

# ADVANCING FUTURES for ADULTS with AUTISM

2009 Think Tank



## WHY Advancing Futures for Adults with Autism?

The United States is on the verge of a crisis as more than 800,000 children identified with Autism Spectrum Disorders (ASD) enter adulthood. In the past decade, estimates of the prevalence of autism spectrum disorders have increased from 2 to 5 cases per 10,000 individuals to 1 in 150. To ensure these children have the opportunity to create more meaningful lives as adults that include homes, jobs, recreation, friends and supportive communities, ASD advocates have formed a national consortium called *Advancing Futures for Adults with Autism (AFAA)* which will facilitate the development of a national agenda through three phases: an expert Think Tank, a National Town Hall and an Autism Congress. The outcome of three-phase agenda will be defined, actionable and strategic solutions to address the needs of the vastly increasing numbers of adolescents and adults who need service modifications, accommodations and supports.

Autism Speaks and New York Center for Autism are leading this effort. AFAA's honorary chair is Global Communities of Support and AFAA regional partners include Alpine Learning Group, The Autism Program of Illinois, The Daniel Jordan Fiddle Foundation, Easter Seals, Hallmark Community Solutions, Organization for Autism Research, Southwest Autism Research & Resource Center, and the UM-NSU Center for Autism and Related Disabilities.

The Think Tank was a path-breaking activity by Autism Speaks and the New York Center for Autism in New York City in January of 2009. The two-day event identified:

- State of the art residential, vocational, recreational, community integration and transition models;
- Innovative approaches to improve models and create new solutions;
- National and state-specific challenges & priorities for adults on the autism spectrum; and
- Resources beyond the government to be partners in this venture.

More than 60 experts on housing, employment, safety, transportation, recreation, technology, human services and autism gathered at the Think Tank to develop strategies for creating the best possible future for adults with ASD and their families. Readers and participants alike are invited to take the ideas contained in this report and run with them, broadly sharing their progress and lessons learned along the way. No single agency can take on the challenges that lie ahead. Instead, it will be the sum of the collective successes of many agencies, policy makers, government officials and autism advocates that makes a measurable difference for adults with autism.

## WHAT IS AUTISM?

Autism is a complex neurobiological disorder, also known as autism spectrum disorders (ASD) is usually diagnosed by age 2 and typically lasts throughout a person's lifetime. ASD make communication and social interaction difficult and involved behaviors that interfere with normal function. Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Symptoms can range from very mild to quite severe. To complicate issues, people with ASD often have other health issues as well.

## WHAT THE FUTURE HOLDS

Growing from adolescence to adulthood can be a challenging developmental period for all young people, but is particularly difficult period for teens with ASD. Just when these youth need services the most, they lose their entitlements and may also age out of their parents' health insurance benefits.

About 1 million people in the U.S. are diagnosed with ASD, and 80 percent of those identified are younger than 22 years old, according to a report prepared by Organization for Autism Research ("OAR") in Arlington, Virginia. "Consequently, there are vastly larger numbers of adolescents and adults who need interventions and services than ever before," says Peter Gerhardt, president of OAR's Scientific Council. "Unfortunately, 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 and society-at-large economically diminished."

By taking action now, AFAA hopes to ensure that adults with ASD break free of the all-too-common status of "dependency" and become engaged, involved, tax-paying members of their communities.

"We need to have a national voice," said Peter Bell, Executive Vice President of Autism Speaks and Chairperson of AFAA, who has a 16-year-old child with autism. The parents at the forefront of the push for research a decade ago are realizing that as their children mature, there is less available for them, so they have become advocates again.

Like the children of other founders of the autism advocacy movement of the 1990s, Mr. Bell's son is entering the early transition phase to adulthood. "We're thinking of jobs and what comes next," he said. "We're wondering what it's going to be like when the bus stops coming to pick him up for school."

Given the scale of the problem, Think Tank participants agreed that government needs to act quickly. Few services are currently available for adults with autism. Most of the existing programs are limited in scope and will not come close to meeting the growing needs. It is critical to link lack of services, opportunities and supports for people with autism to the lack of these same services to all persons with disabilities.

"Our hopes and dreams for our children with autism are no different than those for our children without autism," said Ilene Lainer, Executive Director of the New York Center for Autism, who has two children, one of whom has autism. "We want them to have homes, jobs, and a community that accepts them and that they feel a part of."

Participants in the Think Tank created visions for the next five years, identified gaps in services and laid out strategies for filling them. They also brainstormed broad solutions, such as creating an information clearinghouse to connect the autism community, a national public awareness campaign to debunk myths about autism, and political strategies for getting the issue on a national policy agenda. "This is a long-term issue that we have to support through their lifetime," Ms. Lainer said. "Autism in children has made it to the national agenda, but there's less coverage for adults. We must seize the opportunity now to make a difference."

