



National Town Hall



ADVANCING FUTURES
for ADULTS with AUTISM

Shaping Policies, Services, and Resources

Friday, November 13, 2009 | 10:15am - 4:30pm

University of Illinois at Chicago, 725 W Roosevelt Rd, Chicago, Illinois 60607

National Town Hall



ADVANCING FUTURES
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A Participant's Guide

“The face of autism is rapidly changing with a generation of children who will be entering adulthood over the next 5 - 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. This 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 for
Programs and Services at Autism Speaks*

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Organizational Chairs
Autism Speaks
New York Center for Autism

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Rethink Autism
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Section 1 | Introduction

What is Autism?

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). By definition, the symptoms of autism spectrum disorders (ASD)* are evident before the age of three and typically last throughout a person's lifetime. Autism affects the way an individual perceives the world, making communication and social interaction difficult. It may also result in repetitive behaviors or intensely focused interests. The symptoms of autism and their severity can vary considerably in each individual on the autism spectrum. It is sometimes said "If you've seen one person with autism; you've seen one person with autism."

It is estimated that over the past 10 years the prevalence rate of autism has increased 15-20 fold.

An individual with autism may display some or all of the following characteristics, which may present themselves as challenges or strengths:

- Difficulty understanding language, gestures, and/or social cues
- Literal or excessive speech, often with a concentration on a particular topic
- Difficulty relating to others or participating in a back-and-forth conversation or interaction
- Social awkwardness
- Intense interests
- Repetitive behaviors such as pacing, hand flapping or rocking
- More or less sensitivity to light, sound, smell, taste or touch than others experience
- Anxiety, abnormal fears and/or lack of appropriate fear of real dangers
- Difficulty managing transitions, changes in routine, stress, frustration
- Strong visual skills
- Good rote and long term memory (facts, statistics, etc.)
- Adherence to rules, honesty
- Intense concentration or focus, especially on a preferred activity
- Understanding and retention of concrete concepts, patterns and rules
- Musical, mathematical, technological and/or artistic ability or interest

The strengths and challenges that people with autism possess affect many aspects of their daily lives.

** While we acknowledge that ASD is a term that encompasses a wide spectrum of diagnoses (e.g. autistic disorder, PDD-NOS, Asperger's Syndrome), for the purpose of AFAA and this participant guide, we will use the phrase "adults with autism" to refer to all individuals with an autism spectrum disorder.*

Why is there a growing need for adult services?

Today it is estimated that one in every 100 children in the United States is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric HIV/AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Although the prevalence of autism has increased 15-25 fold during the past 10 years, the reasons for this growth are



largely unknown. Consequently, there are vastly larger numbers of older (adolescent/adult) individuals with autism who may need services and supports than ever before. Autism is a public health crisis that will only grow bigger if we don't deal with it now.

With this increase in prevalence has come an increase in the demand for effective services for adolescents and 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 a society without adequate economic resources to meet these needs. In order for adults with autism to have the services they need, resources must be available and policy changes must be made to ensure that these individuals have access to resources to meet their needs. Federal attention and funding must increase significantly to allow this to happen.

"The group of people with autism spectrum disorder (ASD) diagnosed as part of the first wave of what is typically referred to as the autism epidemic is rapidly approaching adulthood. This group represents only the proverbial tip of the iceberg. Some reports note that 80% of the identified individuals with autism are less than 21 years old. This is a looming crisis of unprecedented magnitude for adults with autism, their families, and the ill-prepared and under-funded adult service system charged with meeting their needs."
– *The Current State of Services for Adults with Autism, Organization for Autism Research*

Where are we now?

Opportunities for housing, employment and community life for adults with autism are extremely limited. While government policy ensures that children with autism have access to the same services and resources as their peers (like public education), many of these rights drop off when individuals with autism become adults. Furthermore, the services that are available to these individuals are very often not coordinated with other kinds of supports. As a result of this lack of coordination and the number of needs that aren't met or covered by the government, adults with autism are unable to fully take advantage of the resources that do exist.

