



Pennsylvania Autism Needs Assessment Reports: SERVICE NEEDS, BARRIERS & UNWANTED OUTCOMES

We recently announced the publication of eight *Pennsylvania Autism Needs Assessment* reports. In this issue of our newsletter we have highlighted the findings of three of the reports: *Service Needs; Barriers & Limitations to Accessing Services;* and *Unwanted Outcomes: Police Contact & Emergency Hospital Care.*

These reports resulted from an in-depth assessment of the extent to which current public systems are meeting the service needs of indi-

viduals with autism and their families. These three reports look at whether Pennsylvanians living with autism are getting the services they need, identify barriers to accessing services, and examine what happens when appropriate services are not available. All too often, the consequences of non-existent or inadequate services are emergency room visits, inpatient psychiatric hospital care, or police contact. The findings from these reports underscore the need to find ways to increase the availability

of all types of services for individuals with autism and their families. Easing access to these necessary services could help avoid traumatic and costly outcomes. The information collected from the survey is intended as a road-map for policymakers, service providers, community organizations, and advocacy groups, to guide the development and implementation of effective services and the efficient use of resources.



Reports Discussed in This Issue

- | No. | Title |
|-----|--|
| 2. | Service Needs |
| 3. | Barriers & Limitations to Accessing Services |
| 4. | Unwanted Outcomes: Police Contact & Emergency Hospital Care |

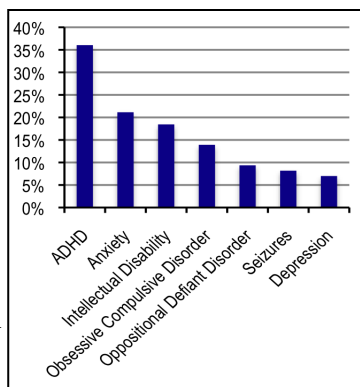
A complete overview of the study can be found in our October Newsletter. Visit <http://bastraining.tiu11.org>



Co-occurring Disorders: Increased Need

Individuals with autism need a range of services to live as independently as possible, participate in their communities and enrich their quality of life. When these individuals have additional, co-occurring disorders, such as physical health problems, intellectual disabilities, or anxiety, their needs increase dramatically.

Approximately **85 % of individuals with autism have a co-occurring disorder**, complicating the amount and type of services they need. It is a challenge to identify physical and mental health professionals to deliver effective services due of lack of training and difficulties with access, reimbursement or funding.



Individuals with autism frequently have one or more co-occurring disorders.

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Types of Services

- ◆ Mental & Emotional Health Services
- ◆ Behavior Support Services
- ◆ Physical Health & Functional Therapy Services
- ◆ Social Skills Training
- ◆ Summer Services
- ◆ Sexual Health Education
- ◆ Primary Care
- ◆ Dental Care

Why Look at Service Needs?



The report on service needs looks at whether Pennsylvanians living with autism are getting the services they need, identifies barriers to accessing services, and examines if the families of individuals with autism consider the services they do receive to be effective. Services that are

examined include Mental & Emotional Health Services, Physical Health Services, Behavioral Health and Transition Services, among others.

Unmet Needs

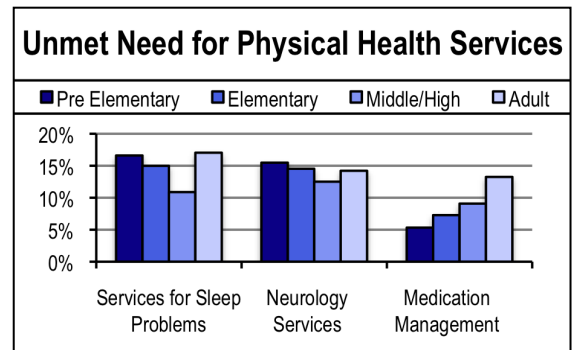
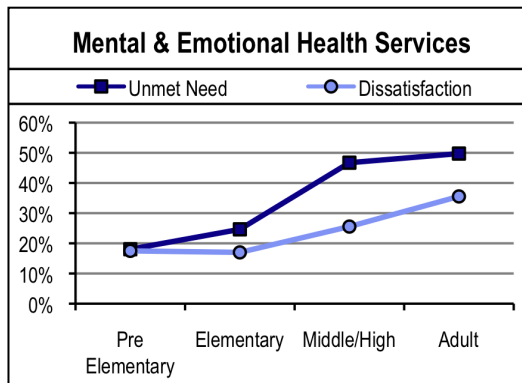
An unmet need for services occurs when an individual needs but does not receive a service, or when an individual needs more of a service than he/she currently receives. Understanding which services individuals with autism and their families need is important in guiding changes to policy and practice.