In Phase Two, AFAA will build on the outcomes of the Think Tank to create a national agenda for adults through a virtual National Town Hall facilitated by AmericaSpeaks in November 2009. This highly interactive event will link more than 1,000 participants in 15 regions across the United States to define key stakeholder groups and identify a national list of priorities, challenges, innovations, and best practices designed to address the needs of all relevant constituent groups.

In Phase Three, AFAA will build on the outcomes of the Think Tank and the National Town Hall to create an implementation plan. An Autism Congress is set to be held in Washington D.C. in 2010, with 60 autism advocates, policy experts, lobbyists, elected public officials, university professors, researchers, self-advocates and families. This implementation plan, aimed at developing cost-effective, evidence-based solutions to the challenges ahead, will help set the national agenda.

## THE THINK TANK APPROACH

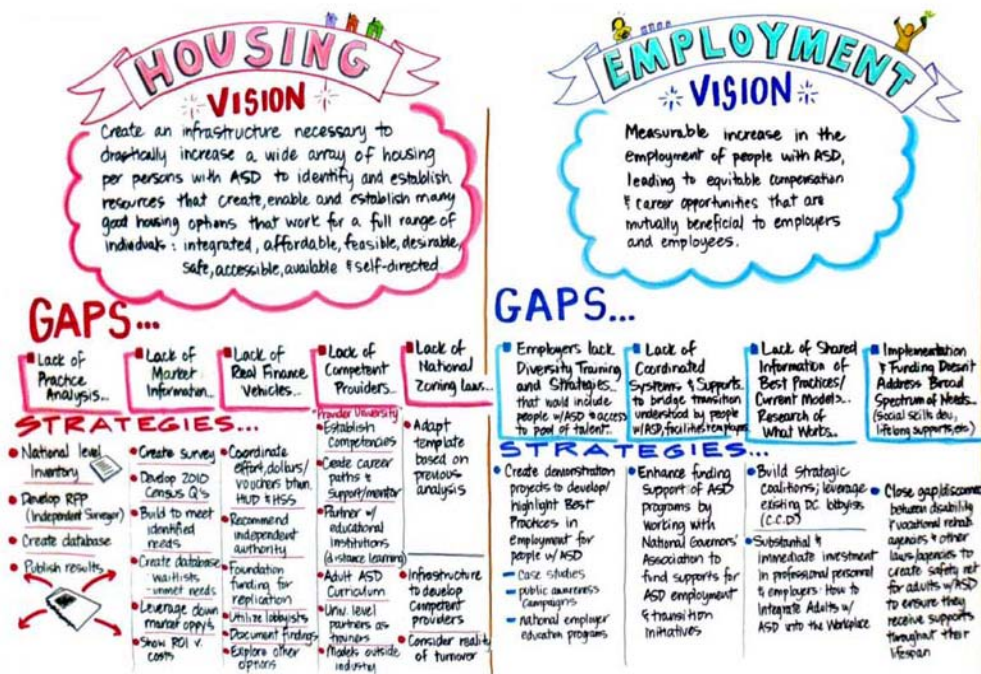
Before a set of national priorities can be defined, the current context in which people with autism and their families are operating within is an important picture to paint. In advance of the Think Tank, the New York Center for Autism commissioned OAR to “provide an overview of the types of service systems and models that currently exist which are designed to provide adults with ASD the continued and necessary support to be engaged, active citizens and lead lives of competence, quality and dignity.”

This report, titled “The Current State of Services for Adults with Autism,” (available at [www.afa-us.org](http://www.afa-us.org)) was presented by Gerhardt to kick-off the AFAA Think Tank weekend. Setting the stage with this context was especially important because a key tenet of the Think Tank was to make sure that the room was not filled just with ASD experts. The problems facing the autism community reach far beyond the autism community, so it was deemed critical to involve outside experts in the discussion. As a result, not only did AFAA bring autism advocates and experts together, it put them in groups with people who do not work in the field of ASD, but who have expertise in fields which are highly relevant to autism, such as government, education, housing, employment, safety, transportation, technology and recreation. By utilizing this structure, autism advocates could adapt ideas and innovations that have worked for other communities in other fields, while experts from outside the field could bring what they have learned about ASD back to their communities.

The Think Tank participants broke into three major groups: Housing, Employment and Community Integration.

