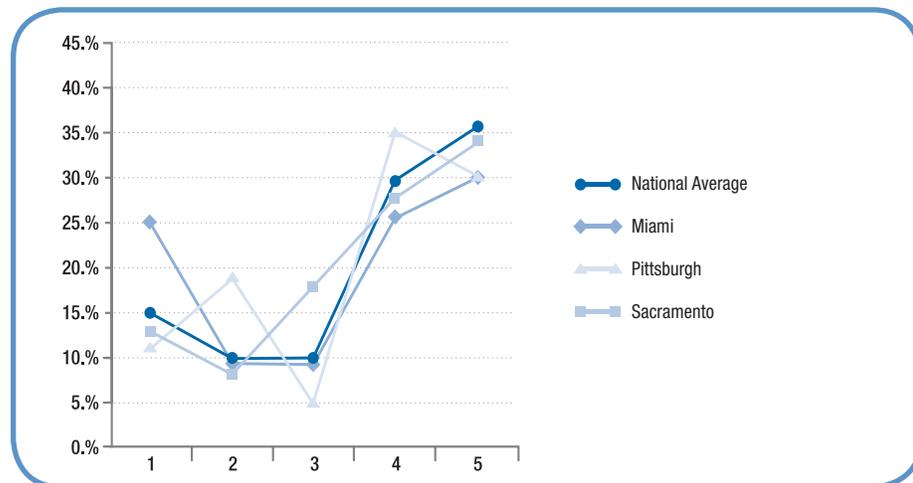
Housing by Stakeholder Group

HOUSING PRIORITIES



Although the housing data by stakeholder group follows the national pattern, some differences are observed. For example, the importance of funding is most significant for parents and families of individuals with autism. This may reflect the heavy financial burden on families of individuals with autism. Also, individuals with autism prioritized “person-centered” options, possibly reflecting the differences in needs of individuals with autism and the importance of choice. And it’s important to note that the “Other Community Members” group ranked the need for a “compelling picture of the demand” as a high priority. This may reflect a lack of awareness in the general population regarding the critical shortage in housing for adults with autism.

Housing by Location

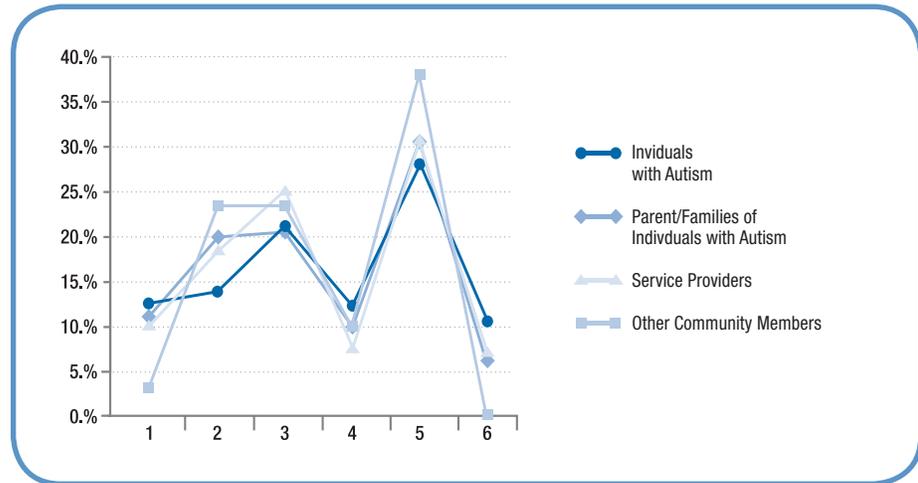


When the data is reviewed by location, what is remarkable is the amount of agreement that exists regarding housing priorities. But there are differences in the degree of support for various strategies. For example, in Pittsburgh the number one housing priority was the need for “person-centered” models while in all other sites the highest priority was the need for expanded funding. Also notable was the relative importance of creating a “compelling picture of the demand” in Miami versus other sites. There were also differences in the relative importance of “motivating the real estate community” in Sacramento versus other sites.

Town Hall sites are encouraged to create local action plans that support the national agenda while addressing the unique challenges and opportunities in their communities.

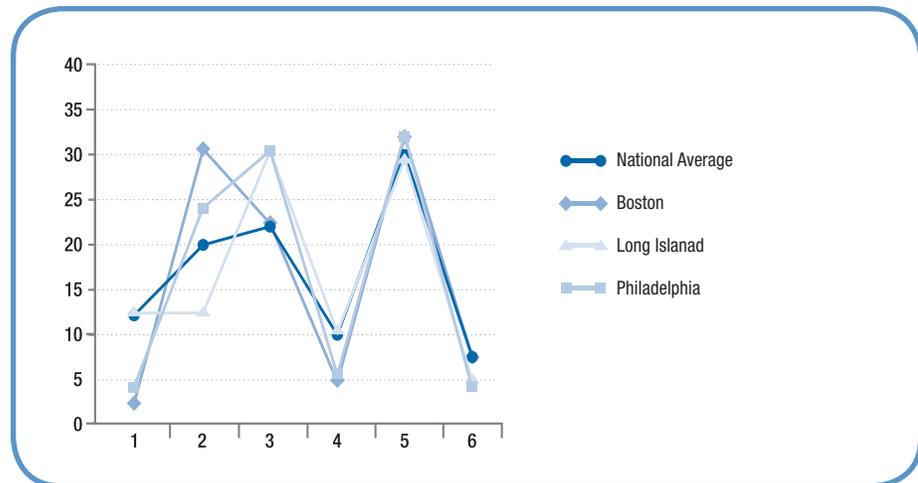
Employment Stakeholder Group

EMPLOYMENT PRIORITIES



There was considerable consensus among stakeholder groups that the number one priority was to create and expand career development and vocational skills training programs while individuals with autism are still in the educational system. This response indicates the strong interest in focusing on pre-vocational and career development skills before educational entitlement expires for individuals with autism at post age 21.

