Meeting the Needs of Individuals with Autism

Considerations for the Future

Bureau of Autism Services
Pennsylvania Department of Public Welfare
Nina Wall-Côté, MSS, LSW, BAS Director
Today’s Agenda

What is Autism?
BAS Overview
Autism in PA
BAS Adult Programs
Training/Resources
What is Autism?
What is Autism?

Autism is a very complex, life-long neurological condition that involves challenges in social, communication, and behavioral development.

It is not a mental illness and not an intellectual disability; however those diagnoses can co-exist.

Some people with autism have an intellectual disability, and/or a mental health challenge, and/or a physical health challenge; others do not.

Autism is something an individual is born with; it is not acquired and individuals do not “outgrow” Autism Spectrum Disorders.
Autism Fast Facts

- You may also hear autism referred to as Autism Spectrum Disorders (ASD)
- Autism is a brain-based neurological condition
- Usually diagnosed by the time a child is three years old
- Males are affected more than females at a ratio of 4:1
- Found in every country, every ethnic group, every socio-economic group and every age group
More facts...

- Individuals who are diagnosed need intervention as soon as possible.

- ASD is a lifelong disability, BUT with the right kinds of supports, individuals can make substantive progress.

- Progress is made at every age. People living with ASD can continue to learn throughout their lifetime, given proper supports and individualized treatments.
A True Spectrum

No two people with ASD are alike, even if they have the same diagnosis.

What is similar are the significant challenges with social interaction.
Justice Intersections

Core deficits in communication and social interactions + “zero tolerance” policies = greater risk for interactions with law enforcement

• Easy prey to peers, victims of bullies
• Sexuality behavior appropriateness characterized by naïveté
• Narrow interests interfere with learning and social adaptation
• Each case is unique

Cross-sector efforts underway to
• Leverage existing resources
• Create systemic programmatic responses
• Identify critical points before, during or after these interactions where prevention or intervention would be effective
Autism in Pennsylvania

Bureau of Autism Services Overview
OUR DEVELOPMENT

THE PENNSYLVANIA AUTISM TASK FORCE
The key recommendations from this report drive the work of the Bureau of Autism Services.

BAS ADULT PROGRAMS
What we are learning about supporting adults with autism helps us adapt our approach.

THE PENNSYLVANIA AUTISM NEEDS ASSESSMENT
The key findings will inform future cross-sector initiatives.
We are here

Commonwealth of PA

Governor’s Office

State

Public Welfare

Labor & Industry

General Services

Insurance

Transportation

Health

Education

Revenue

Aging

BSC licensing managed here

IEP, Transition Services and Special Education managed here

Act 62 managed here
Department of Public Welfare

Early Intervention Services here

We are here – Adult Autism Services

MA Issues managed here

BHRS managed here

Children, Youth And Families

Income Maintenance

Medical Assistance Programs

Administration

DEVELOPMENTAL MENTAL PROGRAMS

Long Term Living

Mental Health and Substance Abuse Services

Child Development And Early Learning
Office of Developmental Programs

We are here

Bureau of Autism Services

Bureau of Policy And Program Support

DEVELOPMENTAL PROGRAMS

Bureau of Financial Management And Budget

Bureau of Supports for People with Intellectual Disabilities
Our mission is to develop and manage services and supports to enhance the quality of life for Pennsylvanians living with Autism Spectrum Disorders and to support their families and caregivers.
BAS VALUES

- Support those living with autism *throughout the life span*
- Support those living with autism *across the spectrum*
- Support families
- Every person living with autism can have an improved quality of life given the right supports delivered by trained staff
- Increased independence and self-sufficiency
- Explore innovative models
Autism in Pennsylvania

Identifying the Scope of Needs
Ongoing Challenges

- Increasing population
- Limited resources
- Families and individuals with autism stressed
- Need for increased capacity of professionals trained to support individuals with autism, especially adults
- Federal eligibility criteria
- Individuals with autism housed in every system
- Multiple systems are complicated to navigate
What does the research evidence tell us about autism prevalence?