The Housing Group, in anticipation of a “tsunami effect” in the need for housing as children with autism grown into adults, was comprised of developers, architects, government representatives, university professors, service providers, and families affected by autism, who determined that the next three to five years must be spent laying the foundation to meet the housing need. The Employment Group included government officials, university professors, and service providers, as well as employers, employment attorneys, and entrepreneurs, and focused on how to improve employment and career choices for adults with ASD. The Community Integration Group studied a variety of issues from safety and transportation to community involvement and recreation. Participants included people representing communities of faith, transportation and safety experts, service providers, recreational innovation specialists, government representatives, families and some adults with ASD themselves.

Attention to all of these issues, along with helping adults with autism learn to advocate for themselves, is critical to the future of what will be the largest generation of adults with autism. “We need to start talking about what it means to have a life of dignity as an adult with autism,” said Gerhardt, who has worked with adults with autism for 30 years.



## HOUSING

A “tsunami effect” will drive unprecedented demand for housing for people with ASD. Given a five-year time horizon for visioning, and the scale of the problem, the Housing Group emphasized the need to create the infrastructure necessary to dramatically increase housing choices for people with ASD. For the purposes of the housing discussion, infrastructure includes an accessible supply of funding, appropriate financing products & services, well-defined market information, an available database of successful housing models, and a sufficient supply of service providers to pair with the physical development of housing. With this infrastructure in place, the ASD and housing community can create a wide array of housing options that work for the full spectrum of individuals with ASD. Participants agreed these housing options should be integrated, affordable, accessible, available, self-directed, feasible, desirable and safe.

According to participants with extensive experience in residential services for individuals with ASD, people with ASD are more likely to find acceptance and opportunity in older, established neighborhoods with a mix of age groups, lifestyles and economic circumstances. These neighborhoods provide opportunities to encounter and interact with others, such as parks, corner stores, sidewalks and pedestrian-friendly streets, which can lead to breaking down the common stereotypes of people with ASD, opening the possibility for finding friendship and a place in the community. By building housing designed with systems and technology which allow people with ASD to live their lives more fully and freely, the palette of housing choices can become more complete. Over a lifetime, circumstances, tastes, preferences and needs change and housing must be available so people may move on when they desire or need to – no different than the general population.

### **SUPPLY AND DEMAND**

Substantial information gaps exist that must be filled in pursuit of a robust infrastructure leading to appropriate housing choices. First, there is not enough information regarding the demand, making it difficult for developers to recognize the magnitude of the opportunity. Developers, lenders and government officials should be asked what information they would need to engage in creating housing for this specific market. Developers generally think of an opportunity in terms of market demand, scale and replication. Given the scale needed to address the sheer numbers of children transitioning into adulthood, the current small-scale, boutique residential care model with limited funding was deemed inadequate on its own to address the future growth in this area.

One developer participant shared, “We need help understanding the right questions to ask to learn what these qualities [for replication] are,” such as which models which are successful yet have less dependence on hard-to-find highly educated staff compared with effective, hands-on training of young college graduates.

#### **Think Tank Brainstorm:**

Develop a request for proposal (RFP) for an independent, non-partisan group to conduct a nationwide inventory to identify which existing housing models are working specifically for those with autism, as well as other special populations. This inventory should capture data on:

Quality

Cost

Impact

Business models (for profit, nonprofit, hybrid, franchise)

Funding sources (e.g. government, private-pay, insurance, combination)

Levels of staff training in various models

Create a database of waiting lists for housing across the nation and another for available and appropriate real estate options.

Develop key questions for the 2010 census; and

Create a database of waiting lists for housing across the nation and another for available and appropriate real estate options.

### **FUNDING & FINANCING**

There is a lack of funding and financing vehicles for the development, construction and ongoing operation of housing.

#### **Think Tank Brainstorm:**

Create a coordinated effort between Housing and Urban Development (HUD) and Health and Human Services (HHS), by executive order if necessary. Participants recommended pushing for this to get underway before May 2009 in order to affect the 2011 budget;

The commission of an independent authority to look into efficiencies such as using lobbyists already working on disability issues;

Educate community development financial institutions (CDFIs) who focus broadly on affordable housing on the specific housing needs facing the ASD community, and support disability-focused CDFIs, such as the newly created Disability Opportunity Fund;

Raise capital for land-banking to take advantage of unprecedented low-cost housing becoming available due to the sub-prime mortgage meltdown;

Leverage real estate opportunities in a depressed market; and

Educate lenders and other financial institutions (private and public) about the growing demand for housing to influence the direction of capital.

### ***A NEED FOR RESIDENTIAL SERVICE PROVIDERS***

A major bottleneck in creating housing for adults with autism is a shortage of qualified service providers and staff to provide support in the home. The Housing Group observed that the home and the services go hand in hand; one without the other does not solve the housing problem. The Housing Group focused on one of the major bottlenecks in residential services - staff turnover – and brainstormed on ways to reduce this key human resource problem.