Consider these examples:

- Dan is a 45-year-old man with autism who lives at home with his mother, Ann. Dan has been on a waiting list for an appropriate group home for the past three years. Ann is becoming increasingly concerned about what will happen to Dan when she can no longer care for him.
- Charlie is a 28-year-old man with high functioning autism. Charlie has earned a master's degree in engineering, but he is not able to maintain a job due to trouble interacting with his co-workers. At Charlie's last job he was praised for his work yet he was fired for not getting along with others. Charlie is depressed that he cannot keep the job that he does well and enjoys.
- Stacey is a 21-year-old woman with autism. Stacey's parents have advocated for her to receive appropriate educational services since she was diagnosed at age three. Stacey has a full day at school, and after school activities that Stacey enjoys. All of this will end when Stacey ages out of the educational system. There are few appropriate programs in Stacey's area that provide the supports





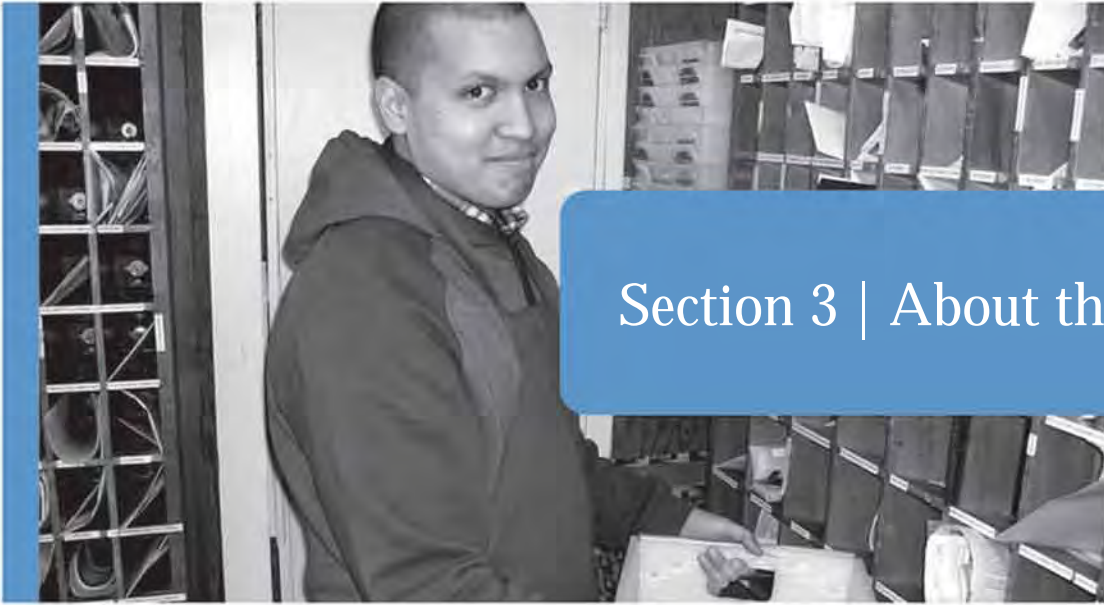
Section 2 | About AFAA

Think Tank in January. From these discussions, we will create a policy agenda for addressing the needs of adults with autism. We will also create avenues by which participants can remain engaged in the issues at local, state, or national levels.

Phase 3: Autism Congress – 2010

We plan to build a consensus statement based upon the priorities of the participants of the National Town Hall, outlining the existing challenges and providing cost effective, evidence-based solutions. This statement will serve as a national agenda from which an action plan will be devised. Included will be an overview of the current program options and opportunities for employment, housing and community life for adults with autism. The conversation will inform and educate participating stakeholders in both public and private sectors. The Autism Congress will set forth recommendations for new public policy and changes to existing policy that will improve the lives of adults with autism.





Section 3 | About the Town Hall

What is the goal of the Town Hall?

The goal of the Town Hall is to hear the voices of a diverse group of individuals in order to develop a shared agenda to broaden the availability and range of services for adults with autism. We will generate agreement on the most important and highest impact strategies to pursue at federal, state and local levels that will improve the lives of adults with autism by increasing access to housing, employment, and community life. We also want to empower Town Hall participants to commit to addressing the needs of adults with autism so that they can initiate proposed solutions in their own communities.

