



**pennsylvania**

DEPARTMENT OF PUBLIC WELFARE

# **Pennsylvania Autism Needs Assessment**

A Survey of Individuals and Families  
Living with Autism

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

**Pennsylvania Department of Public Welfare**

**Bureau of Autism Services**

# Pennsylvania Autism Needs Assessment:

## A Survey of Individuals and Families Living with Autism

### About the Autism Needs Assessment

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.

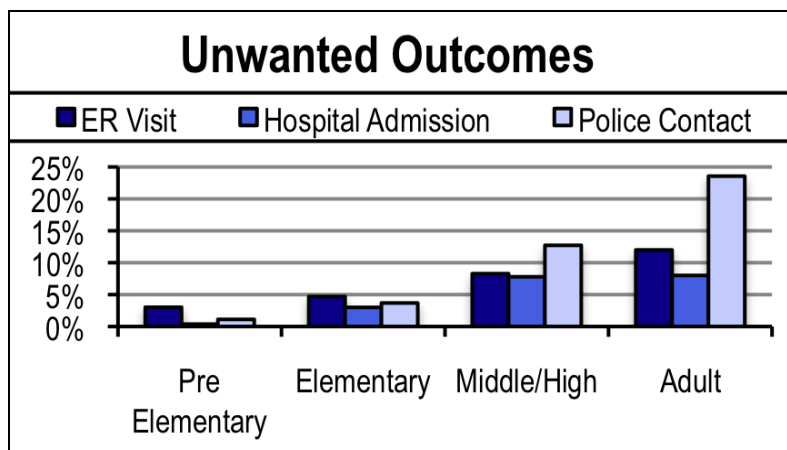
Autism Spectrum Disorders (ASD), referred to as autism throughout these reports, include Autistic Disorder, PDD-NOS, Asperger’s Disorder, Childhood Disintegrative Disorder and Rett’s Disorder. With more than **3,500** responses, the survey is the largest of its type to date in the nation. The findings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

*This report is the **fourth** in a series. The recommendations in this report address **unwanted outcomes** among Pennsylvanians living with autism.*

### Why Look at 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 how often individuals with autism have contact with police and use emergency hospital-based care. The report concludes with specific recommendations to address the unwanted outcomes that Pennsylvanians living with autism and their families face across the lifespan.

Please note that caregivers of adults completed the survey for their adult child and adults completed the survey for themselves. For the purposes of the reports, these responses are grouped together. Please visit [www.paautism.org/asert](http://www.paautism.org/asert) to view responses from each group.



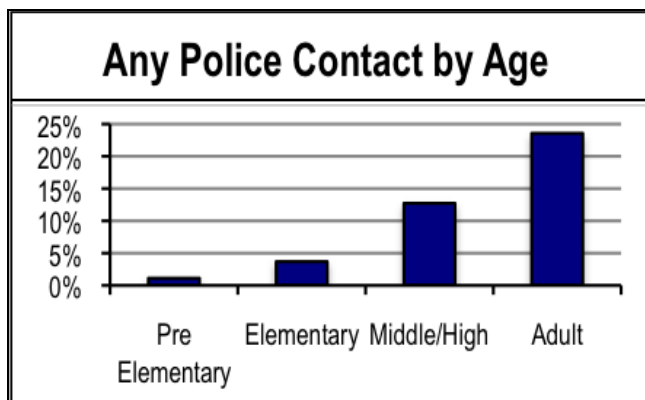
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#### Police Contact

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. 1 in 10 individuals with autism in Pennsylvania report past police contact.