Potential solutions to this problem are outlined in the “Cross-Cutting Issues” section of the report, as this issue impacts not only Housing, but Employment, Community Integration, Transportation and Safety.

### ***ZONING***

Finally, the Housing Group identified that there is little direction provided through national, state or local land use policies or zoning laws that take into account the specific needs of individuals with ASD and other disabilities. Cities and jurisdictions are likely to be more responsive if a national template based on effective and proven case studies can be disseminated to decision-makers in city or county planning, ensuring that the application of the template is coordinated with applicable laws.

## **EMPLOYMENT**

The Employment Group envisioned a measurable increase in the hiring of people with ASD resulting in equitable compensation and career opportunities that are mutually beneficial for employers and workers.

As is generally the case for people with disabilities, currently, there is no coordinated continuum of support to bridge the transition from the teenage years to adulthood for those with ASD and their families. Adults with autism need social skills training and life-long support. The ability to maintain public assistance benefits – including transportation, even if they have jobs – is also critical.

### ***RAISING THE BAR***

Passionate, motivated and technically proficient people are needed to work with, teach and support people with ASD preparing for employment. Unless people with ASD receive this kind of holistic help, they will continue to have low expectations for their career opportunities, as will their potential employers.

As one expert put it, “There needs to be a presumption of employability. These are young adults who need jobs like any other kid coming out of school. People with autism need to feel valued and we need to raise the bar so other people value them.” Furthermore, there currently exist significant disconnects in the transition from school to adult life. A coordinated continuum of support to transcend these disconnects that can be easily understood and navigated by individuals with ASD, their families, professionals, and employers is needed. Any employment model must continue to address the built-in disincentives to wage earning.

### ***Think Tank Brainstorm:***

Provide effective, hands-on training to teachers, aides, administrators, human services professionals and families for transition planning and job development.

Emphasize the importance of internships and volunteer opportunities, along with job shadowing, job sampling and interview training.

Create demonstration projects to develop and highlight best practices in employment for adults with ASD, including case studies, a public awareness campaign and national employer education programs that will engage human resource professionals, employer groups and other stakeholders.

Enhance funding support of ASD programs by working with groups such as the National Governor's Association.

### ***MAKING AUTISM A DIVERSITY ISSUE***

Because employers understand the importance of diversity issues, ASD must fall under that umbrella. Today, employers lack the diversity training that would facilitate the inclusion of people with autism, a potential talent pool for them. The autism community should recognize employers who hire people with ASD and encourage consumers to patronize these businesses. Those companies (e.g. Walgreen's) could receive a corporate "seal of approval," just as environmentally responsible businesses are acknowledged for "green" practices.

### ***INCREASE EMPLOYER AWARENESS***

To help employers understand what skills adults with ASD bring to the table and what working with them is like, the autism community should develop a public awareness campaign and employer education programs that incorporate input from all involved. To make this desirable, there must be an emphasis on the idea that employment will result in decreased reliance on public financing and support for people with ASD.

#### ***Think Tank Brainstorm:***

Identify growth industries to target;

Increase the number of employees with ASD in federal and state government;

Develop presentations on hiring adults with ASD to offer to local and state chambers of commerce and other business organizations such as the National Association of Manufacturers; and

Involve and educate labor unions that employing people with ASD does not threaten their general membership.

# COMMUNITY VISION

Adults with autism are valued, participating members of society, who are supported throughout the fabric of community life & fully engaged in every thread it represents; welcome to pursue their interests, talents & lifelong learning; accepted in their pursuits of friendships, relationships and marriage (if they choose); protected by law & ensured their safety; afforded opportunity for long-term wellness through good, comprehensive healthcare; provided wheels to go anywhere, any time.

## GAPS... LIFESTYLE

- Communities Don't Have Ways to Include People w/ ASD into Existing Organizations & Activities
- Lack of Evidence-Based Practices
- Life long Learning is Not an Entitlement

## STRATEGIES...

- Build Community Plan for Adults w/ ASD & other disabilities
- Reallocation of federal & community money to more Adults w/ ASD into existing programs
- Support the Adult w/ ASD in major programs
- Train on personal
- Pilots to replicate promising practices
- Evaluate promising practices to achieve evidence based practices
- Mechanism to disseminate promising & evidence based practices
- Proclamation: Adults w/ ASD have a right to lifelong learning
- Partner w/ existing organizations to include Adults w/ ASD in LLL programs

