Agenda

- Autism Affairs-One year later
- Autism Affairs initiatives
- Question and answer period
Setting the stage for Autism Affairs

- 2000% increase in ASD’s
- Parents’ and caregivers’ need for services that are effective for their loved ones
- Secretary Richman created the Autism Taskforce in 2003
  - Taskforce comprised of parents, professionals, and educators
Building on the Recommendations of the Autism Task Force

- The Autism Task Force submitted its recommendations in December 2004
- Director of Autism Affairs appointed by Secretary Richman in May 2005
- The work of the past year has drawn upon the key recommendations of the Autism Task Force
Some Significant Challenges

- Epidemic? Dramatic increase in individuals with Autism Spectrum Disorder. CDC cites 1/166 births.
- Lack of basic understanding of the nature of the disorder
- Dearth of trained clinicians, support staff, educators to meet the complex and varied needs across the lifespan
- Absence of standards around diagnosis, assessment and treatment -- children and adults
- Inadequate communication and interaction across systems serving individuals with ASD
- Poor fit with behavioral health system not designed to meet the needs of individuals with ASD
- Currently no autism specific system of support for adults (without a diagnosis of mental retardation)
Challenges lead to:

- Individuals with ASD may “fall through the cracks” (receive a delayed diagnosis or may be diagnosed incorrectly, or may fall into systems where they do not belong, such as criminal justice).
- Pennsylvanians residing in underserved areas, both urban and rural, face increased isolation and heightened difficulty accessing much needed support.
- After referral, there are impossibly long waiting lists for a specialist to give a diagnosis, in some areas as long as two years.
- Services may not be provided in the most therapeutically appropriate or cost effective manner.
- Most adults with ASD are not eligible for services, often losing the functional gains made (and funded) in childhood.
Meeting the Challenges

Summary of our work to date and the goals for upcoming year
How many individuals with ASD live in Pennsylvania?

We do not know how many individuals with ASD reside in the Commonwealth. Autism Affairs is supporting an initiative to develop an estimate of the number of individuals with ASD residing in Pennsylvania. The project is supervised by Dr. David Mandell from the University of Pennsylvania’s Center for Mental Health Policy and Services Research.

This data will be synthesized, analyzed and used for planning as a system of support is developed.
Assessment of Patients in State Psychiatric Hospitals

• Norristown Pilot Project
  • Determine extent to which patients meet the criteria for ASDs
  • Implications for resources offered to these individuals and the institutions in which they reside
  • Research project to begin in January 2007
Physician Trainings

- Autism Affairs supported First Signs in their goals to “improve screening and referral practices and to lower the age at which young children are identified with autism and other developmental disorders.”
- 7 state wide trainings have been held with 650 participants, including medical and educational professionals and parents (http://www.firstsigns.org)
Diagnostic Project

- Dr. Susan Levy of Children’s Hospital of Philadelphia (CHOP) leading a team of professionals in developing a consistent, practical standard for diagnosis of ASDs
- Autism Affairs is supporting the “Train the Trainer” Model in the use of research study standard diagnostic tools, being implemented by Nancy Minshew, M.D. to develop expertise in the use of the ADOS
Collaboration with The Department of Education

- Recommendation of task force called for collaboration between PDE and DPW
- Autism Assessment Workgroup met to establish statewide Autism Assessment standards and recommend assessment tools
Collaboration with The Department of Education

• Cross systems training developed collaboratively with PDE to train behavioral health staff and educators to use evidence based intervention tools and strategies.

• October 6 Autism 101 Training Videoconference
  • Audience included family members, physicians, nurse practitioners, psychiatrists, psychologists, early childhood staff, educators, speech language pathologists, occupational therapists, principals, educational administrators, county caseworkers, behavioral health staff, social workers, guidance counselors, bus drivers, first responders, representatives from the justice system, legislators and policy makers
  • PaTTAN Pittsburgh Distance Learning Center 1-800-446-5607 for copies
Collaboration with The Department of Education

- Autism Affairs co-sponsored with PDE the Summer Institute-National Autism Conference in State College, PA. (July 31, 2006- August 3, 2006)
  - 200 training scholarships awarded to front-line behavioral health professionals (TSS, BSC, Mobile Therapists and Case Management staff) to fund participation at the week long training with nationally recognized experts in the field of Autism Spectrum Disorders.
Collaboration with The Department of Education

- **Summer Institute-National Autism Conference continued**
  - Autism Affairs sponsored a parent panel and self-advocate panel discussion
  - Autism Affairs hosted a family picnic for 265 parent participants and their family members
  - Autism Affairs hosted 2 sessions with Dennis Debbault, a nationally known expert on safety with law enforcement and other first responders
  - Autism Affairs hosted a resource table and solicited materials for organizations to share with parents.
DPW Internal Trainings

- Collaboration with OMAP, OMHSAS, OMR, OCYF, and OCD
- Trainings for Behavioral Health Managements Companies on ASDs
  - CCBH in York, Adams, Berks, Pittsburgh area, and Capital Region counties to date
  - Magellan in Bucks, Montgomery, and Delaware counties
Autism Pilots

Recognizing and Rewarding Good Practice in Meeting the Needs of Individuals with ASD
Promising Models - Six Grants Awarded

