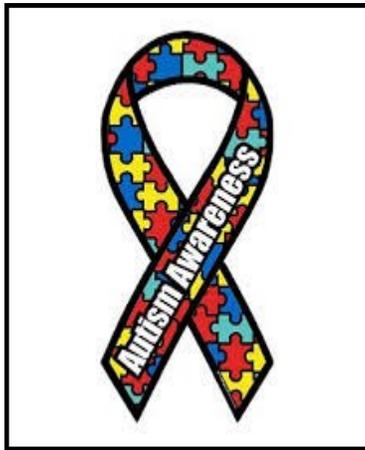


# Patient Safety Tips

Produced by the Patient Safety Authority



## Autism Patients and Families: What You Should Know

As the number of Pennsylvanians diagnosed with autism spectrum disorder (ASD) continues to grow, healthcare facilities are seeing an increase in the number of these individuals seeking care. Negative interactions with the healthcare system and concerns about the quality of care provided to this population have been reported by individuals with ASD, their families and healthcare providers. The Pennsylvania Patient Safety Authority received 138 event reports involving patients with ASD from July 2004 through August 2014. Thirteen of the events were Serious Events and caused harm to the patient. Analysis of event report narratives revealed 12 patient safety concern themes involving patients with ASD. Know what you can do as an ASD patient or family member to improve care while using the healthcare system.

## Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a complex, lifelong neurodevelopmental condition characterized by impairments in communication and social interaction and restricted, repetitive patterns of behavior, interests or activities. Autism symptoms range from mild to severe and vary over time or in response to changes in situations.

## ASD Event Reports

### Age

The majority of the 138 events were reported for patients under the age of 20 (60.9%, n=84), with most of these events reported for patients under age 10 (n=52).

### Facility Type

Although acute care and children's hospitals reported the majority of events (82.6%, n=114), events have been reported for individuals with ASD at each facility type.

### Serious Events (Harm to the Patient)

Though the number of reports involving ASD patients may be small (138), 13 (9.4%) were labeled Serious Events. To compare, in 2013, Serious Events represented only 3.1% of all events (246,606) reported to the Authority.

## Twelve Commonly Reported Safety Concerns with ASD Patients

- Injury or potential injury to self (75, 54.4%)
- Interference or lack of cooperation with care (30, 21.7%)
- Aggressive behavior and/or injury to others (21, 15.2%)
- Chemical restraint and/or sedation used (21, 15.2%)
- Patient communication issues (16, 11.6%)

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## Twelve Commonly Reported Safety Concerns with ASD Patients Cont.’

- Caregiver communication difficulties and/or consent issues (12, 8.7%)
- Mechanical and/or physical restraints used (12, 8.7%)
- Patient did not receive care and/or caregiver signed patient out against medical advice (11, 8%)
- Other medical condition contributed to poor outcome (8, 5.8%)
- Delays in care caused increased agitation (7, 5.1%)
- Staff not prepared to care for special needs (5, 3.6%)
- Other challenging and/or impulsive behavior without injury (4, 2.9%)

### What You Can Do:

- According to ASD experts interviewed by the Authority, a parent, a group home manager or caregiver should have prepared some basic information about the person with ASD—what their issues are, what their medical problems are, as well as some other tips about what to avoid, or how to approach them.
- Keep in mind the challenges healthcare providers have in the healthcare setting, such as time pressures to keep patients moving through the healthcare system, delays in treating patients, particularly in the emergency room, and a general lack of knowledge among staff in caring for patients with ASD. By working with the healthcare providers and letting them know what works and what does not work, you are increasing the chances for success in treating the ASD patient.

### Autism Services, Education, Resources and Training (ASERT)

**ASERT** is a statewide initiative funded by the Pennsylvania Department of Public Welfare’s Bureau of Autism Services that aims to support individuals with ASD and their families. There are three **ASERT** regions in Pennsylvania: western, central and eastern. Each region has established an **ASERT Collaborative**: a partnership of medical centers, centers of autism research and services, universities and other providers of services for individuals of all ages with ASD and their families. These collaboratives are charged with understanding and meeting the needs of this population that are common across the state as well as region-specific.

**ACT** for Autism outlines the steps that can be taken to improve interactions between healthcare personnel and individuals with ASD.

- **A**ssess the treatment environment and the acute needs of the ASD patient.
- **C**ommunicate effectively with the patient, allowing the patient to convey their needs to the provider.
- **T**reat the patient using diagnostic and therapeutic interventions in a manner that is as minimally disconcerting to this population as possible.

For more information about **ASERT** and the **ACT for Autism** training program, go to the **ASERT** website at [www.pautism.org](http://www.pautism.org) or call 877-231-4244.

For more information about data, treatment and resources for ASD patients in the healthcare system, go to the December 2014 *Patient Safety Advisory* article, “Improving Care for Patients with Autism Spectrum Disorder in the Acute Care Setting” at the Authority’s website [www.patientsafetyauthority.org](http://www.patientsafetyauthority.org).