## GAPS... TRANSPORTATION

- Complexity of Geography (our-Quietic)
- Lack of Community Awareness
- Safety & Sensitivity
- ASD-Specific Skills Curriculum
- Lack of ASD Connection into Human Services Transportation Movement

## STRATEGIES...

- Coalition Building
- Innovation pilots
- Volunteerism across Community
- Finding the Invisible Ramp\*
- Transportation system takes responsibility
- Macro-micro
- Training on transportation system
- Creating safety zones, safety support
- Training people with ASD
- Assessment tools
- Training programs (research & design)
- Measure outcomes
- Expand ASD political agenda to include transportation
- "Clump On The Train"

## GAPS... SAFETY

- Lack of Education
- Lack of Baseline Data, Performance Indicators
- Insufficient Technology
- Coping With Negative Stereotypes & Portrayals
- Lack of Funding

## STRATEGIES...

- Organizational Stakeholders to promote advocacy for federal & state policies & funding that provides training & technical assistance for educators, law enforcement & public safety service providers
- Create clearings to promote safety-related, evidence based practices to:
  - providers
  - advocates
  - families
  - safety personnel
- Advocate for public & private funding to develop & pilot model programs, curricula, services that improve the safety of people with ASD
- Develop a curriculum framework for training & tech assistance, act - come back to train (e.g. people w/ ASD, safety personnel, criminal justice personnel, first responders)
- Self-care, internet safety, sexual & travel safety, disaster prep
- Self-empowerment, shared in tech world
- Reach out to existing Community (week) to include autism
- Reach out to Communities around "Safe Haven" possibilities

### COMMUNITY INTEGRATION: TRANSPORTATION, SAFETY AND QUALITY OF LIFE

The Community Integration Group envisioned people with ASD as valued and participating members of society, who are supported throughout the fabric of community life and fully engaged in every thread it represents; welcomed to pursue their interests, talents and lifelong learning; accepted in their pursuits of friendships, romantic relationships and marriage (if they choose); protected by law and ensured of their safety; afforded the opportunity for long-term wellness through good, comprehensive health care; and provided with the wheels to go anywhere, any time.

Because so many people do not understand what ASD is or the range of behaviors exhibited by people with ASD, a public awareness campaign is needed to debunk myths, normalize images and highlight the strengths of people with autism. This campaign should "find the invisible ramp" by also recognizing and validating those who are supportive of people with autism and remind the public that those with ASD have civil rights.

### COMMUNITY INTEGRATION

Most communities do not readily have ways to include individuals with ASD in existing organizations and activities. To avoid exclusion, every "community plan" should integrate people with ASD and other disabilities into community life by reallocating existing resources, making it possible to bring them into existing programs at recreation centers, houses of worship and community organizations. By doing this, and by starting as young as possible, the hope is that the public will gain a better understanding of people with ASD, and that people with ASD will have a better sense of the communities in which they live, ultimately helping to break down stereotypes.

### Think Tank Brainstorm:

- Develop pilot programs for integrating individuals with ASD into the community and share outcomes broadly;
- Create a defined process for community centers to include individuals with ASD in recreation and social activities;
- Leverage President Obama's service initiative to engage volunteers to work with people with ASD.
- Use entitlement money in non-traditional ways to serve individuals with ASD;

Partner with self-advocacy organizations, community colleges, vocational tech schools, libraries and museums to provide lifelong-learning opportunities, based on a belief that life-long learning is an entitlement for people with ASD;

Proclaim that people with ASD have a right to lifelong learning because of their unique needs, with the proclamation including the requirement that include that lifelong learning organizations must make regular programs accessible to people with ASD if they are to receive public funding;

Ensure that identity development for individuals with ASD is about more than just autism, and should expand to include their entire identity -- gender, culture, race, profession, sexual orientation, hobbies; and

Ensure continuing education includes information on social skills, personal hygiene and sexuality.

The success of integrating people with ASD into the community relies heavily on two issues: transportation and safety. Because of the importance of these issues, they were discussed in groups separately before being brought into the broader discussion of quality of life.

## **TRANSPORTATION**

Transportation is an issue that impacts all areas of the lives of adults with ASD. All the work in other areas will be for naught if people who are trying to work and live on their own cannot get where they need to go. Transportation can be the biggest barrier to adults living productive and joyful lives and is the key to success in the workplace, in the community and in gaining personal independence.

As a result, locating housing, jobs and services within a reasonable distance for adults with ASD has to be a priority. A matter of a few blocks may make the difference between independence and dependence.

"Often, the ability of people to have jobs or be integrated in the community is limited solely by transportation. It is also one of the largest cost issues after housing," Ms. Lainer said. "If we don't address transportation, adults with ASD will end up being isolated and will not be able to reach their full potential."