- Autism Affairs issued an RFP with a focus on “Innovative Models of Service Delivery to Children and Adolescents with ASD”
- The effort targeted models that offered innovative approaches, were outcome driven, emphasized training and staff development, offered a focus on family support and strategies for sustainability.
Grants Awarded

**Eastern PA:** Special People in the Northeast; The Center for Autistic Children

**Central PA:** Philhaven; Keystone Family Services

**Western PA:** The Watson Institute; Western Psychiatric Institute
RFP Issued for a Model of Rural Service Delivery

- Autism Affairs issued an RFP focused on the development of a model of service delivery to address the needs of individuals with autism in rural areas of the Commonwealth. The successful application will pilot a model that can be replicated in other rural areas.
- Nine proposals were received. Grants awarded to Gertrude Barber Center and a collaborative partnership between DRMC, WPIC and ABOARD.
RFP to Address the Training Needs of Adult Service Providers

There are very few providers who are prepared to meet the unique need of adults with ASD across settings (home, work, community).

Training modules and regional training teams model under development
Resource Enhancement in economically disadvantaged communities

- The average age of diagnosis for children residing in urban centers is 6-7 years old (if they are “fortunate” to receive a diagnosis—many are not appropriately diagnosed)

- Autism Affairs will support a model to address the needs of this target population so that children receive referrals to critical early intervention services.
Informational Materials

- Families report difficulties accessing information regarding ASD and how to access services and supports for a family member.
- Autism Affairs is developing web-based and hard copy materials which will be made available to families statewide.
- *Autism Affairs will develop regionally specific materials that describe resources and services available to families*
Juvenile and Criminal Justice

- Due to the lack of training and information with respect to the needs of individuals with ASD, many of our sons and daughters are falling into the juvenile and criminal justice systems.
- Autism Affairs will initiate a cross systems initiative to address this emerging problem and to craft broad system wide training to avoid what is a tragic and preventable outcome for many.
- This is an issue taking on national significance and urgency.
Development of a Transition Model for Young Adults with ASD

- Collaboration with the Pennsylvania Department of Education and the Department of Labor and Industry
- We will offer support for the development of a model of transition to work and community living for young adults with Autism Spectrum Disorder
Development of Funding to Support Adults with Autism Spectrum Disorders

- ALAW OBRA Waiver Autism Pilot
  - For individuals with an ASD but absent a diagnosis of MR
  - 24 currently being served
  - Begin serving additional people in different regions through OBRA waiver by January 2007
- Prepaid Inpatient Health Plan (PIHP) Option
- Autism specific waiver
Where Do We Go From Here?

- Training initiatives continue as we develop statewide standards and partnerships
- Strong models of service delivery and training will be replicated
- Adult assessment standards and tools need to be developed
- An adult service/support model will be developed as we look towards a “home” on the organizational chart for Pennsylvanians with ASD
- We will work on the development of adult services for those who do not meet current eligibility.
Autism finds a “Home“ in the System

• We will substantively and operationally redefine behavioral health services for children and adolescents with ASD.
• We will continue to support the needs of individuals with autism and their families across the Commonwealth.
• We will continue to develop partnerships with colleagues in other states as we tackle the national challenge of meeting the needs of this exponentially increasing population.
A Blueprint for Change

- Pennsylvania is one of the first states to house a team dedicated to addressing the needs of children and adults with autism.
- Pennsylvania has a vibrant and well organized parent advocacy community.
- Autism Affairs maintains ongoing interaction with the parent advocacy community.
Looking for quality—Standards and Outcomes

• Autism Affairs, when reviewing program exceptions, is looking for providers to include outcome measures.
• Any ASD focused program description seeking BHRS funding needs to include measures to prove efficacy with a means of data collection for individual children.
• Standardized measures and research-based interventions are needed for programs.
• Our team is open to dialoguing with counties/providers as program models are developed. The process is transparent and we want to encourage proactive, meaningful interaction around program development initiatives.
• Autism Affairs is meets regularly with OMHSAS, OMAP, OMR, OSP and PDE to establish mechanisms to ensure quality and streamline systems.
For Counties

- We are developing relationships with local, regional offices to offer support and technical assistance to administrators and providers across the commonwealth.
- We are open to feedback and information about county struggles.
Program Review Process

• Program descriptions should be directed to:

  Claire Maher Choutka, M.Ed, BCBA
  Clinical Coordinator, Autism Affairs
  Health and Welfare Building, 3rd Floor
  7th and Forster Streets, Harrisburg, 17120

  C-choutka@state.pa.us

• Programs are reviewed and comments/feedback forwarded to provider. Technical assistance is available to resolve proposal issues.
Program Evaluation Template

Autism Affairs Program Evaluation Review
1. Name of Program ____________________
   Provider ____________________________
   Goals of program or mission –
2. Eligible children/adolescents—
   Inclusion Criteria-
   Assessments used
      Standardized/research based
      Program created
      Match of assessment to program
      Other entry criteria-
      Referrals allowed by whom and how?
3. Staff training for this program and specific to ASD?
4. Staff supervision? Problem solving?
5. Program content
   Age appropriateness of program
   Match to skill deficits
   Time frame of programming appropriate to treatment goals
   Research basis
Autism Affairs

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