

# Autism Spectrum Disorder


## Community Safety and Wandering

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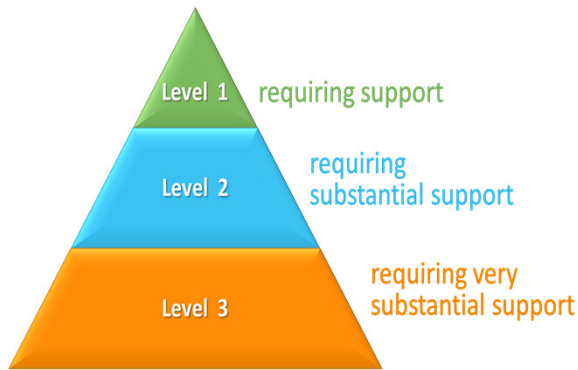
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## Severity Levels for Autism Spectrum Disorder



Safety Challenges, Education, Prevention, and Response are Different for Everyone

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## Common ASD Characteristics Have Potential Safety Implications

Not respond to name or commands

Unfamiliar with rules or expectations

Limited recognition of others' emotions

Focus on object/person/activity

Hypo- and/or hyper- sensitive to sounds, textures, smells, etc.

Difficulty following directions; responding to social cues

Not recognize/respond to pain, harmful temperatures, etc.

Difficulty waiting patiently

Non-verbal or have limited functional communication

Act compulsively or behave inappropriately

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## Many People with ASD Do Not Recognize Common Dangers and Hazards



There are people on the spectrum who may not have the skills to determine things that are inappropriate, dangerous/unsafe, or unsanitary/unhealthy.

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## Preventing Unnecessary Harm

### Understand Critical Safety Rules and Practices



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## Generalization of Safety Lessons Learned ?



People with autism often have difficulty generalizing skills

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## Elopement and Wandering

- unexpected or sudden escape from area
- unlocking or opening protected environments
- wandering away from responsible caregiver(s)
- running away suddenly, with speed
- setting off to an unsafe place or situation
- approaching strangers or involved in unfamiliar social situations



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National Autism Association  
<http://nationalautismassociation.org/resources/autism-safety-facts/>


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## Some Reasons

- To get something, go somewhere, see someone
- Escape, distraction
- Get attention
- Pleasure in running
- Sensory seeking environment, activity

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## Risks include...

- drowning
- exposure
- dehydration
- hypothermia
- traffic injuries (cars, trains, etc.)
- falls
- physical restraint
- unsafe encounters with strangers
- Unexpected encounters with law enforcement

<http://awaare.nationalautismassociation.org/>

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## Identification Options for Individuals with ASD



- autism alert cards
  - medical ID bracelets or necklaces
  - voice IDs
  - iron-on garment labels
- ... and many others

How secure is it?

How is it presented?

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## ASD Identification Cards

My name is \_\_\_\_\_

I have autism spectrum disorder.

Please contact \_\_\_\_\_  
by phone at \_\_\_\_\_

He or she will provide confirmation about my diagnosis,  
describe my specific needs, and respond in case of emergency.

See reverse side of this card for additional information.



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[www.children-specialized.org/kohesautismawareness](http://www.children-specialized.org/kohesautismawareness)

As a person  
with autism,  
I may...

- be unresponsive to pain or extreme temperatures
- not recognize dangerous situations
- respond unpredictably, run away, hide, or wander
- not respond to instructions or questions, or may need extra time to respond
- not be able to communicate as expected or have difficulty conveying my needs
- get bothered by sounds, lights, or crowds
- get overwhelmed or anxious
- avoid eye contact
- exhibit repetitive behaviors or language

Be aware.  
Be safe.

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## Trained Service Animals

### Benefits for individuals with ASD...

- alert others
- develop engagement
- guard against hazardous situations
- help with transitions
- prevent escape / wandering
- protect from unsafe situations
- provide feeling of security (familiarity)
- provide sensory input
- regulate behaviors
- detect onset of seizures
- teach responsibility / caretaking



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## Personal Tracking Devices


- Regions throughout the country have electronic tracking systems available to help locate people who wander
- Several types of personal tracking technology (satellite, cellular towers, radio frequency)
- Important to research which systems are available and will function best for person, family, and location



- Tracking devices can range in price from \$50 to over \$750
- May involve monthly or annual charges and other incidental costs to maintain
- Not everyone has access or can afford

