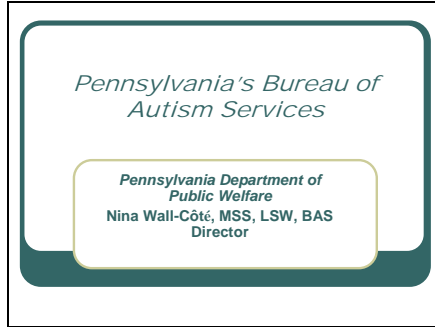


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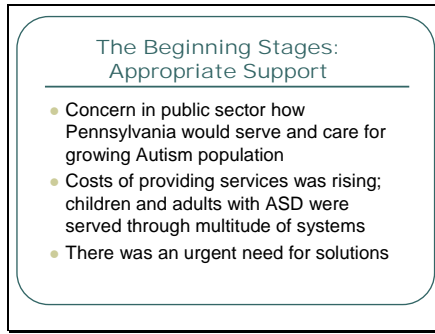
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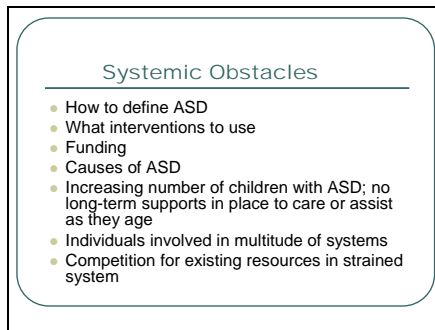
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Slide 3



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Slide 4

The Pennsylvania Autism Task Force  
Convenes in 2003

Department of Public Welfare Secretary Estelle B. Richman recognized the need for the Commonwealth to have a plan to improve the organization, financing and delivery of services to individuals with ASD.

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Slide 5

The Pennsylvania Autism Task Force

In July 2003, Secretary Richman convenes a task force of over 250 family members, advocates, medical and health care professionals, clinicians, researchers, educators, agency and legislative staffers, administrators, and provider professionals.

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Slide 6

The Pennsylvania Autism Task Force

In December 2004, the efforts of the task force culminated in a final report that identifies specific problems and solutions for enhancing services to support individuals with autism.

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Slide 7

Final Report

While the Task Force identified micro-system challenges unique to the Pennsylvania service delivery system, the macro-system challenges and recommendations delineated in the report are not unique to Pennsylvania. Rather, they are obstacles facing policy makers throughout the nation.

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Slide 8

Primary Recommendations

1. Create an Office of Disability within the PA Department of Public Welfare that would include an autism-specific office
2. Develop an autism-specific Medicaid waiver
3. Develop creative mechanisms for blending and braiding funding between the education and Medicaid systems

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Slide 9

Primary Recommendations Continued

4. Situate regional autism centers across the state
5. Create an organization to provide informational materials and resources to families and advocates

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Slide 10

Office of Developmental Programs

In February 2007, the former office of Mental Retardation was renamed the Office of Developmental Programs (ODP) to include both a Bureau of Supports for People with Intellectual Disabilities (BSPID) and a Bureau of Autism Services (BAS).

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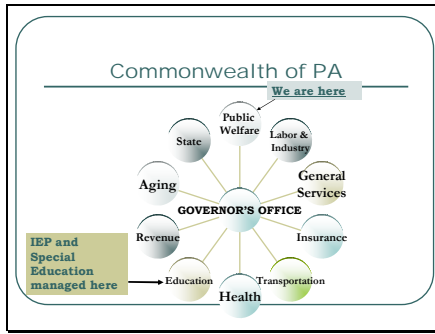
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Slide 11



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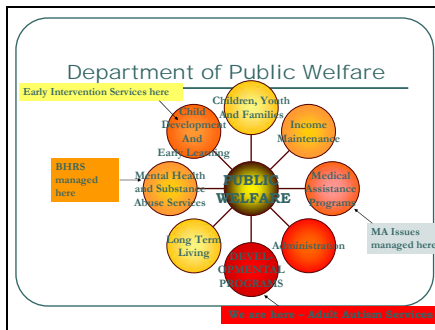
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Slide 12



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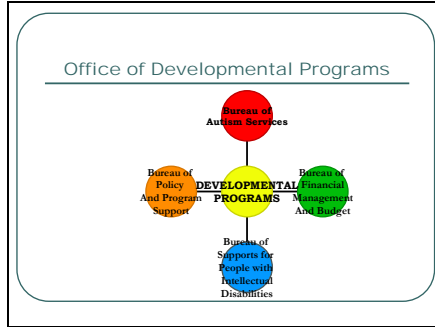
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Slide 13