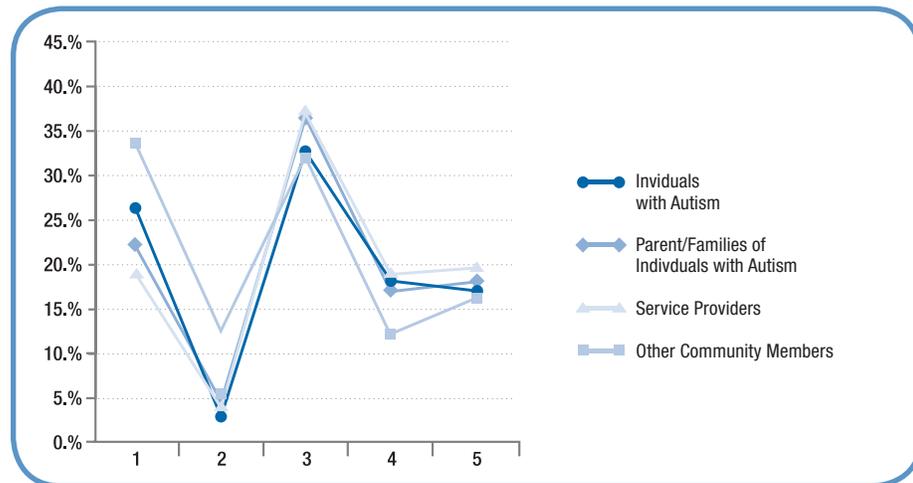
Employment by Location



At the site level different priorities emerged. Boston indicated that their top priority was expanding the number of programs with meaningful jobs and Long Island and Philadelphia expressed the importance of employment supports.

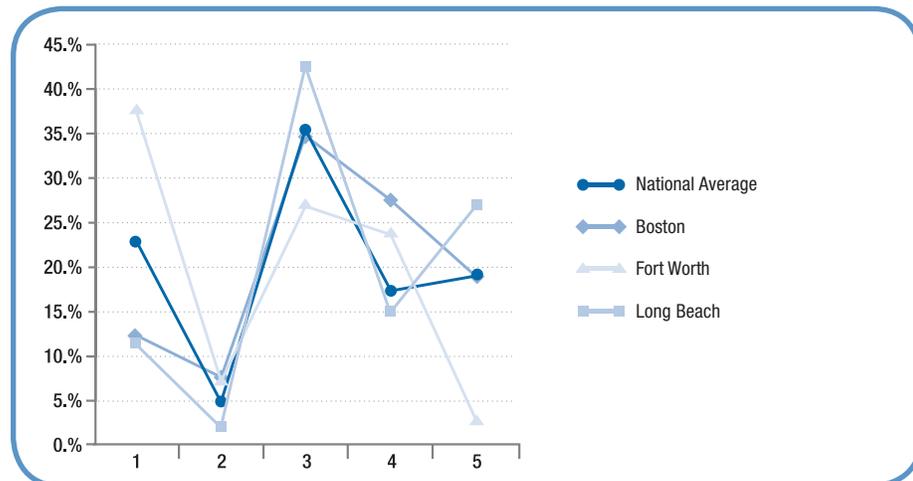
Community Life Stakeholder Group

COMMUNITY LIFE PRIORITIES



In the area of community life the “other community members” group ranked a “public awareness campaign” as the most important priority suggesting a lack of understanding about adults with autism. The other stakeholder groups prioritized the “education of first responders” reflecting their significant concerns over the safety of adults with autism.

Community Life by Location



There were also differences at the site level particularly regarding the importance of creating a “comprehensive public awareness campaign” with Ft. Worth listing an awareness campaign as their top priority. Also note the differences of importance by site for meaningful interpersonal relationship, healthy sexuality and personal safety programs.

AFAA Steering Committee Partners

Alpine Learning Group
www.alpinelearninggroup.org

Autism Speaks
www.autismspeaks.org

The Daniel Jordan Fiddle Foundation
www.djfiddlefoundation.org

Easter Seals
www.easterseals.com

Global Communities of Support
www.gcosinc.org

Hallmark Community Solutions
www.hallmarksolutions.org

The Hope Institute
www.thehopeinstitute.us

New York Center for Autism
www.newyorkcenterforautism.com

Organization for Autism Research
www.researchautism.org

Rethink Autism
www.rethinkautism.com

Southwest Autism Research & Resource Center
www.autismcenter.org

The Autism Program of Illinois
www.theautismprogram.org

Trinity Services
www.trinity-services.org

UM-NSU CARD
www.umcard.org

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www.afa-us.org