What will we discuss?

We will discuss the various issues that currently face the growing population of adults with autism. We will begin by discussing cross-cutting issues, general ideas and themes that encompass all areas of need. We will then focus specifically on housing, employment and community life. After discussing the challenges adults with autism may face in each of these areas, we will formulate realistic strategies and effective solutions that will help improve the lives of these adults.

Who will attend?

The event will be orchestrated from a central hub in Chicago where a national discussion will take place via webcast from 15 satellite sites, as well as an online virtual site. The 1,000+ people participating in the Town Hall Meeting will include a broad range of community members with different connections to autism. A diverse audience is critical to the Town Hall's mission of formulating effective and realistic strategies that will appeal not just to adults with autism and their families, but also to the general public, policymakers and elected officials, real estate professionals and employers.

What is my role as a participant?

As a participant, you are a vital ingredient in the Town Hall. You will be given the opportunity to talk with a diverse group of other participants at your table about the different issues and strategies, to listen and learn, to voice your views, and ultimately to vote on the strategies that you believe should form the agenda going forward. Therefore, to prepare yourself, please review this participant guide in advance of the Town Hall. This way, you will come to the Town Hall with ideas and a readiness to contribute to this very important conversation. We ask you to actively engage in discussions and voice your suggestions and ideas, so that your perspective is represented in the general consensus drawn from the Town Hall meetings.

How does this Town Hall meeting work?

The Town Hall Meeting is designed to engage every single person – across all of the various sites and locations – in a meaningful conversation leading to a collective voice about our priorities for the future. The most important part of this meeting is the thoughtful, solutions-oriented discussions of the opinions of each



What is the agenda for the day?

- Local Site Welcome
- Welcome from Chicago
- Presentation: Challenges and Opportunities
- Presentation: How the Town Hall will Work
- Discussion: Cross-Cutting Issues
- Discussion: Housing
- Themes/Voting: Cross-Cutting Issues and Housing
- Discussion: Employment
- Discussion: Community Life
- Themes/Voting: Employment and Community Life
- Presentation: Organizing for Action
- Discussion: Commitment to Action
- Close

What are the ground rules?

- Participate actively
- Share air time
- Listen with respect
- Stay focused
- Turn cell phones and pagers to silent



Section 4 | Cross-Cutting Issues

“We cannot allow another generation of our adults with autism to go without the vital services that any humane society knows is necessary for a life of dignity and worth.”
– *National Association of Residential Providers for Adults with Autism (NARPAA)*

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.

Strategy #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.

Funding must be allocated and managed in an efficient and effective manner in order to make a substantial impact on the lives of adults with autism. Services that are currently provided to adults with autism are often based on fixed funding streams. With this system, if a person’s needs change (e.g. they no longer need support at home, but now need transportation to and from their job), the funding cannot be reallocated to support these new needs. In order to achieve this level of flexibility, funding regulations would need to change to allow dollars to shift as the needs of individuals change over time.

Strategy #2:

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

Service providers must be well trained, knowledgeable and motivated to be as effective as possible in assisting adults with autism to achieve the lives they desire. All professionals who work and interact with adults with autism, including community officials and first responders must have adequate training, credentialing, compensation, and career development opportunities in order to provide the best and most effective services.

Federal Department of Health and Human Services reported in 2004 that the combined, annual average staff turnover rate for programs serving adults with developmental disabilities is 50% coupled with a vacancy rate of 10-12%. – OAR Report

One reason often cited for this high turnover rate is that direct support staff members are inadequately trained. The professionals are unable to provide the level and complexity of services that are asked of them – whether in a group home, job setting, or day program. In addition, adult service providers often aren’t compensated well enough to support themselves. These factors can lead to feelings of frustration and discouragement – all of which contribute to the high turnover and vacancy rates associated with adult services. All service providers must be committed and available to help adults in specific areas, including finding and maintaining employment, living successfully in their homes, and integrating themselves into the community through recreation and leisure activities.