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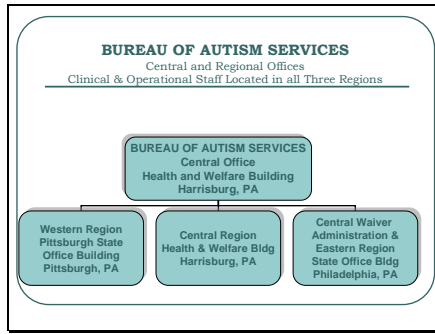
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Slide 14



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Slide 15

**BAS Mission Statement**

The mission of BAS is to develop and manage services and supports to enhance the quality of life of Pennsylvanians living with autism spectrum disorder and to support their families and caregivers. The Bureau will carry out its mission through the creation and administration of adult service delivery models, the development of resources to support individuals with autism and their families across the lifespan and by collaborating with and providing technical assistance to other DPW offices and government agencies.

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Slide 16

Our Values

- Support those living with ASD *throughout the life span*
- Support those living with ASD *across the spectrum*
- Families need our support
- Every person living with ASD can have an improved quality of life given the right supports delivered by trained staff
- Our goal is to increase independence and self-sufficiency
- Need to explore innovative models

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Slide 17

PA Autism Census Project  
University of Pennsylvania School of Medicine, Center for Mental Health Policy and Services Research Center for Autism Research, Children's Hospital of Philadelphia

***The first study to estimate the number of Pennsylvanians living with Autism Spectrum Disorders.***

Purpose:

- To obtain an estimate of the number of individuals living with ASD in Pennsylvania
- To learn about demographic characteristics of that population
- To reveal the scope of need for autism-specific services and programs
- To inform policy development and the design of effective services.

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Slide 18

PA Autism Census Project

**Methods**

- PA does not have consistent data collection requirements across systems, making the task very challenging.
- Looked at data from PDE and DPW (early intervention, county MH/MR, children and youth, HealthChoices, behavioral health).
- We know that people who are undiagnosed or not receiving services are excluded from the count.

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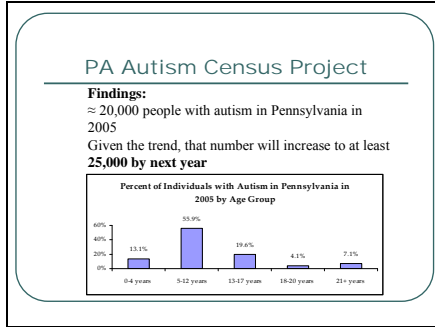
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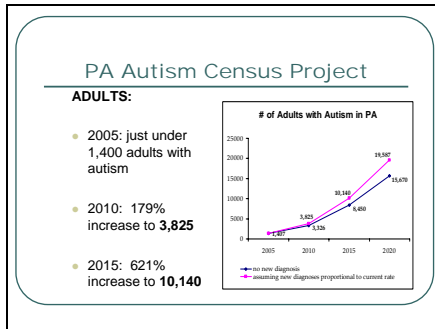
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Slide 20



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Slide 21

### Service Delivery

- Children under age 21 are served through the mental health, intellectual disability, early intervention, and education systems in Pennsylvania
- Adults with ASD absent additional qualifying diagnoses are most often not served anywhere
- Services are likely not autism specific, and therefore, mismatched or inappropriate

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Slide 22

Services Available to Children with ASD in Pennsylvania

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**Special Education**  
 ➤ Services for children up to age 22 or upon graduation

**Early Intervention**  
 ➤ Services for children up to age 5  
 ➤ EI Waiver for children up to age 3

**Medical Assistance**  
 ➤ For children who do not meet SSI disability criteria, Medicaid looks at *child's* income only  
 ➤ EPSDT: physical and behavioral health medically necessary services covered until age 21  
 ➤ Many families use rehabilitation services designed for children with severe emotional disturbances or whose disabilities affect behaviors (Behavioral Health Rehabilitation Services or wraparound)  
 ➤ Two MR/ID Waivers also serve children ages 3 and up

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Slide 23

Early Periodic Screening, Diagnosis, and Treatment (EPSDT)

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- Children and Adolescents with ASD who do not qualify for county MH/MR services are still able to receive medically necessary behavioral health and physical health services through the Medicaid children's health care benefit package.
- Those who qualify for Supplemental Security Income (SSI) based on family income and assets are automatically eligible for Medicaid.
- If they exceed the family financial limits, but meet SSI disability criteria, they can still receive Medicaid under PA's "disabled child" or "PH-95" category which only considers the child's income.