- Broader diagnostic criteria
- Better screening and diagnostic tools
- Increased public awareness
- More accurate counting in schools
- Diagnostic substitution:
  - increase in autism diagnosis corresponds with decrease in diagnosis of ID, ADHD, and other developmental disorders.
  - Many individuals who are now diagnosed with Asperger Syndrome were not diagnosed as having autism in the past
- Other reasons still to be determined
CDC Prevalence Estimates

• 1970: 1 in 2500 (considered a rare disorder)
• 1995: 1 in 500
• 2000: 1 in 150
• 2009: 1 in 110 (1 in 70 boys)
• 2012: 1 in 88 (1 in 54 boys)

Some Explanation of the CDC Numbers

- CDC numbers based on the Autism and Developmental Disabilities Monitoring (ADDM) Network
- ADDM focuses on children aged 8 years - the age of identified peak prevalence.
- The extent to which these increases reflect better case ascertainment as a result of increases in awareness and access to services or true increases in prevalence of ASD symptoms is **not known**.
- ASDs continue to be an important public health concern in the United States, underscoring the need for continued resources to identify potential risk factors and to provide essential supports for persons with ASDs and their families.
- PA’s reporting surveillance site (Philadelphia County) as well as all the CDC data, are consistent with the data from our, BAS, Census Report.
Pennsylvania Autism Census Project

The tidal wave of children with autism are transitioning into adulthood...

How do we provide for them?
PA Autism Census Project

Findings:
• ≈ 20,000 people with autism in Pennsylvania in 2005
• Given the trend, that number has reached 25,000-30,000

Percent of Individuals with Autism in Pennsylvania in 2005 by Age Group

- 0-4 years: 13.1%
- 5-12 years: 55.9%
- 13-17 years: 19.6%
- 18-20 years: 4.1%
- 21+ years: 7.1%
PA Autism Census Project

- 2005: just over 1,400 adults with autism
- 2010: 179% increase to 3,825
- 2015: 621% increase to 10,140
- 2020: 1,292% increase to 19,587
Identifying the Depth of the Needs…

Pennsylvania Autism Needs Assessment

Pennsylvania Department of Public Welfare,
Bureau of Autism Services
and
Eastern ASERT

David S. Mandell, ScD. and Lindsay Lawer, MS
University of Pennsylvania School of Medicine,
Center for Mental Health Policy and Services Research
Center for Autism Research, Children's Hospital of Philadelphia
Who Answered the Survey?

- **3,563** caregivers and individuals with autism completed the survey.

- Four survey modules were developed to capture differences across age groups.

- Individuals with autism over age 18 could complete a separate survey.

**Demographics**

<table>
<thead>
<tr>
<th>Number and Percentage of Respondents</th>
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</thead>
<tbody>
<tr>
<td>Pre Elementary</td>
</tr>
<tr>
<td>Elementary</td>
</tr>
<tr>
<td>Middle/High School</td>
</tr>
<tr>
<td>Adult</td>
</tr>
<tr>
<td>Individual</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>
KEY FINDINGS

- Pennsylvanians with autism of all ages and their families are struggling to find the services they need and are often dissatisfied with the services that are provided.

- As individuals with autism grow into adulthood the needs for supports and services often increase, although services become more difficult to access.

- A lack or shortage of providers is the most common barrier to accessing services.

- The lack of effective interventions for challenging behaviors and mental health problems often lead to preventable crises.

- Although children are being diagnosed at younger ages, diagnosis and follow-up care is still a long and difficult process.

- Most adults with autism are unemployed or underemployed because the necessary supports are not available.

- Caring for an individual with autism takes an economic and emotional toll on families.
Key Recommendations

• Expand the capacity to provide appropriate diagnosis and assessment of children and adults with autism.

• Increase the availability of, and access to, all types of autism services to support individuals with autism and their families.

• Provide training in best practices to meet the needs of individuals with autism and their caregivers.

• Identify opportunities to develop cross-sector solutions and share resources.
Complete Report Series:
www.paaautism.org/asert

Report 1: Statewide Summary
Report 2: Service Needs
Report 3: Barriers & Limitations to Accessing Services
Report 4: Unwanted Outcomes: Police Contact & Emergency Hospital Care
Report 5: Getting a Diagnosis & Follow-Up Care
Report 6: Employment Challenges
Report 7: Family Impact
Final Report: Report Recommendations
Autism Services, Education, Resources, and Training

Mission:
To enhance the lives of Pennsylvanians with autism of all ages and abilities by:

• improving regional access to quality services and interventions
• providing information and support to families, training professionals in best practices
• facilitating partnerships among providers of services throughout the Commonwealth
Why ASERTs?