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## Project Lifesaver




Endorsed by the  
National Sheriffs'  
Association

Available in every  
NJ County

- Specially-trained sheriff's officers
- Family education
- Process to initiate a response in an emergency
- Care and maintenance of unit
- Battery-operated radio transmitter technology
- Worn on wrist or ankle
- Unique pulse-wave radio frequency emitted from device 24/7

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## Many Types of Personal Locators



Collaboration of reliable organizations related to autism and safety. Website provides many wandering prevention resources.



www.awaare.org

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## Kevin and Avonte's Law: Passed March, 2018



**Kevin and Avonte's Law of 2017**  
**Summary**  
 Prepared by the Autism Society Public Policy Staff  
 March 29, 2018

- Provides first responders with tools to more effectively prevent and respond to wandering
- Improves quality of police interactions
- Helps develop training and emergency protocols for school personnel and other community officials
- Assists to establish/enhance notification and communications systems for rescue/response

and MORE!!!

<https://www.autism-society.org/wp-content/uploads/2018/04/Kevin-and-Avontes-Law-Summary-March-2018.pdf>

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## Medical Diagnosis Code (ICD10)

### Z91.83 Wandering in diseases classified elsewhere




- promotes better data collection for and understanding of wandering
- prompts important discussions about safety among healthcare providers, caregivers, and the person with a disability to the fullest extent possible

10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD)

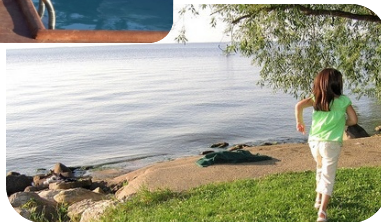
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## Drowning is the Leading Cause of Injury-related Death Among People with ASD




- Many people with ASD are attracted to water and may not know how to swim
- May have little regard or understanding of water temperature or depth

National Autism Association 2012 study. *Pediatrics*. Accidental drowning accounts for approximately 90% of lethal outcomes.

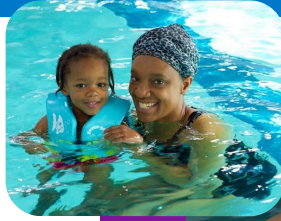
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## Water Safety Recommendations



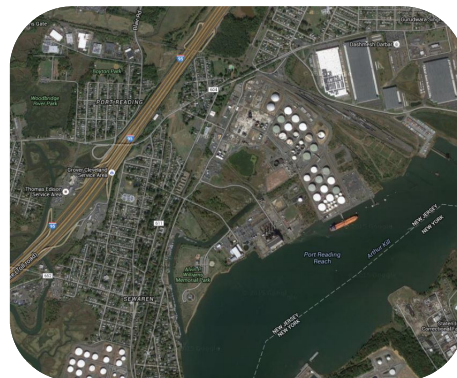
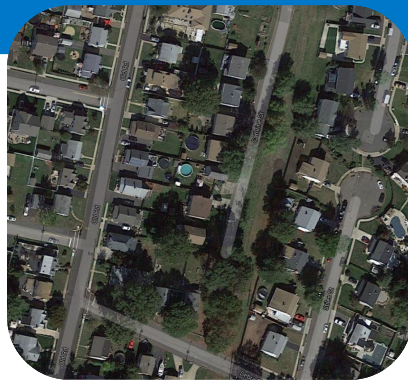
- Swim lessons
- Water safety education
- Preventative measures
- Community education
- Build relationships with local emergency responders

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## Search & Rescue

- Search areas with water **FIRST!**
- Expand typical search perimeters and don't ignore dangerous places
- Person may run and hide (and not respond to verbal commands)
- Find the connection!
- Techniques may need to be modified.
- Do not underestimate determination and speed
- Expect the unexpected



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## Autism and Wandering PSA


60-second PSA  
raising awareness  
about autism and  
wandering by the  
National Center  
for Missing &  
Exploited Children



<https://youtu.be/C2hiMlcZdQk>

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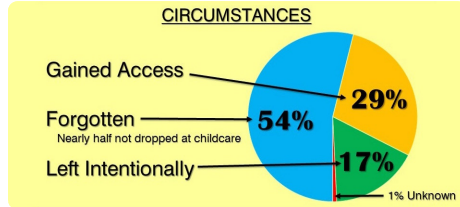


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## Hazards of Leaving Vehicles Unlocked

### Vehicular Heatstroke



<https://csftl.org/vehicular-heat-stroke-meeting-jan-null/>

- Person with ASD can elope/wander and hide in vehicle
- Person with ASD can be left in a vehicle

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## Traffic Control Devices

- Many states, counties, municipalities have these signs for various medical conditions. Varies from state to state; No federal standard.
- Local agencies manufacture/place signs in proximity of home.
- May give parents a false sense of security. No proven effectiveness. (But no controlled empirical studies.)
- Will not necessarily make person safer, but triggers call for more education and training for consumers, families, agencies, and schools.