Examples of ways to attract qualified and motivated staff include the creation of clear career paths and opportunities for advancement. Mentorship and ongoing staff development are useful motivators in all professions, and may help increase job satisfaction and retention. Another idea is to acknowledge the high turnover in this profession, and turn it into a strength by borrowing from existing models of work that teach problem-solving, patience, understanding and leadership. Lastly, compensation that reflects the level of skill and responsibility expected cannot be ignored.

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 successful lives.

Life skills training in areas such as safety, hygiene, home life and social skills is absolutely essential to living as independent of a life as possible. Many adults with autism must be provided training in these areas in order to live, work, and participate in the community. Therefore, it is essential that these individuals have access to education and training in life skills through classes, coaches, mentors, etc. to assist them in the transition to adulthood, and to assist them throughout their lifetime, as needed.

For example, Southwest Autism Research & Resource Center (SARRC) opened a 10,000 square foot Opus West Vocational and Life Skills Academy (VLSA) earlier this year. The academy is designed to help young adults and adults with autism express interest in potential careers while learning necessary life skills that will enhance their ability to live and work more independently. The academy works to model best-practices in the area of vocational and life skill development with community integrated programs, for individuals age 13 and older, that include typical mentoring and staff support. Programs like these enhance the ability of adults with autism to live successful and independent lives, and as a result, have a very significant impact on the futures of adults with autism.

(www.autismcenter.org/vocational.aspx)

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Section 5 | Housing

For most adults with autism, housing options are scarce. They live with family members or in institutional settings, and as a result, are often unable to gain the independence they seek as adults. In most states, individuals who do find a fit with a particular residential option may have to wait months, and often years, on waiting list before their names are called.

The current waiting list for housing and services in New Jersey is in excess of 8,000 individuals. The DHS-DDD has been able to serve approximately 50-150 individuals a year, mostly on an emergent basis. Adults with autism are told they should expect to wait many decades before their number comes up.

- Addressing the Needs of Adults with Autism Spectrum Disorder: recommendations for a Plan of Action for the State of New Jersey, Oct 2009

(www.state.nj.us/humanservices/ddd/boards/AATFrpt.pdf)

Making a meaningful difference in the availability of housing options suitable for adults with autism is no small task. The development of housing, setting aside the concept of supportive housing, is a capital intensive and time-consuming process, and depends on a wide array of financing options, experienced professionals and a general acceptance that a sufficient supply of housing is a necessary part of our society.

The development of supportive housing, where a person with autism or other

disability can live and have access to the supports they need, depends further on the availability of qualified service providers and funding.

The choice of the word “underpinnings” in the Five Year Vision for Housing below is deliberate. In construction, underpinning is the process of strengthening the foundation of a structure, often because the original foundation is simply not strong enough. The basic foundation on which the creation of supportive housing is built must be strengthened over the next five years if we are to pave the way for a dramatic increase in housing options.

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.

The Home Itself

Strategy #1:

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.

Aside from those directly affected by autism, the general public is largely unaware of the housing crisis, and as a result, little is being done to address it. Once the picture is painted clearly, the need for scalable solutions also becomes clear. To move towards effective and scalable solutions, financial institutions, government agencies and others integral to the creation of housing must be shown the extent of the crisis and inspired to act.



For example, it would be extremely helpful to present the demand for housing in a format that is familiar to those involved in the creation of housing. A widely-published, national market study that clearly shows the demographic trends over the next five years, the number and type of housing units needed (e.g. apartments, group homes, SROs, in-law units) and preferred locations (e.g. urban, urban-edge, rural, transit-oriented) will give people and institutions the information they need to get creative about solutions.

Another key driver of engagement is the ability to articulate what success looks like. By the end of 2009, The Urban Land Institute Arizona, Southwest Autism Research & Resource Center, and Arizona State University will publish a landmark study on residential options available for people with special needs. Providing in-depth information on over 20 housing models available for people with special needs, this study will provide advocates with a powerful inventory of best practices for use for their own inspiration and in key discussions with those who direct capital and influence housing policy.

Strategy #2:

Increase collaboration and coordination between housing agencies and service agencies at the local, state and federal levels.

By increasing collaboration between housing agencies and service agencies, adults living with autism can expect to have access to more comprehensive and supportive housing options.