People with ASD will need to be prepared given that transportation can be unpredictable. Because transportation needs vary depending on the individual and whether they live in cities, suburbs or rural areas, the problems and solutions will vary. Geography and infrastructure pose challenges, particularly in areas where options other than driving are limited. And, because navigating the physical and social environment can be challenging for people with ASD, safety issues must be addressed in connection with transportation initiatives.

### **Think Tank Brainstorm:**

- Build coalitions with groups with similar transportation needs (e.g. AARP and the Brain Injury Association);

  - Encourage people with ASD who can drive to become drivers for those with ASD who cannot;

  - Help those who have the skills to drive by creating accommodations that alleviate the anxiety of test-taking;

  - Provide training that helps adults with ASD have an easier time at state motor vehicle departments;

  - Organize carpools, leveraging existing groups, which can also create social opportunities;

  - Include the needs of people with ASD in the national "Mobility Management Initiative;"

  - Contract with companies that provide transportation in connection with public agencies (e.g. taxi services, airport services, Zipcar-type services) and tie funding through a coordinated planning process;

  - Use existing volunteer networks such as Best Buddies in colleges and volunteer escorts;

  - Leverage the new national campaign for volunteerism to expand escort or driving programs;

  - Develop a network of people designated to assist, wearing "I'm here to help" badges in public transportation hubs, and teach people with ASD who to turn to for help;

  - Providing sensitivity training and de-escalation training for employees working in public transportation to help keep the adults with autism safe while traveling;

  - Utilize a transportation-focused assessment tool which would help determine which skills individuals have and what they still need to learn to be able to safely navigate their transportation system;

and

  - Offer a training program specific to transportation implemented during school years with measurable outcomes as preparation for adulthood.

  - Look for housing, employment, recreational opportunities on major transportation lines.

## SAFETY

People with ASD need education and skills in order to live their lives with optimal safety. Others in society, particularly those in the public sector who may come in contact with adults with ASD, also need education and skills to maximize the safety and fair treatment of people with ASD. Currently, there is a lack of education, funding, data collection and technology focused on safety for this population.

People with developmental disabilities including autism, are seven times more likely to come in contact with law-enforcement professionals than the population as a whole, according to an autism risk management website operated by one of the members of the safety group. With the goal of preventing small incidents from escalating, it is important to teach a safety & awareness curriculum for safety personnel, the legal system, community leaders, teachers, family members and people with ASD. A safety curriculum for individuals with ASD should include content such as self care, sexuality, Internet safety, emergency preparedness and environmental safety at home and in the community.

### ***Think Tank Brainstorm:***

Organize stakeholders to pass federal and state legislation and policies and necessary funding that provides or mandates training and technical assistance for educators, service providers and those who work in law enforcement and criminal justice;

Collect safety resource information to augment and interpret current databases managed by a variety of existing autism groups (i.e., putting safety into a Web site of a national autism organization such as Autism Speaks);

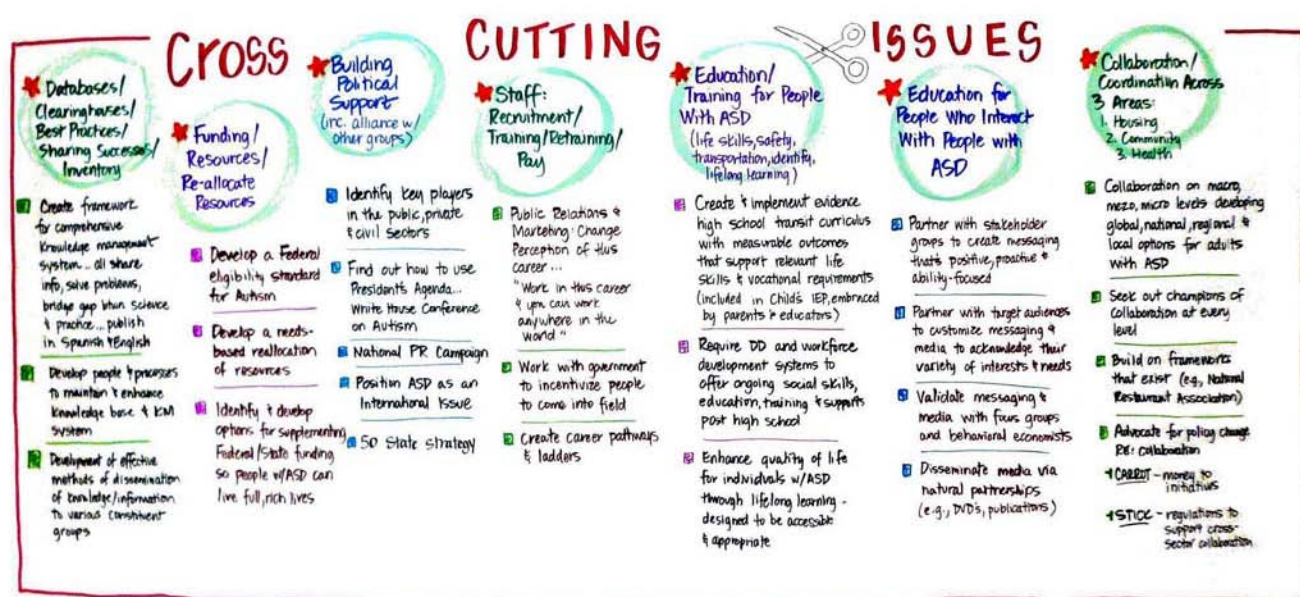
Create a clearinghouse which promotes safety-related, evidence-based best practices to key groups including educators, service providers, those who work in law enforcement and criminal justice, as well as to families and community members;