Dissatisfaction

Individuals with autism from every age group report that their needs for mental and emotional health services are not being met and that they are dissatisfied with many of the services they receive.

Reviewing and understanding individuals' and families' satisfaction with services they receive will inform efforts to improve quality of services.

UNMET NEEDS



From the playground to the office water cooler, social skills are a critical factor to success.



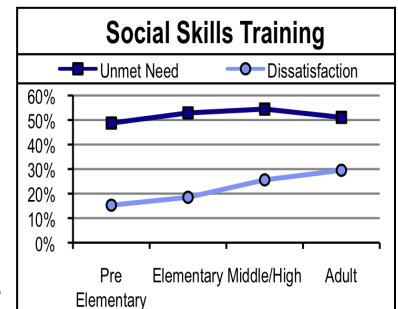
Social Skills Training: Most Commonly Reported Unmet Need



Social skills training has been identified as the

most commonly reported unmet need for both children and adults. This finding is consistent with the questions and training requests we receive as a Bureau from families, self-advocates and professionals.

The need for social skills training is critical because it is an area that impacts so many aspects of an individual's life.



Barriers to Accessing Services

There are multiple barriers to accessing services that individuals with autism and their families face every day. Identifying and describing these barriers is a critical step to take in order to improve the systems that serve the autism community.

Barriers to accessing services include:

- ♦ a lack of or shortage of providers
- ♦ inadequate transportation
- ♦ behavioral issues
- ♦ cost or lack of insurance

Caregivers struggle to find providers who understand autism and have the training required to address the needs of an individual with autism.

Finding service providers is more difficult as individuals with autism age. Caregivers of adults find it especially difficult to find knowledgeable, skilled providers.

Finding transportation is often a challenge. It was reported as a barrier by twice as many caregivers of adults as compared to caregivers of younger children.



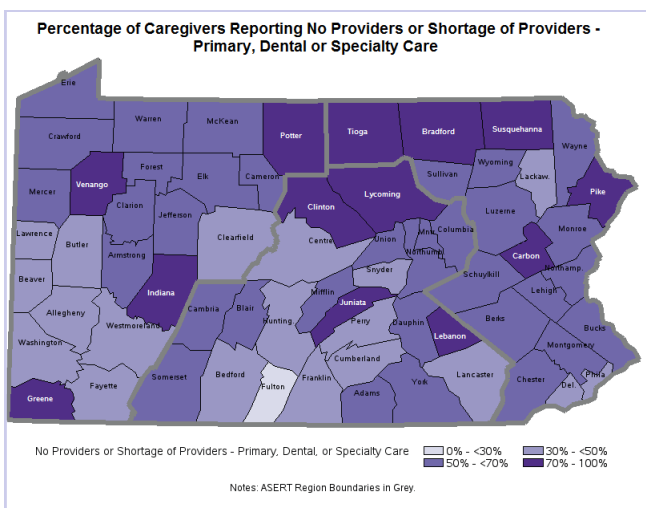
Adults who respond for themselves most often report that transportation is a barrier to accessing services. Even where it is available, public transportation may not be an option for individuals with autism and their families.

Another serious problem is that many providers of primary care do not have the experience or expertise to serve individuals with autism, who may present behavioral challenges.

Finally, the cost of care and issues with insurance coverage can be huge barriers to accessing services.



“Caregivers in rural areas more often report a lack of providers for specific services.”



Recommendations: Barriers to Services

Train and provide ongoing support for providers to meet the needs of individuals with autism.