This strategy depends in large part on the efforts of “intermediaries” – organizations who act as a bridge between housing agencies and service agencies. For example, a nonprofit intermediary may meet with city housing departments to educate them on the need for specific housing options in their community. In parallel, they may work with local service providers to develop programs that offer person-centered support to individuals living in city-funded affordable housing developments.

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, as well as increase the opportunities for independence and integration.

The development of incentives is a useful tool for motivating specific kinds of housing development. For example, in urban areas, a city may encourage transit-oriented development by offering a reduction in the number of parking spaces required if a proposed site is located near a major transit hub. This enables a developer to build the same number of units on a smaller, and therefore less costly, piece of property. Another incentive, which can work in urban and suburban environments, is the provision of a property tax abatement for housing which meets certain city needs or objectives. These kinds of incentives can be readily adapted to motivate the development of housing which meets the needs of adults with autism.

The Services in the Home

Strategy #4:

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

There is an important shift in the kinds of services that adults with autism and other developmental disabilities are seeking. Residential service models which truly take into account the individual needs of each person make the best investment of scarce public and private resources. The successful movement towards self-determination – where the person with autism has the ability to control some portion of their public dollars, and to make choices about how best to organize their supports – will have a powerful impact on the future for adults with autism.

Supporting models where the owner of the home and the provider of services are separate and distinct is another important way to increase the number of person-centered residential services available. When the owner and service provider are the same entity, the resident is forced to move if his service needs change or if his service provider is not doing a good job. In the case of adults with autism, where continuity and routine are so important, this housing instability is especially problematic. This model of separation of ownership and services is best demonstrated by the Bay Area Housing Project, an innovative public/private partnership which had the collective goal to create permanent, stable, community-integrated housing for individuals leaving an institution in the heart of Silicon Valley. Today, 60 state-of-the-art houses in 19 neighborhoods are serving as stable living environments for people with developmental disabilities.

Strategy #5:

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

It will take the expansion of both government and private sector resources to truly respond to the demand for person-centered residential services. Given the budget constraints of government at every level, it will be especially important to direct efforts towards the increase of private funding.

There has been a substantial shift over the last decade in the approach of philanthropy, which supports investment in the scaling of successful, evidence-based solutions to social problems. For example, KaBOOM! is a national non-profit organization whose vision is to have a playground within walking distance of every child in America. Once the organization was able to prove the effectiveness of their unique community-built

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playground model, they were able to raise \$14 million from the Omidyar Network to substantially scale their work and widen their impact. There is a tremendous opportunity for charitable foundations to identify the pockets of excellence in residential services and to fund their replication into other communities.



Section 6 | Employment

“The greatest impediments to the development of integrated lives of quality and dignity for adults with autism are system inadequacies coupled with a public perception of adults on the spectrum being unemployable”
– OAR Report

Though awareness about autism has grown in recent years, there are still many adults with autism who are unemployed but have the potential to work. Adults with autism have a wide range of skills and competencies to contribute as employees. There are many examples of adults with autism performing efficiently and successfully in the workplace.

For example, Specialisterne is a software testing, quality control and data conversion company in Denmark that employs approximately 40 adults with autism. The company, started by the father of a son with autism, has managed to turn the characteristics of individuals with autism into a competitive business advantage, as the employers have found that some individuals with autism have strengths and skills that make them

A 2008 study of 200 families of adults with autism found that only 19% of individuals were employed at the time, and 78% of the families were unfamiliar with any agencies or professionals that might assist them in finding job opportunities. (University of Miami/Nova Southeastern University CARD Study 2008)

incredibly gifted software test executors. Specialisterne’s employees are such fast and efficient software testers that major corporate customers like Microsoft, Oracle and leading Danish IT companies choose their services over those of other similar companies. (www.specialisterne.dk)

Unemployment and underemployment are key issues facing adults with autism. Many adults with autism who are employed are assigned menial tasks that do not meet their potential. The vast majority of employers are unaware of the breadth and variety of skills and talents that adults with autism can bring to the workplace.

