



pennsylvania

DEPARTMENT OF PUBLIC WELFARE

Pennsylvania Autism Needs Assessment

A Survey of Individuals and Families
Living with Autism

Report Recommendations

Pennsylvania Department of Public Welfare

Bureau of Autism Services

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Needs Assessment Report Recommendations: Overview

The Bureau of Autism Services, in its effort to improve care and quality of life for Pennsylvanians with autism and their families, conducted the **PA Autism Needs Assessment**. This effort has been a key task of the ASERT (Autism Services, Education, Resources and Training) Collaborative and has been led by University of Pennsylvania School of Medicine, Center for Mental Health Policy and Services Research and the Center for Autism Research at The Children’s Hospital of Philadelphia.

Autism Spectrum Disorders (ASD), referred to as autism throughout these reports, include Autistic Disorder, PDD-NOS, Asperger’s Disorder, Childhood Disintegrative Disorder and Rett’s Disorder. With more than **3,500** responses, the survey is the largest of its type to date in the nation. The findings from this needs assessment highlight challenges that Pennsylvanians with autism, of all ages, face everyday.

This overview provides a summary of the recommendations that emerged from each of six reports. Report #1, the **Statewide Summary**, is an overview of the Needs Assessment findings from each of the topic reports listed below. The Statewide Summary does not include separate recommendations, and is therefore not included in this compilation report.

The reports represented in this summary are as follows:

- #2. Service Needs**
- #3. Barriers and Limitations to Accessing Services**
- #4. Unwanted Outcomes: Police Contact and Emergency Hospital Care**
- #5. Getting a Diagnosis and Follow-Up Care**
- #6. Employment Challenges**
- #7. Family Impact**



For further information, please visit the ASERT website www.paautism.org/asert or contact your regional ASERT Collaborative:

- ◆ Eastern Region: 1-877-408-0154
- ◆ Western Region: 412-235-5484
- ◆ Central Region: 1-877-231-4244

We encourage you to review the complete series of reports, and data by geographic region for each topic: **Statewide Summary, Service Needs, Barriers to Accessing Services, Unwanted Outcomes, Diagnosis, Employment Challenges, and Family Impact.**

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Report #2: Service Needs

Individuals with autism and their families need a range of services to live as independently as possible, participate in their communities and enrich their quality of life. This report 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. Pennsylvanians with autism and their families are struggling to find the services they need and are often dissatisfied with the services that are provided. These challenges increase as individuals grow into adulthood.

1. Increase the availability of all types of autism services to support individuals with autism.

Individuals with autism have an ongoing need for services to address the core deficits of autism and any co-occurring disabilities. They also need services that support participation in their communities. However, many individuals with autism and their families are struggling to find services and coordinate care. Consistently across age groups, around 1 in 3 caregivers report needing more services. Of particular concern is the high unmet need for social skills instruction, sexual health education and summer services. These services are often not available, nor are they funded through traditional service systems. By creating incentives, more providers could be encouraged to offer these services.

2. 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 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.

3. 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 availability 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. The experience that providers within the Adult Autism Waiver and the Adult Community Autism Program (ACAP) are gaining should inform best practices in all systems where adults with autism are being served.

4. Increase satisfaction with services by implementing best practices.

Among those who are receiving services, a large proportion are dissatisfied. Training and consultation on best practices will enhance the quality and effectiveness of services individuals with autism receive. Reimbursement for these services should require the use of best practices when available and measure improved outcomes and satisfaction.

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Report #3: Barriers and Limitations to Accessing Services

Individuals with autism and their families face multiple barriers to accessing services. Identifying and describing these barriers are critical steps in improving the systems that serve individuals with autism and their families. This report describes the barriers to accessing services for primary care, dental care, specialty health and education services, and family support services for individuals with autism and their families.

1. Increase the capacity of the Bureau of Autism Services adult programs to serve additional participants.

The number of adult Pennsylvanians with autism is growing rapidly. Between 2010 and 2015, the number will increase by 265%, resulting in **over 10,000 adults with autism**.^{*} There are currently insufficient resources to meet the needs of adults with autism (*Report #2, Service Needs*) and the extent of the problem will only multiply as more and more children transition to adulthood. Without additional capacity in the BAS programs, a crisis situation will develop. ^{*}See the *PA Autism Census Report*: www.paautism.org

2. Develop innovative models and solutions to address barriers and increase access to services.

Individuals with autism have complex needs that cannot be met by only one program or service delivery system. It is important to find new ways to connect people with autism to the services and supports that meet their diverse needs. Solutions need to be cost effective and make use of existing resources. As creative solutions are explored, there must also be a way to measure and evaluate their effectiveness. Both public and private sectors must be involved in finding ways to combine efforts to address the growing challenges.

3. Increase the number of service providers for individuals with autism and their families across Pennsylvania, particularly in rural areas.

A lack of local providers is the most frequently reported barrier to services across all age groups and all types of services. Developing incentives for providers to either practice in rural areas, or to use technology such as telemedicine, could increase access for individuals who otherwise would not receive care.

4. Increase the availability of transportation to care.

Caregivers of adults with autism reported difficulty accessing services due to a lack of transportation. Creating transportation options for individuals with autism and their families could help them get to the care they need. This may also require changes in billing options, so that providers can be compensated for transportation.

5. Increase awareness of insurance coverage for autism services.

Individuals with autism and their families struggle to pay for needed services. Many individuals with autism are Medicaid eligible, although not all are Medicaid enrolled. Educational campaigns are needed to make families aware of available resources such as Medicaid that can defray the costs of care. The recently-passed autism insurance mandate may increase coverage for autism services, but careful monitoring is needed to determine whether insurance companies are implementing the mandates as designed.