Adopt relevant best practices from other organizations who are concerned for the safety of their constituents (e.g. *Center for Aging Services Technology* and *Senior Checked*, a group that “certifies” providers and implements Smart Homes ideas that already help elderly and disabled individuals safely stay in their homes longer);

Direct people to the Autism Risk and Safety Management website: [www.autismriskmanagement.com](http://www.autismriskmanagement.com); and

Teach swimming to children and adults with ASD, and teach others how to prevent drowning accidents, enlisting organizations who already work on these issues with a broader population such as the American Red Cross.

## CROSS-CUTTING ISSUES



As each group brainstormed about ways for dealing with specific issues, they came up with numerous ideas that cut across all areas. On the second day of the Think Tank, the group categorized the cross-cutting ideas into seven buckets, and divided into seven groups to discuss these issues more fully.

### DATABASES, CLEARINGHOUSES AND INVENTORIES

A lack of databases, clearinghouses or inventories of best practices is a problem that each group identified as an overriding obstacle. To deal with this gap, participants suggested creating national, searchable database to collect, retrieve and disseminate information that would (1) allow people to share knowledge, (2) provide the information needed to solve problems, and (3) bridge the gap between science and practice.

All databases should:

1. Be published in both English and Spanish;
2. Be easily searchable;
3. Utilize an effective method of widely disseminating the information to various constituencies;
4. Include clear protocols and responsibility for keeping the information current.

Building comprehensive databases will go a long way towards defining and finding the right resources, and informing a political agenda, both of which are other crossing-cutting issues. Given the many competing priorities of government funding for people with special needs, the private sector may be the only solution for funding the development of this comprehensive database. Universities and Centers for Excellence are a good resource for data.

### ELIGIBILITY AND RESOURCE ALLOCATION

The determination of eligibility for services, and the funding streams which accompany this eligibility, has far-reaching implications across all issue areas. Participants agreed that ASD advocates should:

- Develop and propose a federal eligibility standard for ASD;
- Develop a needs-based reallocation of resources;
- Identify and develop options for supplementing federal and state funding so people with ASD can live richer, fuller lives, and
- When appropriate, work with other disability advocate groups to ensure that all people with disabilities, including those with ASD, are eligible for resources.

## **BUILDING POLITICAL SUPPORT**

A grassroots movement is needed with a clear message to the community that includes a public relations approach to gain a ground swell of attention to the issue of adults with ASD. It may be useful to make this a part of an overall approach that elevates awareness and attention to all persons with disabilities. To help grow this movement and, in turn, build the necessary political support to impact policy and funding, the ASD community needs a national public relations campaign to dispel myths, combat fear, and to create an accurate perception of the characteristics of adults with ASD. The message should focus on the abilities of people with ASD and should be segmented for housing, employment and community integration audiences. Autism advocates should partner with these audiences in the development of the campaign so the message is appropriate and will resonate with the specific audience (i.e. law enforcement, faith community, neighbors).

To further build political support, advocates must first identify key influential players in the public, private and civil sectors. Autism is already an issue on President Obama's 24-point agenda. It is important for advocates to quickly figure out how to leverage that agenda to (1) pass legislation with necessary funding for programs specifically for adults with ASD, and (2) pave the way for a White House Conference on Autism.

Several Think Tank participants agreed that one way to gain political clout on Capitol Hill would be to commission a white paper on the dramatic increase of adults with ASD to be delivered to every member of Congress by a person with ASD, followed by a meeting with each of the 22 members of the Congressional Autism Caucus to advocate for desired legislation.