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:

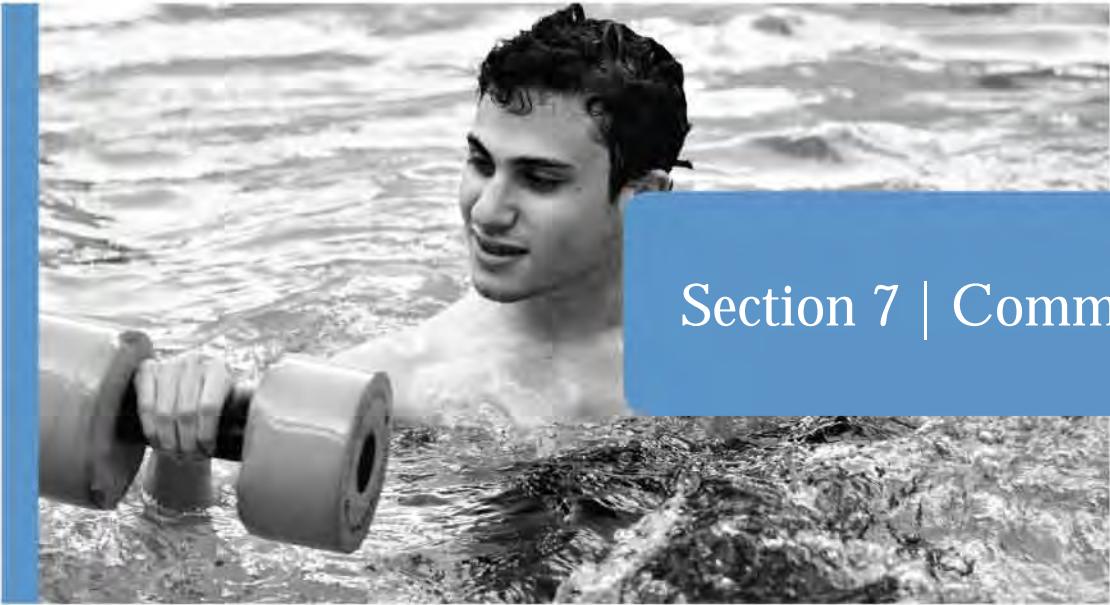
Demonstrate to employers the benefits of employing adults with autism.

Case studies, video, print and in-person outreach could be used to illustrate examples of adults with autism, such as the employees at Specialisterne, succeeding in a particular job because of their strengths and abilities. The content of the outreach should highlight the mutual benefits of employing adults with autism so that employers fully understand the potential for gains if they choose to hire an adult with autism.

Adults with autism can be valuable assets to a company or organization with a modest amount of extra assistance from a co-worker, mentor, or paid job coach. It is critical that we make employees aware of the range of adaptations that can be easily implemented to employ an adult with autism, and the great benefits that result for the individual, their coworkers and the company.



For example, Walgreens' Distribution Centers employ a large number of individuals with disabilities, trained to work side-by-side with other team members – with the same productivity goals, and pay. Walgreens has adapted its distribution centers to capitalize on the strengths and abilities individuals with autism and other disabilities bring to the workplace. For example, they have converted their computer displays from lines of type to touch screens with a few icons, added help buttons to summon assistance, and instead of posting printed cards to remind workers about having their bags inspected, they show a video of someone opening a bag. These adaptations are costly, but the costs are made up by the increase in efficiency at these distribution centers. In fact, one distribution center currently employs 264 people, more than 40% of whom have various disabilities. This particular center is 20% more efficient than the company's older facilities. Walgreens' employment of adults with autism and other disabilities is a very clear example of the mutual benefits of employing adults with autism. With only a few adaptations to the workplace environment, Walgreens has improved the productivity and efficiency of its distribution centers, while significantly enhancing the lives and independence of adults with disabilities. (www.walgreensoutreach.com)



Section 7 | Community Life

Community integration is an essential component of a full and happy life. Adults with autism can be vital members of their communities, and yet a lack of awareness and understanding among the community members can often present a major barrier to their participation in community life. With increased awareness, the community will welcome adults with autism into the community, and include them in local organizations and recreational and leisure activities. The success of integrating people with autism into the community also relies heavily on two issues: transportation and safety. Adults with autism must have adequate safety training and the necessary means of transportation to be able to interact with and participate fully in the local community.