<http://mutcd.fhwa.dot.gov/pdfs/2009/mutcd2009edition.pdf>

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## Transportation Safety – Personal Vehicles

removing, unbuckling, dismantling, getting out of safety restraint (sensory? behavioral?)

spontaneously exiting vehicle

unsafe or injurious activities while traveling

stimming with handles, buckles, etc.

communication challenges

distracting driver

unlocking, opening doors

reaction to stimuli outside vehicle

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## Increasing Safety in Personal Vehicles

**EMERGENCY RESPONDER ALERT**  
Passenger May Need Additional Help in Emergencies  
Needs Communication, Assistance, and Information at Car

- Decals
- Emergency information sheet
- Identification

- Assistance from a specially-trained Certified Passenger Safety Technician (CPST)
- AAP's "Car Safety Seats and Transportation Safety"
- SafeKids.org

- Specialty safety restraints
- Child safety locks
- Locked doors

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## Car Seats and Transportation Safety Restraints

- Some problems may include sensitivity to straps and/or behavior issues
- Passengers with ASD may require adaptive car seats or safety restraints

**NOT REGULATED**



May affect use and safety of restraint in crash which can result in serious injury or death

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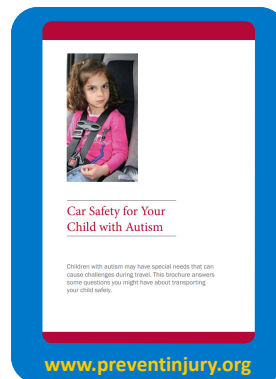
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## Vehicle Safety Restraint Concerns



Certified Child Passenger Safety Technicians (CPST)

Find a Tech: <http://cert.safekids.org/>



[www.preventinjury.org](http://www.preventinjury.org)

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## Familiarization with Vehicles



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**Air  
Travel  
Safety**

Education

Preparation

Identification

Support

Flexibility

Attention

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## Transportation Security Administration



Transportation Security Administration (TSA) helpline designed to assist travelers with disabilities and medical conditions, prior to getting to the airport

**1-855-787-2227**

Assignment of a **Personal Support Specialist**

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## Interactions with Security Officers



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## Community Policing (Emergency Responders and Other Community Service Providers, Too)

- Relationship building (SAFE PEOPLE)
- Raise awareness about people with ASD; dispel misperceptions
- Safeguard citizen with ASD
- Encourage acceptance and inclusion



**NEVER use police officers as threats/punishment for “bad” behaviors**

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## Making Community Connections

- Police station tours and open houses
- Community events (National Night Out, town street fairs, health and safety fairs, etc.)
- Child safety seat inspections for personal vehicles
- Bicycle safety fairs (helmets)
- Community education (workshops at libraries, schools, etc.)
- Community service and charity events
- Participation in local disability-focused organizations, school systems, homeowner associations, recreation groups, etc.
- Home visits



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## Making Connections with People with ASD in the Community, Families, Schools, and Organizations to Develop Positive Relationships



www.scpr.org



lowellsun.com



clevelandbanner.com



womanista.com




unionleader.com



delcotimes.com

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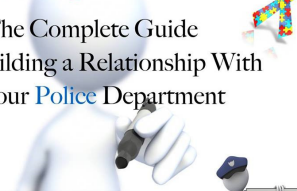
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## Empowering Autism Families:

The Complete Guide  
to Building a Relationship With  
Your Police Department




"Asking your police department to familiarize itself with your Special Needs child is a valid and reasonable request."

Jerry Turning  
Police Officer, Parent, and blogger

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## Let's Talk about Cyber Bullying



- “malicious” text messages/ emails
- untrue posts (scripted?)
- unfiltered social media posts
- embarrassing pictures/videos
- believing fake profiles
- imitating (not realizing consequences)
- not understanding/realizing intent (social cues/skills)
- What is “friending”?
- privacy settings/restrictions?

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## What Can Happen...