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Slide 24

Gaps in the Current PA Service System for Adults with ASD

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**Mental Retardation/Intellectual Disability:** two waivers  
 ➤ Waiting lists  
 ➤ Do not cover those with an IQ over 70

**Non-ID, Developmental Disabilities Waiver**  
 ➤ Service package designed for people with physical disabilities

**Mental Health**  
 ➤ Services limited to those with co-occurring mental illness.  
 ➤ Not designed to meet needs of people with an ASD diagnosis

**Vocational Rehabilitation**  
 ➤ Too limited to help people with ASD get & maintain jobs

**Those without services, or with inappropriate services, are ending up unemployed, homeless, and in prison.**

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Slide 25

1966 Mental Health/Mental Retardation Act

- Required Pennsylvania to establish MH/MR programs using state-funded grants
- Intended to provide a comprehensive service delivery system that included treatment and rehabilitation in both institutional and community settings to eligible consumers

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Slide 26

1966 Mental Health/Mental Retardation Act

- Many individuals with ASD and an Intellectual Disability are able to receive supports through these county programs or through Medicaid waivers.
- Others with mental health challenges are able to receive services through the county as well
- Those with ASD absent an IQ in the MR range (i.e. 70 or below) or who have a co-occurring diagnosis of a mental illness do not meet eligibility requirements for these services.

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Slide 27

Behavioral Health Rehabilitation Services (BHRS)

- Provides trained professional support for children and adolescents in home and community (including school) settings to reduce or replace challenging behavior.

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Slide 28

Rehabilitation vs. Habilitation

- *Rehabilitation* services are meant to “reduce physical or mental or **restore** eligible beneficiaries to their best possible functional level.”
- *Habilitation* services are meant to “help individuals acquire, retain, and improve self-help and adaptive skills, but are not intended to remove or reduce individuals’ disabilities.”

Binder, 2008

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Slide 29

Rehabilitation vs. Habilitation

- Habilitation services are not covered under EPSDT.
- EPSDT entitlement ceases at age 21.
- Individuals with ASD may continue to receive services through Home and Community-Based Services or through county MH/MR programs.
- Unfortunately, many receive no services at all.

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Slide 30

Autism Insurance Legislation:  
ACT 62

- This legislation was introduced to mitigate the heavy burden caused by health insurance companies’ discrimination against individuals with autism.
- It creates a liability for private insurers to cover services for children with autism that would have turned to MA for assistance.

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Slide 31

Purpose of ACT 62

- Insurance companies were not paying for diagnostic tools
- Insurance companies were writing "exclusion" policies
- Children were being provided habitation services that looked like rehabilitation
- Needed to eliminate medical "loopholes" in insurance policies

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Slide 32

Autism Insurance: ACT 62

In regards to autism insurance reform, Act 62 does three main things:

1. Requires private health insurance companies to begin covering the costs of diagnostic assessments for autism and of services for individuals with autism who are under the age of 21
2. Requires the PA Department of Public Welfare to cover those costs for individuals who have no insurance coverage, or for individuals whose costs exceed \$36,000 that year
3. Requires the PA Department of State to license professional behavior specialists and to establish minimum licensure qualifications for them.

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Slide 33

Autism Insurance: ACT 62

- Implementation of the law has proven to be challenging
- One challenge has been services should be covered no matter where the service is provided (i.e. home, school, or community)
- ABA is an appropriate service in a school setting; insurance companies claimed it should be covered as an educational service and paid for by school districts

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Slide 34

Pennsylvania Programs for Adults with ASD

- Primary goal was to develop autism-specific programs for adults over the age of 21 with ASD not served by any system.
- In May 2008, CMS approved BAS' application for an Adult Autism Waiver to serve 200 individuals statewide.
- In January 2009, CMS approved the innovative program called the Adult Community Autism Program (ACAP) to serve 200 individuals using a Prepaid Inpatient Health Plan (PIHP) model.
- Both programs are the first of their kind in the nation

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Slide 35

Innovative Autism Programming

- Designed to meet the unique needs of the adult autism population, these two programs the following features:
  - Administered at the state level directly by BAS
  - IQ is **NOT** an eligibility factor
  - Providers required to complete autism-specific training & demonstrate competence
  - Clinical & Technical assistance available to providers
  - Service planning and measures of success based on individualized goals
  - Services based on proven approaches to help individuals realize their goals

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Slide 36

Program differences

- Adult Autism Waiver (AAW) is a traditional Home and Community Based Services waiver designed to provide long-term services and supports for community living.
- AAW does not include physician services
- ACAP is not a waiver, but rather a managed care program that does provide physician, behavioral, and community services through an integrated approach to create a coordinated system of supports.

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Slide 37

Regional Collaborations

In response to the ATF's fourth recommendation, the BAS funded the development of three Autism Services, Education, Research, and Training (ASERT) regional collaborations, promoting partnerships among the mental health, MR/ID, early intervention, education, and medical systems across the Commonwealth.