Individuals with autism need regular preventive care. They also require, more than others, services through the mental health care system. This survey shows that these services

are not available because primary, dental and mental health care systems have difficulty addressing the challenging behaviors that may accompany autism. Providers need **autism specific training** that fits within current continuing education models. Providers who serve more rural areas should receive

training through consultation, telemedicine and distance learning.

Increase access to all types of services for adults with autism.

As individuals age out of existing services for children, including those provided by the school system, the avail-

ability of services diminishes greatly. Adults with autism and their families are desperate to find services and supports to meet their changing needs. As service providers expand their programs to include adults with autism, they should consult with experienced professionals who can assist in their efforts.

Unwanted Outcomes: Police Contact & Urgent Hospital Care

The most common reasons for hospital admission across all age groups are:

- ◆ Aggression and/or defiant/oppositional behaviors (74%)
- ◆ Self-injury (41%)
- ◆ Anxiety and depression (36%)



Both the untreated or undertreated symptoms of autism and co-occurring disorders can result in unwanted outcomes including police contact, emergency room visits, and inpatient psychiatric hospital care.

These experiences are traumatic and costly for individuals with autism and their families, and could be pre-

vented or addressed more effectively and cost-efficiently through community-based services.

The report on unwanted outcomes looks at how often individuals with autism have contact with police and use emergency hospital-based care.

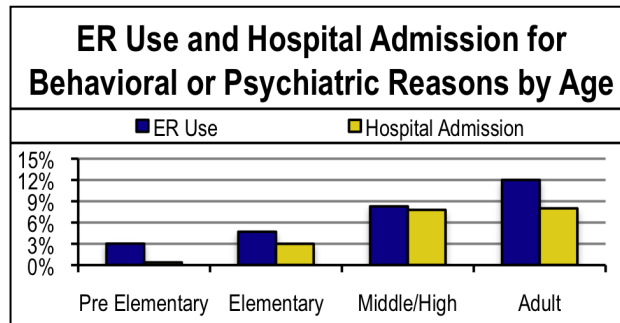
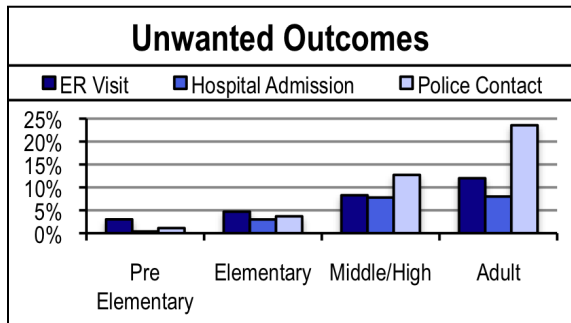
Police contact includes calls to the police, warnings issued by police, being charged and/or sentenced, and time spent in jail or a juvenile detention facility.

One in ten individuals with autism in Pennsylvania report past police contact.

As individuals with autism age, they are increasingly likely to have police contact. Almost 25% of adults with autism report police contact, as opposed to less than 8% of all other age groups.

Hospital-based care consists of emergency room (ER) visits and admission to a hospital for behavioral or psychiatric reasons.

Out of all age groups, adults with autism report the most ER visits and hospitalizations for behavioral or psychiatric reasons.



Recommendations: Unwanted Outcomes

Implement statewide first responder training for law enforcement and other first responders.

Police contact is traumatic for both the individual with autism and the family. In order to decrease unwanted outcomes, law enforcement personnel need tools and training to prepare them to effectively interact with

individuals with autism who are in crisis.

Prevent hospital-based care by connecting individuals with autism and their families to community-based services, and develop services where they are lacking.

Hospital-based care is one of the most distressing and expensive ways to deal with behav-

ioral crises resulting from untreated behavior issues or co-occurring disorders, both for families and the Commonwealth. For most individuals, emergency room use and hospitalizations may be avoided with access to appropriate community services.

Ensure better access to quality care for individuals with autism who

are hospitalized for behavioral or psychiatric reasons.

Aggression and self-injurious behavior are the two primary causes for adults with autism to be hospitalized for behavioral or psychiatric reasons. Strategies used to treat those behaviors in other individuals are often ineffective for people with autism, and in some cases even increase their level of distress.