- Imitation of others (dangerous actions)
- Sharing personal information
- Cyber-identity theft
- Credit card scams
- Internet stalking
- Inappropriate language / unintentional messages
- Exposure on chat rooms
- Cyber bullying
- Susceptibility to malicious internet viruses

If parent/caregiver owns the technology and the child is **under the age of 18**, the child does not need to give consent to be monitored.

Use Your Best Judgment

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# Cyber Safety Tips and Tools

## How to Check Privacy Settings



**Facebook:** Provides detailed tools for users to control what others can see. Social network privacy and security settings page to get a guide to adjusting your privacy settings.

**Snapchat:** Be careful to not share photos or videos with people you don't know. Snapchat has a "My Privacy" page to help you control who can see your snaps.

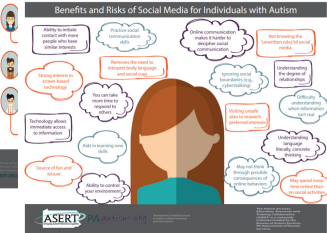
**Instagram:** Privacy settings are not as robust as other social media apps. Instagram has a "Privacy" page to help you control who can see your posts.

**Twitter:** Twitter has a "Privacy" page to help you control who can see your tweets.

## Social Networking: A guide to best practices

- Be skeptical: Do not believe anything you read, especially if it comes with a link or a request on social media.
- Check privacy settings: Check your privacy settings on the platform you are using for the social network you are using.
- Good passwords: Use strong, unique passwords that contain letters, numbers and special characters. Your devices' "forgot" screens will prompt you to create a good password.
- Protect your password: Never share your password with anyone, and if you think your password has been stolen, use a new one to log into the original service and change your password.
- Stay updated: Make sure all of your apps and devices are up to date. The software that runs on them is often updated.
- Be thoughtful: Think twice about posting anything online. You may not have control over where it goes and how many people can see it.
- Be wary: People on the Internet are not always who they say they are. Be careful to not give out too many personal details and be respectful to others.

- Benefits and Risks of Social Media
- How to Check Privacy Settings
- Social Networking: A guide to Best Practices



SOURCE: [www.paautism.org](http://www.paautism.org)

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# Monitoring Your Child's Media Use



The best way to monitor media that kids use is to experience the media yourself. Test apps and play games before your kids use them. **View and play apps and games together with your children. And watch what they watch so you can talk about what they're seeing on their screens. You know your kids best, so you're the best judge of what they can handle.**

When closer monitoring and more control are needed, **parents have a number of ways to keep track of the media their kids watch, play, and use. These tools may not shield kids from all inappropriate material, but they can help.**

<https://kidshealth.org/en/parents/monitor-media.html>

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## Monitoring Your Child's Media Use



### Parenting, Media, and Everything In Between

Everything You Need to Know About Parental Controls

<https://www.commonsensemedia.org/blog/everything-you-need-to-know-about-parental-controls>

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## No More Victims

Protecting Those with Autism from  
Cyber Bullying, Internet Predators & Scams



"Essential reading!"

- Dr Temple Grandin, author of *The Way I See It* and *The Autistic Brain*

Dr. Jed Baker, author of *No More Meltdowns*

No More Victims:  
Protecting those with Autism  
from Cyber Bullying,  
Internet Predators, and Scams

Dr. Jed Baker

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## Community Safety: Prevention, Tools, and Resources

- Identification Kits; National Child Identification Program
- Cell Phone
- Medical ID, other identification
- Personal Tracking Devices
- Communication with Neighbors
- Identification of Preferred Locations
- Connections with Local Emergency Responders/Law Enforcement
- Home Security Products, (Alarms, Locks, etc.)
- National Center for Missing and Exploited Children

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## Teach Functional Safety Skills