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.

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.

Unfortunately, there is little awareness or understanding of the rich contributions that adults with autism can bring to the workplace and to the community. In order for adults with autism to succeed and have fulfilling lives, it is imperative that the community is aware of the potential of adults with autism.

A campaign of information might include presentations at community meetings, posters, public service announcements, etc. Given the wide variety of new, online social media tools, a public awareness campaign can also take advantage of Twitter, Facebook, blogging, e-mails and YouTube to help influence public perception. Prominent featuring of adults with autism on TV and film as contributing and active members of the community is another strategy that can be used to raise public awareness, and to show the many faces of adults with autism.

The focus of this campaign would be to increase community awareness about autism while reducing fear, debunking myths and encouraging dialogue. An effective campaign would make the general public aware of both the strengths and challenges faced by adults with autism. With increased public awareness and education, the community is more likely to understand, welcome, and enable adults with autism to assume meaningful roles in their communities.

Strategy #2:

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

Ensure that organizations provide opportunities for adults with autism to participate in programs in their neighborhoods and communities. Individuals in the community may act as mentors to advance the assimilation process by helping adults with autism gain skills and self-confidence. For example, local tennis teams may have individuals in the community work with and train adults with autism, perhaps as doubles partners, so that these adults are better able to become a part of the program.



Recreation and community programs don't just include sports teams and other physical activities. Many community activities exist in cities and towns, such as chess teams, movie nights, and book clubs, church groups, etc. For example, the Rock Hill Parks and Recreation Department in South Carolina has a theater troupe called the Merry Pranksters. Over the course of many rehearsals, these actors and actresses, who include people with disabilities, learn more than just their lines. They learn that they each have an individual talent, and when combined with the talents of others, the result is amazing and inspiring. This is a perfect example of a city run program that through group recreational activities, works to include adults with developmental disabilities like autism into the community. (www.cityofrockhill.com)

Strategy #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.

A model curriculum for first responders, including law enforcement officials, and individuals within the judicial system would help them accommodate the unique needs and challenges of adults with autism in safety situations. These officials would then understand autism and its signs so that they would be able to identify when an individual with autism is in a dangerous situation, and respond accordingly.

For example, Autism Risk & Safety Management, an organization founded by Dennis Debbaudt, the leading global voice on autism safety, provides training and resources for law enforcement, emergency first responders, parents, educators, care providers and the autism community. Autism recognition, response and risk management training sessions will help law enforcement, fire rescue and emergency medical response, and criminal/juvenile justice professionals recognize the behavioral symptoms and characteristics of a child or adult who has autism, learn basic response techniques, learn about the high risks associated with autism, and

A survey of individuals with autism and their families indicated that 35% of individuals with autism had been the victim of a crime and that 23% have had interactions with first responders due to wandering. (Autism Information for Law Enforcement and Other First Responders, Autism Society of America Report)

will offer suggestions, options and specialized tactics about how to address those risks, increase officer and citizen safety, and avoid litigation. The training can be tailored to meet the needs of local communities and agencies. (www.autismriskmanagement.com)

Strategy #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.



Nationally, almost 15 million people in this country have difficulties getting the transportation they need. Of these, about six million (40 percent) are people with disabilities. About 560,000 disabled people indicate they never leave home because of transportation difficulties.

– Research and Innovative Technology Administration: Bureau of Transportation Statistics