The main focus of the ASERTs is to respond to the information gathered from the PA Autism Needs Assessment.

The Critical Role of the ASERTs

The ASERT (Autism Services, Education, Resources, and Training) collaboratives are a key component of our strategy for supporting individuals with autism and their families throughout the Commonwealth.

Each ASERT collaborative is a partnership of medical centers, centers of autism research and services, universities and other providers of services involved in the treatment and care of adults and children with autism. The ASERTs have been designed to bring together resources locally, regionally, and statewide.

Each ASERT collaborative is charged with addressing the needs of their entire region, including the needs of the most rural regions of the state

and the most under-served populations.

Families and individuals living with autism often find themselves isolated in general. Geographic or cultural conditions can further compound a sense of isolation. For example, according to the United States Census Bureau, 48 of Pennsylvania's 67 counties are considered to be rural. Many rural families do not have access to information or quality services and supports that would help them in meeting their needs or the needs of their family member living with autism.

It is our vision that the ASERTs will connect existing resources and pockets of expertise, and address the regional gaps in effective services and supports.

Coming in 2012!

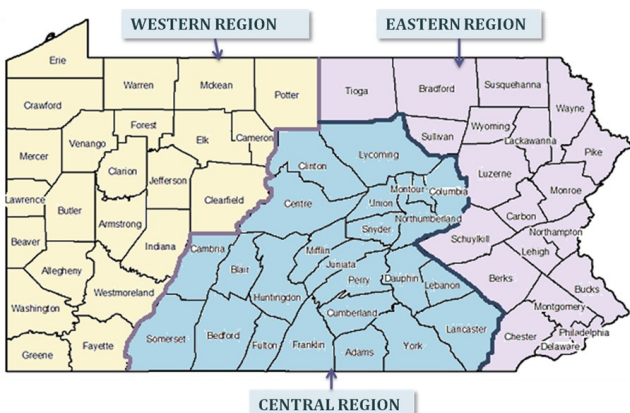
A new statewide ASERT website & Toll-Free Number:

Streamlining resources and making it easier to find the information you need.

The ASERT 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



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BAS Adult Programs

The Bureau of Autism Services administers two programs for adults with autism, the Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP). These two programs are designed to help adults with autism live in their communities the way they want to, based on their identified needs.

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

1-866-539-7689

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

Both programs will be serving their maximum number of participants by the end of December 2011, 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. This will be based on the date and time individuals first called the toll

-free number to request an application for that program.

If you think you may be eligible, or know someone who might be, you are strongly encouraged to request an application by calling the toll-free number.

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. Please note you must leave two separate messages, one in each program's voicemail box, if you are interested in requesting an application for both programs.

SAVE THE DATE!

5th Annual PA Autism Training Conference (PATC)
June 12-14, 2012
Lancaster, PA



Featuring critical topics identified in the Needs Assessment reports, such as adult diagnosis, anxiety/depression, employment, and supporting siblings.

BAS Virtual Training & Resource Center (VTC)



Don't forget to visit the recently updated BAS Virtual Training & Resource Center (VTC).

This free, comprehensive online resource center has been designed to enable professionals and families to easily access trainings, documents, and other resources in one convenient location.

<http://bastraining.ti11.org>

A number of the available resources address the needs identified through the Pennsylvania autism survey.

Here are a few highlights:

ABOUT US

History, Mission & Values

Updates: Presentations & Newsletters:

- ↳ Needs Assessment Webcast
- ↳ October 2011 Newsletter

AUTISM IN PA:

Resources & Reports

- ↳ PA Autism Needs Assessment Reports

ADULT AUTISM WAIVER PROVIDER TRAINING AND INFORMATION

TRAININGS:

NON-AAW TRAININGS

PA Autism Training Conference (PATC) Recorded Presentations:

- ↳ Dual Diagnosis & Co-occurring Disorders (2008/2009)
- ↳ Multi-System Kids with Complex Needs (2008)
- Community & Professional Training Videos:
 - ↳ First Responders Training
 - ↳ Community Inclusion for Adults with Autism
 - ↳ AUTISM 101: Adult focus
 - ↳ Community DVD series



Wishing Everyone
Health & Happiness
this Holiday Season