## **STAFF RECRUITMENT AND CAREER DEVELOPMENT**

In addition to a public relations campaign to improve the lives of those with ASD, there needs to be a campaign to improve the perception of careers working with them. Communicating to people that becoming educated or trained to work with people with ASD can lead to a lifelong rewarding career with transferable skills could be one way to recruit people.

"This is an international issue. You can work anywhere in the world," said one participant who has trained people in several countries, including Thailand and Vietnam.

But there is some work to be done beyond perception to make working with adults with autism an attractive career choice: jobs need to pay better wages and the path up the career ladder needs to be better defined. Government, at the encouragement of advocates, may be able to play an important role in encouraging people to come into the field through such techniques as accreditation programs and international recruiting.

### ***Think Tank Brainstorm:***

- Create clear career paths and support for staff, partnering with educational institutions to train staff;
- Integrate mentoring into ongoing staff development;

- Create a "Service Provider University" with a joint emphasis on quality and scale to graduate a large number of individuals qualified to work with people with ASD;

- Borrow from existing models of service such as Teach for America and AmeriCorps and create a service movement that trains and employs young people to work with individuals with ASD. The programming would:

  - Make clear how this experience will teach valuable skills - leadership, problem-solving, patience and understanding that will help graduates in whatever careers they choose.

  - Establish a three-year service commitment, incorporating "turnover" into the model. If graduates love the work, they will stick with it. If not, they can move on to other careers without feeling like they "quit", and will inevitably be lifelong advocates for people with ASD.

## **TRAINING FOR PEOPLE WITH ASD**

Adults with ASD need to be trained in life skills, safety, transportation, job skills, workplace etiquette, social skills and personal hygiene. This training must be accessible and appropriate, provided through many avenues, and create many opportunities for lifelong learning.

One avenue is through high schools, creating and implementing high-school transition curriculum with measurable outcomes, whose specific goal is to develop the life skills needed as an adult. Another avenue is through the Individualize Education Program (IEP) for every child with autism where vocational skills training could be incorporated.

Another avenue would be through existing developmental disability and workforce development networks, systems and programs which could offer social skills education, training and supports after high school.

## **TRAINING FOR PEOPLE WHO INTERACT WITH PEOPLE WITH ASD**

Those who interact with people with ASD also need training and education. These people include, but are not limited to, teachers, families, neighbors, first responders, faith leaders and people in the criminal justice system and in the community. There should be training in the areas of accessibility, safety, negative images, multiple identities and competencies as well as raising expectations. Education or training in these areas can mean the difference between acceptance and exclusion of people with ASD.

## **COLLABORATION**

Collaboration in housing, employment and community is necessary on macro, mezzo micro levels to develop global, national, and regional and local options for adults with ASD. One expert pointed out that in many cases, there is no need to re-invent the wheel. Other disability organizations or agencies serving the population at large who cares about similar issues (e.g. The American Red Cross) can become critical partners in achieving the goals of a richer, safer and more fulfilling life for people with ASD.

This movement could be well-served to replicate existing frameworks such as the National Restaurant Association which promote public-private partnerships, including business opportunities to motivate industry by win-win relationships. Lastly, while voluntary collaboration is important, the autism community should advocate for change by using the carrot and stick method with the carrot being money for initiatives and the stick being regulations to ensure all parties play by the rules.

## **WHAT'S NEXT?**

The *Advancing Futures for Adults with Autism* Think Tank was a first step toward a year of gathering information and support, with a goal of bringing an agenda to Washington D.C. The next step is a National Town Hall meeting, where people in fifteen locations around the country will be connected via satellite to gather more input.

"We will bring together at least 1,000 voices from throughout the United States with sites from coast to coast," said Bell of AFAA. Mr. Bell said he wants active participation by people with ASD and their families, who can't easily advocate for themselves. "We want them to be involved in the process — to make sure their voices are heard," Mr. Bell said.

The next three to five years are crucial for laying the groundwork to address the numbers of children with autism moving into adulthood. Currently there is nothing to fill the gap as they leave behind the entitlements they received as children. The few existing exceptional adult programs and services in each state need to be held up as models and replicated on a large scale. Maintaining the status quo is unacceptable and changes must be made to handle what promises to reach a crisis without preparation.

Throughout the Think Tank, participants repeatedly emphasized that people with disabilities are not broken and therefore do not need to be "fixed." "Rather," as one participant noted, "it is the social environment that must be fixed or modified so our fellow citizens with ASD can take their rightful place among us as friends, neighbors, co-workers and employees."

**Addendum: End of Conference ideas, see attached file**