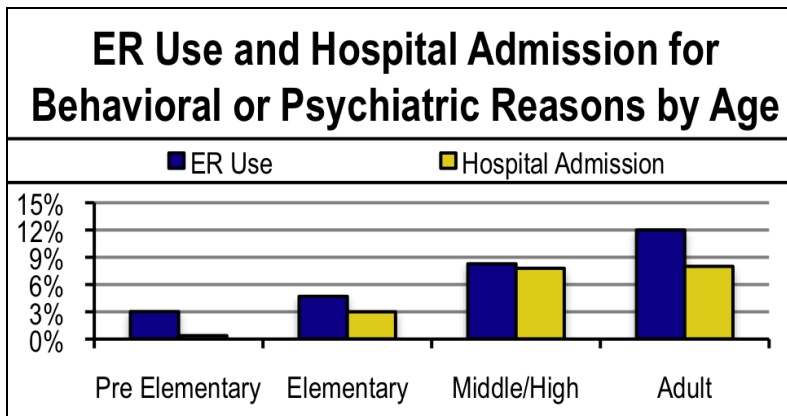
- ◆ As individuals with autism age, they are increasingly likely to have police contact. Almost 25% of adults with autism report police contact, as opposed to less than 8% of all other age groups.
- ◆ In most cases, contact involved a call to police, with 1% of individuals with autism serving jail time.
- ◆ Half of individuals who had police contact also report being hospitalized at some point.



#### Emergency and Inpatient Hospital-Based Care

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.

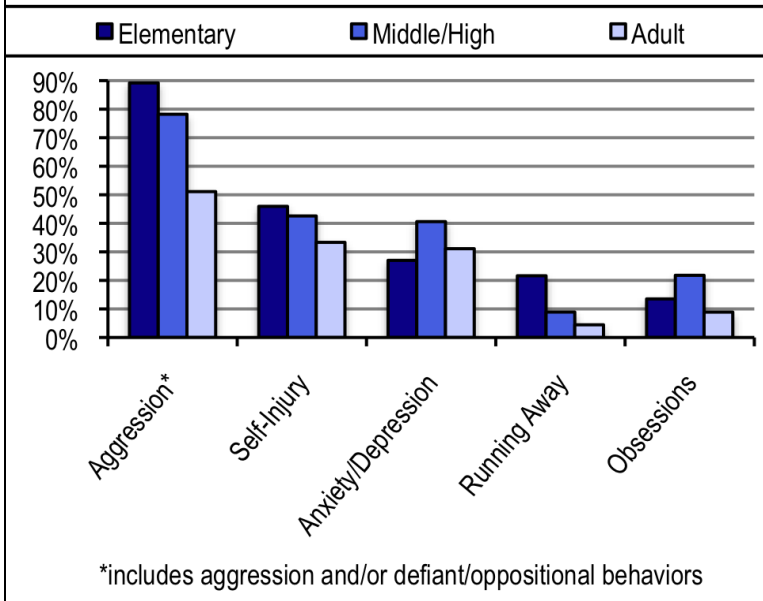


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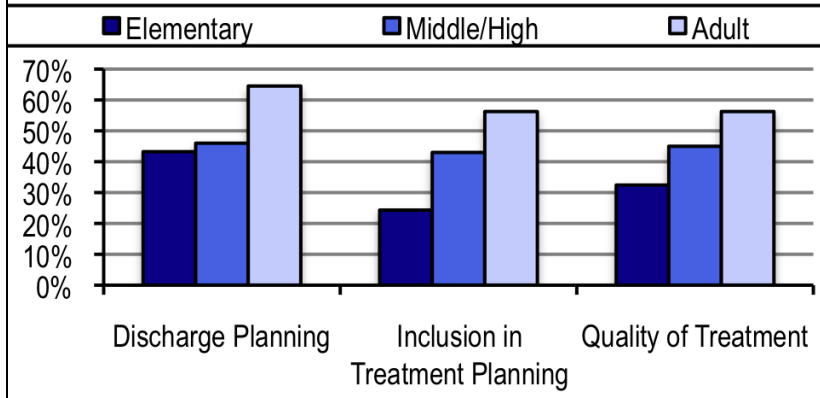
#### Emergency and Inpatient Hospital-Based Care

##### Reasons for Hospital Admission



- ◆ 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%)
- ◆ Dissatisfaction with hospital care increases with age.
  - Over half of caregivers of adults report dissatisfaction with discharge planning, inclusion in treatment planning, and quality of treatment.
  - Caregivers in all age groups report the most dissatisfaction with discharge planning (43% to 65%).

##### Dissatisfaction With Hospital Care



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### Recommendations

#### 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.



For Unwanted Outcomes data findings, please visit the ASERT website [www.paautism.org/asert](http://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 Snapshot, Service Needs, Barriers to Accessing Services, Unwanted Outcomes, Diagnosis, Employment Challenges, and Family Impact.*