- Catalyst to bring together resources locally, regionally, and statewide
- Leverage existing resources and expertise
- Address regional gaps in effective services & supports

48 out of PA’s 67 Counties are Rural
One ASERT in each region
Collaborating statewide
ASERT Current Projects

Based on the Needs Assessment findings, the ASERT collaboratives are focusing on three major areas: Clinical Services, Education & Resources, and Training.

*Examples of projects under development are:*

- **Adult Diagnostic & Assessment Clinic**
- **Statewide Emergency Responders Training**
- **Training Webinars**, covering topics such as autism diagnosis and co-occurring medical conditions
- **Autism Life Care Model**: A comprehensive system of care to support an individual with autism, his/her family and the community throughout critical phases of development, by assessing the strengths and weaknesses of adolescents early in the teen years.
- **Evaluating & Implementing Employment and College Preparation Programs for Adults Living with ASD**
- **Adult and Adolescent Multimedia Social Skills**: Developing a social skills intervention aimed at adolescents and young adults with ASD; and developing training materials for professionals to deliver this intervention.
2011-2014 ASERT Collaboratives

WESTERN ASERT

Director
John McGonigle, PhD

Outreach & Resource Specialist
Ryan Cramer

1-412-235-5408

www.asert.pitt.edu

CENTRAL ASERT

Director
Amanda Pearl, PhD

Outreach & Resource Specialist
Kristen Riley

1-877-231-4244

www.autismcentralpa.org

EASTERN ASERT

Director
Lindsay Lawer, MS

Outreach & Resource Specialist
Megan McCarthy

1-877-408-0154

www.paautism.org/asert

Coming soon!
A new statewide ASERT Website & Toll-Free Number
Bureau of Autism Services

Adult Programs: Creating Options to Meet the Growing Need
Meeting the Need

With effective supports, individuals with autism are able to be part of the community, hold jobs, and reach their potential to live as independently as possible.
Innovative Services for Adults with Autism

ADULT AUTISM WAIVER

ADULT COMMUNITY AUTISM PROGRAM (ACAP)

Programs designed to help adults with autism live in their communities the way they want to, based on their identified needs
Seeing Outcomes

• Our program participants are making progress toward their goals!

• With the support of their trained service providers, participants are:
  ▪ volunteering in their communities
  ▪ gaining employment in competitive fields
  ▪ moving into independent living quarters

— all with their input, based on their identified needs
What are some of the differences between the BAS adult autism programs and other programs for adults in Pennsylvania?

• Specifically designed to meet the needs of adults with an ASD

• Administered at the state level directly by BAS

• Do not use IQ as an eligibility factor
What are some of the differences between the BAS adult autism programs and other programs for adults in Pennsylvania?
(continued)

- **Providers required to complete autism-specific training & meet standards**
- **Clinical & technical assistance available to enrolled providers**
- **Service planning and measures of success based on individual goals**
- **Services based on proven approaches to help individuals with an ASD realize their goals**
What are the goals of BAS adult programs?

- Increase person’s ability to care for themselves
- Decrease family/caregiver stress
- Increase quality of life for both the person and the family
- Provide specialized supports to adults with an ASD based on need
- Help adults with an ASD reach their employment goals
- Support more involvement in community activities
- Decrease crisis episodes and psychiatric hospitalizations
BAS Adult Program Update

- Both programs are serving their maximum number of participants, and will not be able to enroll additional participants. However, we will continue to accept requests for applications.

- Applications will not be sent until the capacity to support additional participants is available.

- Once either program is able to begin accepting additional applications, requests for applications for that program will be processed in the order they were received.

- If you think you may be eligible, or know someone who might be, you are strongly encouraged to request an application by calling our toll-free number: 1-866-539-7689
Application Questions

- Requests for applications are processed in the order they are received: if you think you may be eligible, or know someone who might be, you are strongly encouraged to request an application as soon as possible.

- Individuals can request an application for both programs at the same time. If you think you meet eligibility for both, you can decide which one is a better fit before enrolling in one of them.

- Individuals can request an application at any time. Applications received within 90 days of the applicant turning 21 will meet the age criteria; they will not be enrolled until they are 21 or older.