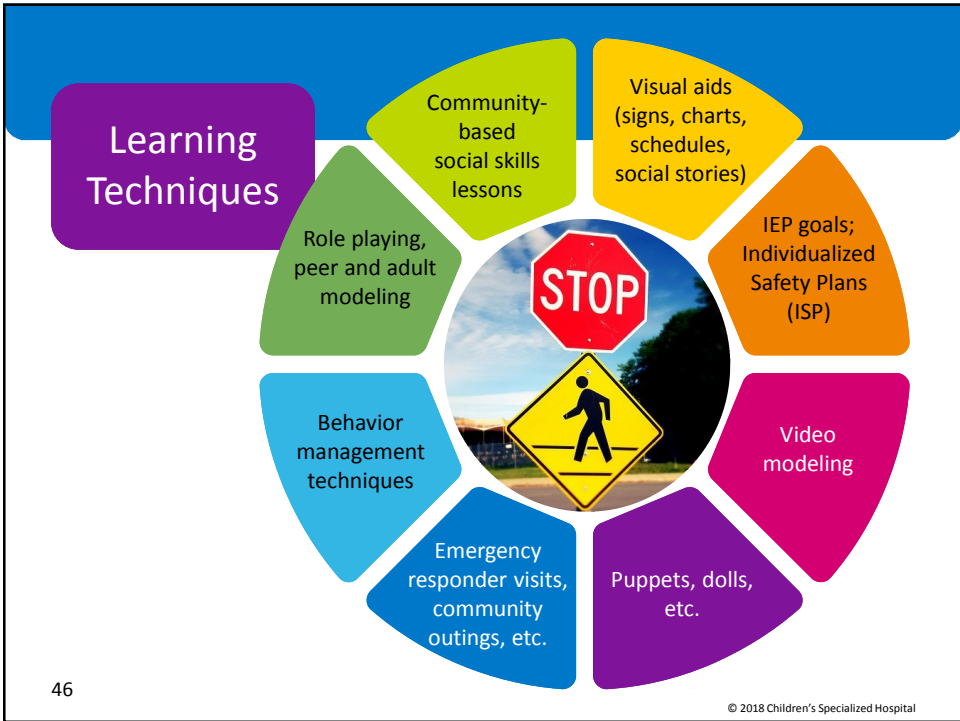
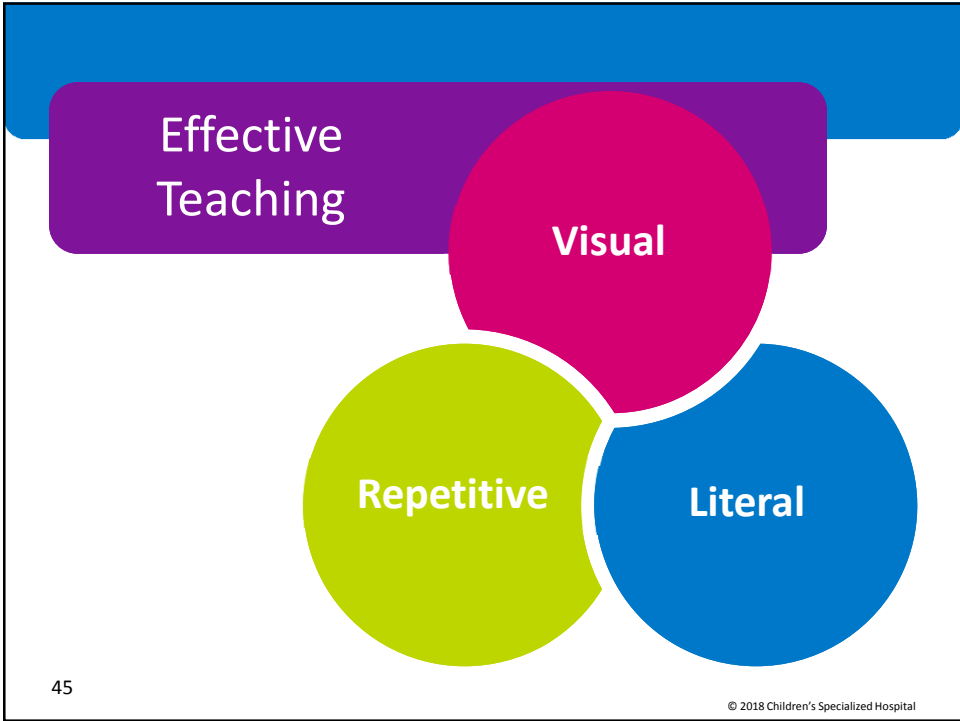