6. Train service providers to address behaviors that may accompany autism.

Caregivers of individuals with autism report that behavior issues can be a barrier to receiving care. Service providers, especially of general services like primary care and dentistry, require hands-on training and ongoing support to address these problems in their practice. An enhanced reimbursement rate for caring for children and adults with significant behavioral challenges could create incentives for primary care practitioners to provide care to this underserved population.

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Report #4: Unwanted Outcomes—Police Contact & Urgent Hospital Care

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 prevented or addressed more effectively and cost-efficiently through community-based services. This report looks at the contact that individuals with autism have with police, and their use of emergency hospital-based care.

1. 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.

2. 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 behavioral 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.

3. 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. Consultation with regional care professionals could increase the effectiveness of psychiatric management. Another option would be to create autism-specific units within the hospital. The dissatisfaction with the treatment planning process suggests the need for training of hospital staff members to ensure that individuals and their families feel valued and included from intake to discharge.

4. Link hospitals into community-based systems of care.

Too often, families are responsible for the transition from hospital care to community care. Hospital staff may not be trained to help families of individuals with autism implement treatment plans at home and in the community. In order to address the dissatisfaction with discharge planning, hospitals should take an active and leading role in preparing for successful transition. They should also be more closely linked with community providers. This link should include appointment scheduling and sharing of information that will allow the community provider to successfully address the challenges that led to hospitalization in the first place. In addition, hospital-based treatment plans should include training for family members so that they can effectively implement behavioral strategies at home.

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Report #5: Getting an Autism Diagnosis and Follow-up Care

Community awareness of autism has increased exponentially in the last two decades. As a result, caregivers notice developmental delays earlier and professionals diagnose autism in children at a younger age. Even so, autism diagnosis and follow-up care is often a long and difficult process. Receiving a diagnosis and services earlier in life results in better outcomes. This report addresses the process of getting an autism diagnosis and follow-up care in Pennsylvania.

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

Accurately diagnosing children and adults with autism is a highly specialized skill. Much of the delay in diagnosing individuals with autism is due to the lack of geographically accessible, qualified professionals with this specialized skill set. Diagnosing an individual with autism also requires more time and interaction between professionals from different backgrounds and areas of expertise than a typical doctor's office visit allows.

Targeted autism-specific training, combined with ongoing consultation with experienced professionals, is needed in order to increase the capacity for accurate and timely diagnosis. In order to decrease wait and travel time, priority should be placed on providing resources and training to practitioners supporting rural and other underserved areas. Developing incentives and a means for multiple practitioners to coordinate assessment is also important to ensure an accurate diagnosis.

2. Develop regional databases of services and supports that families can use to learn about places to obtain accurate diagnosis, and that families and clinicians can use to refer to and access appropriate follow-up services.

Families and individuals need support after receiving an autism diagnosis. They need to be easily connected to available, reputable, and effective services, specialists, support groups and information to guide care. Services often are fragmented, however, and there often is little information available about where and how to access these services. Regularly-maintained databases that provide this information should be developed. This information should be available on-line and also in print form in doctors' offices, libraries and other high-traffic areas.

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Report #6: Employment Challenges

Finding and maintaining employment is a critical component of improving quality of life. Although many individuals with autism are fully capable of working, most are unemployed or underemployed because the necessary support services are not available to help them find and keep jobs. This report looks at employment status, the barriers to finding and keeping employment, and the use of employment services.

1. Develop accessible employment services that address the specific challenges faced by adults with autism in the workplace.

Adults with autism often have highly specialized skills, can be especially focused in their work life, and can be highly reliable and valued employees. The challenges they face are often in the domains of social interactions with supervisors, colleagues and customers. Effective vocational services for adults with autism would address these challenges and help them find appropriate employment sites, create resumes, perform well during the interview process, and maintain success once employment is secured.

2. Support individuals with autism in the workplace so they can maintain employment.

Individuals with autism may continue to need support in order to maintain employment. On-the-job supports for adults with autism can help bridge the social and communication challenges that affect workplace performance.

3. Create opportunities for dialogue with potential employers about the benefits of hiring individuals with autism.

It is important to gain an understanding of the needs of potential employers, and how to educate those employers on the benefits of hiring individuals with autism. These benefits include decreased hiring and training costs, as well as increased retention, productivity, efficiency, and above average adherence to safety procedures and attendance. Internships and alternative work arrangements, such as telecommuting, could be other useful mechanisms to help individuals with autism gain and maintain employment

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Report #7: Family Impact

Both individuals with autism and their family members need support across the lifespan. Families living with autism face many challenges coordinating services, identifying trained service providers, paying for services, maintaining employment and finding supports for their family. Caring for an individual with autism takes a significant economic and emotional toll on families. This report examines the challenges that families face in caring for an individual with autism.

1. Connect families to each other by expanding the availability of support groups.

Families caring for an individual with autism can provide emotional and informational support for other families living with autism. This support can be critical when a diagnosis is first received, and at different transition points throughout the lifespan. Accessible support groups would facilitate interactions between families who have similar experiences acquiring services and providing care for their family member with autism.

2. Develop resources to connect families to support services.

Resources need to be developed to address the existing barriers that make it difficult for families and individuals with autism to access support services. These resources should include information and guidance about how to locate and pay for services such as family mental health counseling.

Creating a cohesive, comprehensive database of family support service providers, both regionally and state-wide, is an example of a resource that could help families learn about available services to help them meet their individual needs.

3. Increase availability and affordability of care services.

Services like respite care can enhance family well-being, help caregivers maintain employment and increase the likelihood that family members with autism will remain in their communities. Partnering with providers to develop autism-specific respite programs within existing care service systems would increase the number of available care providers. Expanding the number and type of providers eligible for reimbursement for providing care services and increasing care service reimbursement rates would further create incentives for the care services families living with autism need.