- Individuals on wait lists for other programs can request an application for these programs without losing their placement on the wait list.
Adult Autism Waiver & ACAP Applications

To request an application for either program call toll-free in PA:

1-866-539-7689

Applications may not be requested by email and are not available on-line.

Information to leave:

- Name of person who wishes to apply
- Telephone number
- Address
- County of residence
- If you are calling on the behalf of the person who wishes to apply also leave your name and daytime phone number.
Adult Autism Waiver & ACAP
Shared Features

The features that make the Adult Autism Waiver and ACAP different in some way from other adult programs in Pennsylvania are the characteristics they share!

*Plus: Consistent Eligibility requirements*

*The individual served must:*

- Be a PA resident
- Have a diagnosis of an autism spectrum disorder (ASD)
- Meet MA income eligibility *(determined by County Assistance Office)*
- Meet functional eligibility
- Be 21 or older
Functional Eligibility

Individual must have substantial functional limitations that are likely to continue indefinitely in three or more of the major life activities listed below.

These functional limitations, which must be evident before the person reaches the age of 22, include limitations in:

- self-care
- understanding and use of receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
AAW & ACAP: Differences

Visit [www.autisminpa.org](http://www.autisminpa.org) for a comprehensive PA Program Comparison chart and a complete list of services provided in each program.

- The **Adult Autism Waiver** is a traditional HCBS waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults with an ASD. The Adult Autism Waiver does not include physician services.

- **ACAP** is not a waiver. It is a managed care program that includes some innovative approaches to service provision. It provides physician, behavioral, and community services through an integrated approach to create a coordinated system of supports.
<table>
<thead>
<tr>
<th>Adult Autism Waiver</th>
<th>Adult Community Autism Program (ACAP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priority given to individuals not receiving ongoing state/federally funded services</td>
<td>Currently available in 4 counties</td>
</tr>
<tr>
<td>Available statewide</td>
<td>ACAP becomes the participant’s health plan</td>
</tr>
<tr>
<td>Participant retains Health Choices; physical health services not included as a waiver service</td>
<td>Integrated physical/behavioral health &amp; community services</td>
</tr>
<tr>
<td>Choice of an enrolled provider for all services</td>
<td>Keystone Autism Services and their network of providers (e.g. primary care physician) provide most services</td>
</tr>
<tr>
<td>Does allow for residential 24/7 care if a need is determined through assessment</td>
<td>At intake, participant cannot require 16 or more hours of awake support</td>
</tr>
</tbody>
</table>
AAW Priority Categories

- **Priority 1**: Those who are not already receiving state-funded or state and federally-funded home and community-based services.

- **Priority 2**: Those currently enrolled in state-funded or state and federally-funded home and community-based services.

Everyone who is placed into a priority category will receive a status letter to confirm that category.
BAS Adult Autism Waiver

Adult Autism Waiver
Services & Supports Directory (SSD)

- Searchable by provider or service
- A complete directory is also available via download with all service providers listed either by county or by service category

Accessible by visiting: [http://bastraining.tiu11.org](http://bastraining.tiu11.org) (AAW Provider Training & Information)
BAS Programs: Enrolled Provider Training

**Pre-Enrollment Training**
~ course designed for direct service providers

**Post-Enrollment Waiver Provider Trainings**
- Provider Follow-up Training
- Behavioral Specialist Follow-up Trainings
- ISP Development & Review
- Level of Care Assessor Follow-up Training
- Supports Coordinator Supervisor Training
- Plus weekly trainings designed to meet on-going needs identified by our providers

**ACAP**: Keystone Autism Services provides ongoing training to its provider network for the Adult Community Autism Program (ACAP)
Questions about the Adult Autism Waiver or ACAP?

Please visit [www.autisminpa.org](http://www.autisminpa.org) or call 1-866-539-7689 for detailed information including:

- Program Overviews
- Eligibility
- Application Processes
- Services
- Provider Networks
- Becoming a provider of services
- Contacting the program teams directly
Bureau of Autism Services

Training & Resources
PATC 2012

5th Annual Pennsylvania Autism Training Conference (PATC)
“Envisioning Autism Services: Practical Strategies & Solutions”

Registration Is Now Open!
Visit www.bastrainings.org

Tuesday – Thursday
June 12 – 14, 2012

Eden Resort Inn & Suites
222 Eden Road
Lancaster, PA 17601
KEYNOTE SPEAKERS:

Tuesday, 6/12  Adult Autism Program Providers Day: Not open to the general public

Wednesday, 6/13  Peter Gerhardt, EdD, Community Integration & Employment Transitions

Thursday, 6/14  Dennis Debbaudt, Autism Risk & Safety Management

Breakout Session Topics:

• Managing anxiety/depression
• Social skills across the lifespan
• Justice intersections/sexuality
• National trends in genetic research
• Self-advocacy/bullying
• Adult diagnosis
• Sibling research/personal perspectives
• Community inclusion case studies
• ASERT Projects and Needs Assessment findings
Building Training Capacity

• 5000+ trained to conduct FBAs since Spring 2007
  ▫ 1,465 individuals met the standard during the 2010-11 FY

• 300+ trainers statewide able to conduct FBA sessions
  ▫ 150 trainers currently conducting sessions

• FBA and PBS Trainings conducted by regional ASERTs

“This training has assisted me in my treatment planning, assessing patient issues and targeting the most important aspects of patient needs.”
~FBA training participant
Introducing the new BAS Training Systems Entry Page: www.bastrainings.org

You can now access all of the BAS training systems from one easy entry point.

VIRTUAL TRAINING & RESOURCE CENTER (VTC)
A free resource for Adult Autism Waiver providers, other professionals, and individuals/families with ASD

COURSEWHERE REGISTRATION SYSTEM
To register for live trainings and conferences, including the PA Autism Training Conference (PATC)

SPeCTRUM
An online training course designed for providers working in the BAS Adult Autism Programs

Visit www.bastrainings.org & follow the prompts to create a master login account, then get connected to the BAS training sites you would like to use!
Navigating the VTC

• The BAS Virtual Training and Resource Center (VTC) was originally designed to house trainings for Adult Autism Waiver providers, but has been expanded to include various resources for families, individuals and the general professional community.

• Because this site is designed as a course management system, each visitor will need to create a free account to access the materials.

• The material, whether it is a resource or a training, is organized as individual courses.

• The first time you access one of the specific categories, you will be asked if you want to enroll in the course. When you are given this option, please choose yes.
VTC Overview of Content

**ABOUT US**
- History, Mission & Values
- Updates: Presentations & Newsletters
  - BAS Outreach Packet
  - BAS Outreach PowerPoint
  - BAS Newsletters
  - BAS Webcasts

**AUTISM IN PA**
- Autism Fast Facts
- Autism Supports & Resources
  - Adult Programs
  - Online Resource Manual
  - Supports by County
- Pennsylvania Autism Census Project
- Pennsylvania Autism Needs Assessment
  - PA Autism Needs Assessment Reports
- Pennsylvania Autism Housing Project

**TRAINING**
- PA Autism Training Conference (PATC)
- Community & Professional Training Videos
- Functional Behavioral Assessment
- Community Inclusion for Adults with Autism

**ADULT AUTISM WAIVER INFORMATION**
- Adult Autism Waiver Overview
- AAW Provider Training & Information
  - Services & Supports Directory
- Required & Supplemental Trainings
- Provider Handbook
Virtual Community Trainings

- First Look*
- Second Look*
- Third Look*
- SPeCTRUM*
- Introduction to Autism
- Autism 101 (adult-specific)

*Available in libraries statewide!
What needs to happen?

- Address increasing needs across the lifespan, not just those of children
- Focus on the needs across the ASD continuum
- Support families
- Streamline information and resources
- Ongoing professional training (e.g. colleges/universities)
- Collaborate with potential employers
- Develop cross-sector collaborations to share resources and responsibility (e.g. public-private partnerships)
Stay updated!

- Check our websites for current information
- Read the BAS newsletter
- Join a BAS webcast
- Attend a BAS training

All this and more can be found on

www.autisminpa.org

or

www.bastrainings.org
Bureau of Autism Services
Nina Wall-Côté, MSS, LSW

For More Details on our Programs or Initiatives

- Email us: DPW-AutismOffice@pa.gov
- Visit our General Website: www.autisminpa.org
- Visit our new Training Systems Entry Page: www.bastrainings.org
- Call us: Toll-Free in Pennsylvania at 866-539-7689