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## Safety Plans

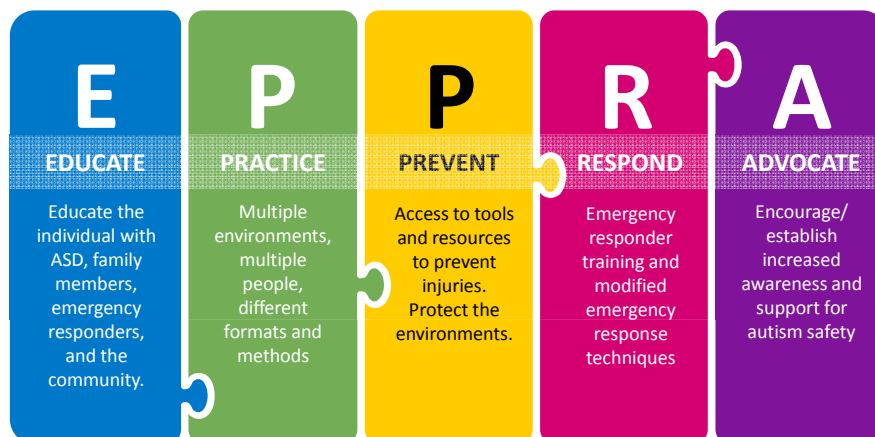
- Assess and determine critical safety risks
- Develop a related safety team to establish goals
- Work with team to establish methods of instruction, prevention, and response
- Practice (in naturally-occurring environments)
- Practice, assess, practice, assess...

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# KOHL'S Autism Awareness

## THE COMMUNITY HUB



[www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)

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**KOHL'S Autism Awareness**  
**autism SAFETY**  
It's a responsibility.

Providing information to 911 Dispatch Centers

[www.childrens-specialized.org/KohlsAutismAwareness](http://www.childrens-specialized.org/KohlsAutismAwareness)

Providing medical and functional information about a person with ASD to the local 911 dispatch center so they could:

- When needed, ask a rescue agency to you then contact information near your home should...
- This form Substituting help (e.g., when you get information)
- You can't the dispatch center!

**Individual Diagnosed with Autism Spectrum Disorder - Confidential Information: For Emergency Use**

Person's name: \_\_\_\_\_  
 Long-distance telephone number of this person's residence: (\_\_\_\_) \_\_\_\_\_  
 Physical description: \_\_\_\_\_  
 Respond to nicknames, sounds, favorite name, etc.): \_\_\_\_\_  
 Check and explain those that apply:

**Medical / Functional Challenge**

- avoids eye contact with others
- cognitive impaired
- difficulty expressing or receiving information
- lacks understanding of danger
- does not respond to instruction or commands
- fine motor difficulties
- hearing impaired
- hyper- or hypo-sensitive to light, sound, pain, smells, touch, other
- issues with balance, clumsiness
- lacks understanding of danger
- mobility impaired
- no functional method of communication
- nonresponsive to visual signs with uniforms or badges

### 911 means EMERGENCY

A guide to interacting with individuals who may have autism spectrum disorder during emergency calls

A person who interacts differently during an emergency call may have autism spectrum disorder (ASD)

- A person with ASD may:
- not be able to understand danger or identify a true emergency
  - be unfamiliar with common safety rules and expectations
  - have trouble handling disorderly/chaotic situations
  - have difficulty understanding questions or instructions
  - act confused by flashes of search or other sensory input
  - be easily distracted or upset by noises or other sensory input
  - not be able to respond quickly or accurately
  - repeat words or phrases and/or speak out of context (they speak as if scripted)
  - become anxious or withdrawn
  - be more interested in physical environment rather than people
  - not understand the consequences of actions
  - act unselectively or compulsively
  - not understand or acknowledge pain

**autism SAFETY**

Child/Adolescent's Name \_\_\_\_\_  
 Nickname \_\_\_\_\_  
 Legal Guardian \_\_\_\_\_  
 Primary Emergency Contact \_\_\_\_\_  
 Work \_\_\_\_\_  
 Date of birth: \_\_\_\_\_

Color:  White  African American  Hispanic  Other  
 Hair:  Black  Brown  Red  Other  
 Eyes:  Blue  Green  Brown  Other  
 Height: \_\_\_\_\_  
 Weight: \_\_\_\_\_  
 Blood type: \_\_\_\_\_  
 Religion: \_\_\_\_\_  
 Ethnicity: \_\_\_\_\_


My name is \_\_\_\_\_ I have autism spectrum disorder.  
 Please contact \_\_\_\_\_ by phone at \_\_\_\_\_  
 He or she will provide information about my diagnosis, describe my needs, and help me in an emergency.

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**Printable symbols to label things that are "hands off"**

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**Autism Family SAFETY Handbook**

Developed by the experts at Children's Specialized Hospital

**Be safe.**

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Thank you.

Questions?

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