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Slide 38

ASERT

The mission of the three ASERT collaboratives is 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

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Slide 39

Needs Assessment

- ASERT Regional Centers have been conducting a state-wide needs assessment.
- Largest survey about adults with autism to date.
- First to focus comprehensively on service experiences rather than clinical presentation.
- A formal report will be forthcoming

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Slide 40

Needs Assessment: Preliminary Findings from the Adult Survey

- Co-occurring psychiatric disorders were common.
  - These co-morbidities may be driving much of the medication management so commonly reported.
  - Given the few psychiatrists – or other mental health professionals – in the Commonwealth with experience managing these conditions in adults with autism, it is pressing that a network of professionals be developed to share expertise and experience in managing these conditions and their treatment.

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Slide 41

Needs Assessment: Preliminary Findings from the Adult Survey

- A fifth of the sample was currently in some higher education setting, another fifth was not in school but wanted to be.
- A tenth of adults for whom caregivers responded and a fifth of adults responding for themselves were actively seeking employment, compared with a third who currently were employed.
  - Respondents reported using a number of different strategies to find support.
  - Reported many difficulties related to interactions with potential and current employers, co-workers and fellow students, including perceptions of discrimination.
  - Many of the challenges they faced, such as creating a resume, interviewing with potential employers, or sharing their condition with supervisors, are readily addressable through training programs and other types of support.

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Slide 42

Needs Assessment: Preliminary Findings from the Adult Survey

- Obtaining regular preventive care was not a problem for most respondents.
  - Medication management, mental health counseling and case management were commonly-received specialty services, and satisfaction was generally high with these services.
- Much less commonly received were social skills and vocational training, both of which were highly requested by respondents.
  - These findings suggest the importance of making sure that the community mental health system is aware of how to identify and address the needs of adults with autism, and the need to make other services with practical application readily available.

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Slide 43

Needs Assessment: Preliminary Findings from the Adult Survey

- Disciplinary actions in the school and police contact were relatively frequent among respondents.
  - Given that most respondents of school age most likely have behavioral goals in their individualized education plans, the use of actions such as detention, suspension and expulsion is highly suspect and deserves further investigation.
- The high proportion of police contact, coupled with the sometimes-heart rending qualitative comments describing the encounter, suggest the critical need for better first responder training regarding the needs of adults with autism.

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Slide 44

Needs Assessment: Preliminary Findings from the Adult Survey

- The survey results also suggest that raising a child with autism has significant effects on the family, including loss of wages and the need for greater support inside and outside the home.
  - Relatively few families used respite services, counseling or support groups, although these services were commonly listed as needed.
- Another critical family issue is that two thirds of families did not have a plan for how to support their child after they were no longer able to care for the child.
  - A relatively easy yet important service to develop for these families would be guardianship and estate planning.

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Slide 45

Autism Policy Conference

BAS hosted National Policy Conferences in 2007 and 2008 where 26 states were represented.

2008 Objectives:

- To review and discuss ongoing challenges and successes states face in developing and implementing policy to improve support for individuals across the lifespan with autism.
- To identify and develop innovative solutions to three key issues at state and national levels.
- To provide a starting point for states, charged with providing services, to participate in the development of a national agenda regarding autism.

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Slide 46

Policy Conference Discussion Included:

- Develop creative funding for autism services
  - Better use of existing funding
  - Creative ideas for funding supports for individuals who do not meet federal level of care
  - Creative ideas for state only funded programs
- Coordination of service provision across systems
  - Lack of cross-system training and standards
  - Coordination and collaboration of funding sources
  - Federal constraints
- Developing policy to support adult services
  - Capacity
  - Employment

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Slide 47

For Consideration

- Widespread media attention to autism issues still rarely shows the face of an adolescent or an adult.
- Life-long developmental disability where individuals live normal life spans and will continue to need significant supports as they age
- Policy makers and public administrators are already contending with a severe lack of appropriate services, trained professionals, and uniform standards.
- Fewer resources to address these systematic challenges unless considerable changes are made to prepare for their needs.

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Slide 48

Challenges Remain

- Advocating for continued program development and funding to increase capacity within existing programs to meet needs of an exponentially increasing population
- Identifying ways to support individuals with ASD who do not meet the federal guidelines for programs such as the Adult Autism Waiver and ACAP
- Collaborative efforts across state lines are needed.

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**Contact Us**

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FOR MORE DETAILS ON OUR PROGRAMS OR INITIATIVES:

- > **Visit our General Website:** [www.autisminpa.org](http://www.autisminpa.org)
- > **Visit our Training Website:** <http://bastraining.tiu11.org>
- > **Email us:** [DPW-AutismOffice@state.pa.us](mailto:DPW-AutismOffice@state.pa.us)

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