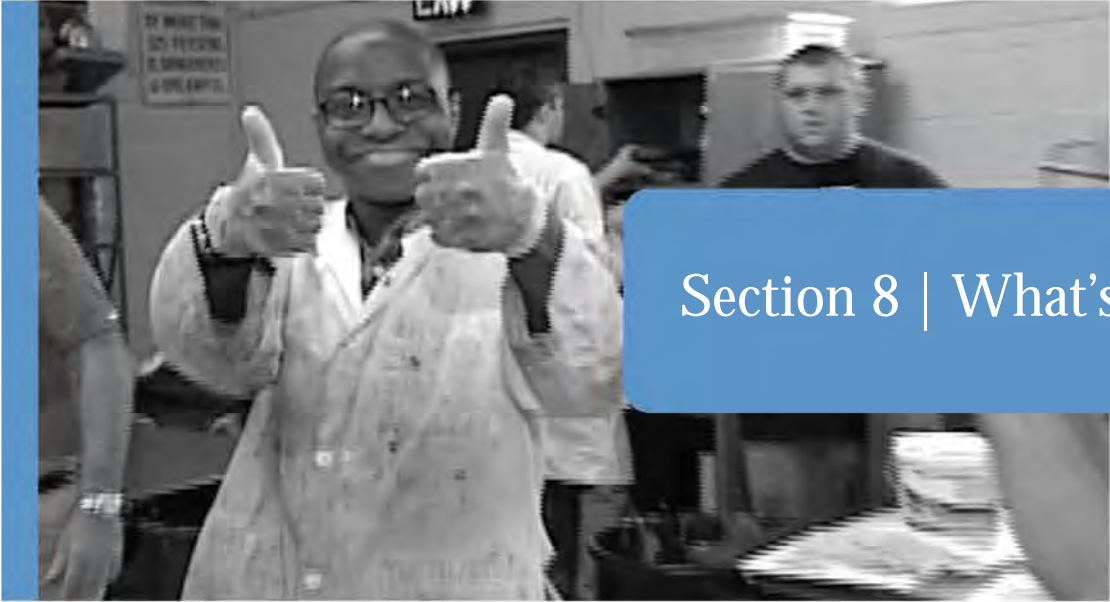
A lack of transportation is a major barrier for adults with autism. Access to places of employment, recreation and community activities, places of worship, family and friends, and health care providers is essential if adults are going to be able to take advantage of the opportunities that will help them to lead independent, successful lives.

Many transition programs do not teach individuals how to utilize various modes of transportation. Adequate transportation training is critical for adults to successfully interact with the community, or to commute to and from work.

In addition, a program targeted to transportation service providers will enable them to appropriately interact with and serve adults with autism. The program will teach transportation providers about some of the possible challenges of individuals with autism, and how to successfully support these individuals to ensure safe and effective transportation.

Notes





Section 8 | What's Next?

The mission of AFAA is not complete on November 13th; in fact, this is the moment we want to shift into a higher gear. After the completion of the Town Hall, more than 1,000 of us - people who are committed to improving the lives of adults with autism - will have come together and forged the pathway forward toward solving this growing problem. But it is going to take all of us, and many more, to follow this path if we are going to succeed in reaching our ultimate goal - to Advance the Futures for Adults with Autism.

AFAA has committed itself to a third phase - the Autism Congress - by which we will advance the priorities that come out of the Town Hall with national level policymakers. In addition, there are several actions that AFAA is committed to take to follow through on the results of this Town Hall.

Document the Town Hall

By the end of 2009, we will publish a report that captures the key recommendations from this Town Hall. This report can be used to guide actions by local organizations and activists, and will be the basis for the Autism Congress. We also plan on preparing a 20 minute video about the Town Hall that can be shared with all those who want to know what happened here and how they can help out.

Develop a Resource Guide

Drawing on input from the Town Hall participants and others, AFAA will add lists of key resources on its website that can be used by organizations and individuals, including best practices, model programs, and services that are available to support the recommendations.

Create Mechanisms for Ongoing Engagement of Participants

AFAA will set up an online mechanism by which participants can engage with others around the country about the key areas we have discussed in the Town Hall. These discussions will hopefully lead to increased support, more information, and a growing population looking to take collective action. And while our intention is for these groups to be self-organizing, AFAA will take leadership in two to three of these groups based on the priorities that are identified in the Town Hall.

Your Help is Needed: “Many hands make light work”

Up to now, the responsibility for this issue has been carried on the shoulders of a few organizations and individuals. This is the moment where we have many more “shoulders” who will hopefully be inspired to join the effort. Therefore, you are now asked to take action to put your ongoing commitment into motion. Some of the things you are encouraged to do are:



