

# **Autism Recognition & Suggested Responses for Professional First Responders**

**Prince William County Dispatchers**

**Manassas, VA**

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**Presented by Scott Campbell**

From the Autism Society of Northern Virginia (ASNV) and  
Parents Of Autistic Children of Northern Virginia (POAC-NoVA)

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# Objectives

- Discuss why first responder professionals need to recognize autism spectrum disorders.
- Discuss behaviors and characteristics commonly seen in individuals with autism spectrum disorders.
- Explain the problems that a person with autism may have in emergency situations.

# **Why should first responder professionals be concerned with recognizing autism spectrum disorders?**

- Safety of others & go home safe to your families.
- Positive, proactive community relations.
- Make best use of available time and resources.
- Enhance communication skills.
- Avoid exposure to liability and bad press.

# What are Autism Spectrum Disorders?

- Definition - Pervasive Developmental Disorders or Autism Spectrum Disorders are developmental disabilities that typically appear during the first three years of life.
- Pervasive Developmental Disorders include Autism, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder (CDD), or Pervasive Developmental Delay-Not Otherwise Specified (PDD-NOS).
- Autism is a broad-spectrum neurological disorder that causes the brain to process information differently.
- It is not a mental or psychological disorder.
- Autism impacts the normal development of the brain in the areas of social interaction and communication skills, along with some form of repetitive behaviors.
- Specific cause is unknown, & there is no definitive cure.

## **A Spectrum Condition**

- Delayed speech is usually the first sign of a possible development delay.
- Affects persons in varying degrees, severity and symptoms.
- Independence levels vary.
- Individuals with autism spectrum disorders are more like us than different.
- Each person with autism is unique.
- May display strength in some cognitive skills.
- Lasts their entire lives to some degree.

# Incidence

- No racial, ethnic, or social boundaries.
- Income, lifestyle and education levels have no effect.
- It is not caused by the way parents raise their children.
- Affects about one half million Americans!
- America's fastest growing developmental disability at  
1 in 91 to 112 children per reports from the Fall of 2009 using  
data from 2006 on 8 year-olds.  
[2,320 or 1 in 75 in FCPS for 2010, 987% growth since 1997]  
{1 in 70 children of active-duty military families}
- Four more prevalent for boys (1 in 58 to 70) than for girls!
- New case is diagnosed about every 20 minutes. Over 70 a day!
- Fastest growing developmental disability with 10-17% annual growth.
- Costs \$3.2M per person during their lifetime, or at least \$35B per  
year per Harvard School of Public Health Report, April 2006.
- Having a child with autism affects the entire family!

# **Student (ages 2 to 22) Autism Totals as of 12/10**

Alexandria City	92
Arlington County	324
Clarke County	18
Fairfax County	2,320
Falls Church City	22
Fauquier County	82
Fredericksburg City	17
Loudoun County	729
Manassas City	88
Manassas Park City	25
Prince William County	762
Spotsylvania County	216
Stafford County	239
Warren County	50

# DSM-IV Definition and Diagnosis

- **Diagnostic Criteria for Autistic Disorder:**
  - 1. Qualitative impairment in social interaction.
  - 2. Qualitative impairment in communication.
  - 3. Restrictive repetitive and stereotypic patterns of behavior, interests, and activities.
- Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
  1. Social interaction.
  2. Language as used in social communication.
  3. Symbolic or imaginative play.

# Autism: Behaviors & Characteristics

- May not understand what you say. Possible scripting!
- Appear deaf and may not respond to verbal cues.
- Be unable to speak (50% nonverbal), speak with difficulty, rambling speech, or echo what you say.
- Engage in repetitive behaviors and repeat words.
- Act upset for no apparent reason or have tantrums.
- Appear insensitive to pain.
- Appear anxious or nervous.
- Dart away from you unexpectedly.
- Engage in self-stimulatory behaviors or “stims”, like hand-flapping, body rocking, finger-flicking, spinning, or shaking parts of their body.



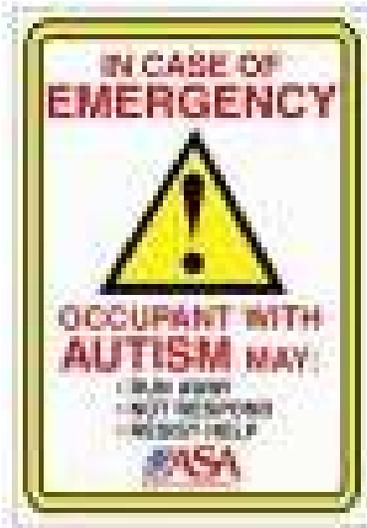
# **Autism: Behaviors & Characteristics**

- If verbal, answers may seem loud, blunt, or tactless.
- May not recognize jokes, slang, or body language.
- Communication frustrations when you do not understand their sign language or gestures.
- May appear argumentative, stubborn, or belligerent.
- May exhibit inappropriate laughing or giggling.
- Unusual reactions to sensory environment- touch (87%), sound (87%), vision (86%), bright lights, smell (30%), or sometimes animals.
- May cover ears, look away and have little eye contact.
- Have difficulty judging personal space and confuse pronouns.

# **Autism: Behaviors & Characteristics**

- May also exhibit forms of self-injurious behaviors, biting, spitting, screaming, tantrums, stripping, or self-induced vomiting when frustrated.
- Can be good rule and command followers.
- Pigeon-toed gait or contorted posture.
- May stare at you with an atypical gaze or into space.
- Display discomfort with change or new situations.
- May inappropriately place objects in their mouth.
- Attachment to objects that are not age-appropriate.
- May have information pertaining to their condition on an ID card/bracelet/necklace, non-permanent tattoo, or clothing tags, including in their shoelaces.

# Examples of Autism Awareness Items



**Three Things You Can Do Today To Protect A Person With Autism**

- Place the printed alert on the front door in areas of easy access or in your automobile. Do not place the alert in the back of a driver or the individual's view.
- Complete the attached Personal Information Form and make copies of it for your home, car, cell phone, and computer. Print appropriate emergency contacts.
- Use your mobile phone to send text messages to emergency services, neighbors, and family members in the event of an emergency.

www.asa-usa.org



# Examples of Autism Awareness Items

ALERT

## EMERGENCY ALERT

Communication/Social Needs

PERSON  
WITH

# AUTISM

IN VEHICLE



PLEASE READ INFORMATION  
FROM DRIVER

Zaryczny 2004



## AUTISM

### HELPFUL HINTS FOR INTERACTIONS WITH INDIVIDUALS WITH AUTISM

- ✓ Use simple language; speak slowly and clearly
- ✓ Use concrete terms and ideas
- ✓ Repeat simple questions: allowing time (10-15 seconds) for a response.
- ✓ Proceed slowly and give praise and encouragement
- ✓ Do not attempt to physically stop self-stimulating behavior
- ✓ REMEMBER: Each individual with autism is unique and may act or react differently.

PLEASE contact a responsible person who is familiar with the individual.

For more information call the Autism Society of America at 1-800-3-AUTISM  
<http://www.autismsociety.org>

*Resource supplied by LEAN On Us*

## AUTISM



### COMMUNICATION

- *May* be non-verbal or have very limited verbal abilities.
- *May* appear deaf may not respond to verbal cues.
- *May* repeat words or phrases in place of normal communication
- *May* have difficulty expressing needs; use gestures or points.

### BEHAVIOR

- *May* have tantrums - display extreme distress for no apparent reason.
- *May* exhibit inappropriate laughing or giggling.
- *May* appear insensitive to pain
- *May* be sensitive to touch, sound, or bright lights.
- *May* exhibit self-stimulating behaviors: hand flapping, finger flicking, body rocking.

### IN CRIMINAL JUSTICE SITUATIONS

- *May* not understand rights.
- *May* have difficulty remembering facts or details of offenses.
- *May* become anxious in new situations
- *May* not understand consequences of actions.

# Examples of Autism Awareness Items

 **Public Autism Awareness** 

**My child has Autism**  
 He / she is not being naughty and we are not being bad parents for not reprimanding them. Children with autism can often behave in an unpredictable manner, because they find it hard to cope with many everyday situations. They are quite simply doing their best. Please be patient.

For more information about autism please visit [www.autism-society.org](http://www.autism-society.org)

**WHAT YOU ARE WITNESSING IS A CHILD WITH AN ILLNESS**

This child is not a brat, does not need discipline, and we are not bad parents. Autism is a neurological disorder that makes certain buttons in ways that most people don't understand.

People with autism are often confused and upset and need to know that are socially inappropriate, both as a parent. Please be patient while we teach our child how to function appropriately in the community.

To learn more about autism, please visit [www.autism-society.org](http://www.autism-society.org)

[www.ButtonsAndmore.com](http://www.ButtonsAndmore.com)

**Emergency Contact Information**

Contact Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Comments: \_\_\_\_\_

*You are the voice for your child*

Dedicated to Raising Autism Awareness

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 **I am a Person with Autism**

For this reason I may not be able to communicate. I can't always control my behavior and I may not respond well to verbal cues.

**Please Be Patient with Me**

If I'm found alone, lost or in trouble. Please read the emergency information on the back...Thank you





*Autism Society of America*

**AUTISM** is a disorder of brain function affecting 1 in 250 people.

*Children & adults with autism may:*

- ✓ not understand what you say
- ✓ appear deaf
- ✓ be unable to speak or speak with difficulty
- ✓ engage in repetitive behaviors
- ✓ act upset for no apparent reason
- ✓ appear insensitive to pain
- ✓ appear anxious or nervous
- ✓ dart away from you unexpectedly
- ✓ engage in self-stimulating behaviors (i.e., hand flapping or rocking)

*For law enforcement or medical emergency personnel: This individual may not understand the law, know right from wrong, or know the consequences of his or her actions.*

[www.autism-society.org](http://www.autism-society.org)



# Autism Risks

- May not know what to do or how to seek help.
- May not be able to communicate contact information, what hurts, or what happened.
- May not react well in emergencies (re-enter burning home or touch downed power lines).
- May not recognize real danger. Have NO real fear!
- May have very high tolerance for pain, heat and cold.
- May react poorly to changes in routine for apparent trivial reasons.
- May seek inappropriate age relationships and touch in socially inappropriate ways. Indecent exposure.
- Will likely flail against physical restraint or continue to struggle.
- May have other medical conditions, such as seizure disorder (up to 30-40%), asthma, or hypotonia - low muscle tone.

## **Autism Risks, Continued**

- May not respond to stop or other commands.
- May flee when approached due to sensory overload.
- May inappropriately approach or run towards you.
- May invade your personal space and have little eye contact.
- May repeat words or body language of first responders.  
Often trained to be imitators!
- May answer no or why to all questions.
- May not recognize badge, uniform or marked vehicle or understand what is expected of them if they do.
- Behaviors draw attention and may limit credibility.
- Elopement: lost and wandering. Trespassing.
- Attracted to water, reflections, shiny objects, or high places.
- Some foods make the symptoms and behaviors worse.

# Autism Risks, Continued

- Three times more likely to have to quit their jobs or reduce work hours to care for their kids. They pay more for their kids' health needs, spend more time providing for that care, and are more likely to have money difficulties. (Kogan, 2008)
- Thought to be higher stress levels and divorce rates of 80-90%.
- Up to seven times more contacts with law enforcement.  
(Curry, 1993)
- Persons with disabilities over age 12 experienced violent crime at rates that were almost twice the rate among persons without disabilities for each violent crime measured. (DOJ, 2010)
- Experienced serious violent crime at rates that were over three times more frequent compared to persons without disabilities.  
(DOJ, 2010)
- Maltreatment of children with disabilities is 9.5 per 1000 for physical abuse versus 4.5 for children without, and 3.5 per 1000 for sexual abuse versus 2.0. (Goldson, 2002)
- 64% of the children who were maltreated had a disability.  
(Sullivan & Knutson, 1998)

## Autism Risks, Continued

- Approximately 61 percent of females and 25 percent of males with developmental disabilities will be sexually molested by age 18. (Mitchell, 2006)
- Children with intellectual disabilities were 4 times as likely as children without disabilities to be sexually abused. (Sullivan & Knutson, 2000)
- 83% of the developmentally disabled females and 32% of males are the victims of sexual assault. (Johnson & Sigler, 2000)
- 90% of people with developmental disabilities will experience sexual abuse, but only 3% of sexual abuse cases involving people with developmental disabilities are ever reported. (Valenti-Heim & Schwartz, 1995)
- 49% of people with developmental disabilities who are victims of sexual violence will experience 10 or more abusive incidents. (Valenti-Heim & Schwartz, 1995)
- Multiple studies show that approximately 90% of individuals with developmental disabilities know their abusers.

# **Wandering & Autism:** the leading reason for first response contact

- Often seek water sources (40% of deaths).
- Individual is in unsafe location.
- Running into traffic, enter homes of others, or looking into windows of homes.
- Go with or run from strangers.
- May be seeking special treatment.
- Elopement prevention and care may look like abuse.
- Lack of ability to prevent elopement or self-injurious behaviors may lead to criminal charges.
- Up to 50% non-verbal. (14% unable to talk by age nine and 60% not able to speak fluently per University of Michigan Study, 2004)

# Other Common Reasons for First Response

- Medical emergency incidents or escalated behaviors at home, retail setting, or schools.
- Person is acting out, and no one recognizes them.
- Person appears to be a threat due to suspected substance abuse or obsessive/ compulsive behaviors.
- Parent or caregiver actions misinterpreted.
- Injury, incapacitation, or death due to accidental actions of individual with autism.
- Medical emergency, fire or natural disaster - person is alone and upset at scene.
- Self-imposed isolation may lead to lack of assistance and resources.

# Suggested Responses

- **Use their first name before EACH command** by one speaker.
- **Speak slowly, clearly and use simple language** for deliberate, one-step commands or instructions. Offer choices.
- **Use concrete terms** and ideas.
- **Repeat simple and direct questions.** Rephrase & verify as needed.
- **Allow up to 10-15 seconds for responses.**
- **Give lots of praise and encouragement** (compliment and reassure).
- **Do not attempt to physically block self-stimulatory or other non-dangerous, inappropriate behavior**, since it is their way of adapting to the situation and calming themselves.
- **Remember that each individual with autism is unique** and may act differently than others.
- Check for information pertaining to their condition on an ID card/bracelet/necklace or clothing tags, including in their shoelaces.

# Suggested Responses

- Approach in quiet, non-threatening manner.
- Seek and use available information from persons at scene on how to de-escalate behaviors and identify sensory triggers.
- Talk calmly in moderated voice on one issue at a time, since talking louder does not improve understanding and may elicit an undesirable response on their part.
- May need to repeat and rephrase questions.
- Avoid jokes, metaphors, or slang and minimize body language.
- Maintain safe distance and do not crowd them.
- Be alert to sudden outbursts - be able to appear to retreat to de-escalate.
- Avoid impulse to act quickly.
- Avoid rapid pointing or waving.
- Expect a possible seizure as a reaction to overstimulation.
- Use the individual's working dog to the best extent possible.
- Do not give food, since it makes problem behaviors worse.
- Do not use a penlight to check eyes, since could cause seizures.

# Suggested Responses

- Reduce noise, light, animals and stimuli as much as possible and be aware of sensory issues - fight, flight, or freeze!
- Use their communication device, if they have one.
- Consider using a clipboard or tablet to get yes/no answers or draw questions out in pictures.
- Evaluate the individual for injury with a very thorough deliberate or secondary survey, since they may have a very high tolerance for pain.
- Model the behavior that you want the individual to display.
- Model and use calm body language such as slow breathing and keeping your hands low.
- Give and let them hold a piece of equipment while you use a second one on them. Do not take away a favored object, but use it to better connect with them. Use a doll to show them before-hand what you want to do to or with them.
- To quickly move a person, be prepared to wrap them in a blanket with their arms inside to calm them down and prevent thrashing.
- Are a bolt risk after rescue, so you must stay with them.

# Suggested Responses

- Use communications, not physical restraint. Use space, posture and positioning instead, but do not leave unattended.
- If the individual needs to be restrained, approach them from the side, since they may tend to throw their head back when being restrained. Get lots of help and do it quickly. Probably necessary for all IVs and trauma cases.
- Never place the individual in a prone position unless absolutely necessary, since they may not be able to support an airway. Get them to their side as soon as possible.
- Avoid touching, if possible (especially the shoulders and face) unless necessary for the physical exam.
- Speak to them at their eye-to-eye level, not talk down!
- Warm up the stethoscope before using it in an examination.
- Use of BP cuff and Pulse Ox will probably be difficult.
- Have parent ride in unit in sight of individual to lower stress.
- **BOTTOM LINE: Treat them like they are two years old, in spite of their actual chronological age.**

# **Is sensory over-stimulation a factor?**

**Look for outward behaviors.**

**Move person to a quiet place.**

**Calm creates calm.**

- Reduce sensory climate
- Sirens
- Lights
- Crowds
- Odors
- Touch
- Geographic containment
- Restraint; last resort
- Avoid face down take down
- Positional asphyxia
- Consider buffers
- Seizure, medical conditions
- Hypotonia-low muscle tone

# What NOT To Do!



Restraint of 10 year-old girl with autism by untrained public school employee in 1998.

From the Cornell University Residential Child Care Project: “At least 64 children died and thousands were injured while being restrained in face-down and other methods. About half of the restraints that caused deaths were unnecessary.”

# Emergency Room Responses

- Listen to caregiver and consider their higher stress level.
- Your time is valuable, but having person wait, even for treatment of minor injuries, will ultimately increase your response time.
- New environments increase anxiety for person.
- Transitions from room to room may be difficult.
- Consider sensory diet overload.
- Seek consultation or quiet room.
- May jerk away from basic care and touch.
- Whenever possible, upgrade triage.
- Let person settle down and become comfortable.  
Let them get themselves under control!

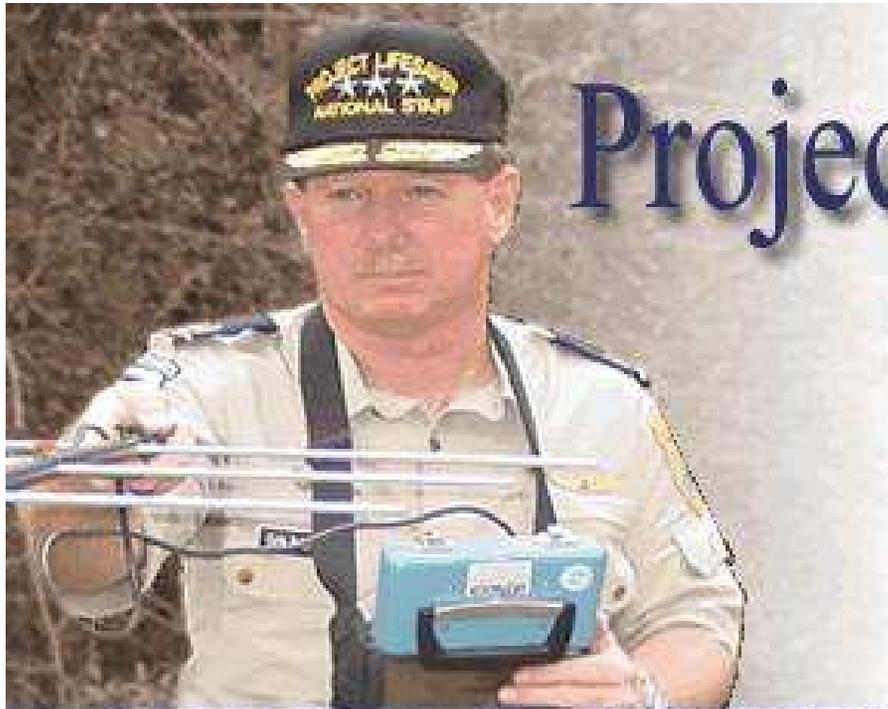
# Medical Team Considerations

- Choice- If possible, offer a choice during procedures.
- Distraction- Use questions, favorite toys or objects and counting and singing to take attention from procedures.
- Imitation and Role Modeling- Use a doll or other object to show them before-hand what you want to do to or with them. Allow them to imitate by vaccinating doll first.
- Rewards- Agree on a reward up front if the child complies with your requests and procedures.
- Easy Request, then Difficult Request- Easy to hard.
- Visuals- Explain through pictures rather than by written or oral communications.
- Body Hold Techniques- Use caregiver to do what has worked in the past.
- Pain Management- Offer analgesia before injections.

*From North Shore LIJ Center for Autism at [www.northshorelij.com](http://www.northshorelij.com)!*

# Dispatchers and 911 Flags

- Listen to caregiver and consider their higher stress level.
- Understand and consider risks of autism for all first responder professionals - police, fire, EMT and ER.
- Flag with key data to alert first responders as a “location of interest”.
- Information sheets at 911 data base with name, address, phone numbers and emergency contacts.
  - Photo, physical description, likes/dislikes and fears.
  - Favorite places to go and/or hide.
  - Type of disability.
  - Best method to communication.
  - Possible compulsive activity.
- Fairfax County Medical Needs Registry Form at <http://www.fairfaxcounty.gov/specialneeds/medicalneedsregistry.htm>.



# Project Lifesaver

The reliable rapid-response partnership with law enforcement aiding victims and families suffering from alzheimer's disease and related disorders such as Down's Syndrome and Autism.



**ENDORSED BY THE NATIONAL SHERIFF'S ASSOCIATION**

- Get more info in Autism Society of America's Safe and Sound Campaign at [http://www.autism-society.org/site/PageServer?pagename=research\\_safeandsound](http://www.autism-society.org/site/PageServer?pagename=research_safeandsound)
- Recommend also enroll in the Alzheimer's Association's Safe Return program at [www.alz.org/SafeReturn](http://www.alz.org/SafeReturn).

Project Lifesaver relies on proven radio technology and a specially trained search and rescue team. Clients that are enrolled in the Project Lifesaver program wear a personalized wristband that emits a tracking signal. When caregivers notify the local Project Lifesaver agency that the person is missing, a search and rescue team responds to the wanderer's area and starts searching with the mobile locator tracking system. Search times have been reduced from hours and days to minutes.



# •Project Lifesaver

- Rapid response program which places personalized radio transmitters on persons who are at risk of wandering and getting lost, since April 1999.
- 99.9% success rate with average location time of less than 30 minutes.
- As of 30 October 2011, have located 2,451 individuals in over 1200 locales.
- 95% located are Alzheimer's adults and 5% are individuals with autism or another developmental delay.
- Go to <http://www.projectlifesaver.org> for more info.
- Mechanical locks and audible alarms to keep person in the house.
- Plexiglass or bars on windows are sometimes necessary.
- Dress the person in bright colored shirts & coats for a quicker search!

# Cell Phone and Other GPS Options

- **Verizon Wireless- Chaperone** options.
  - **Chaperone** lets you easily locate your family members handset from your Verizon Wireless phone or PC - in real time, at any time.
  - **Chaperone with Child Zone** lets you define a zone - specific area, such as a school or summer camp. When your family member enters or leaves the zone with their handset, Child Zone will automatically send an alert to your phone with the time and location of your family member's handset.
- **Cingular** offers Firefly phones designed for kids with GPS built-in. More info is at [www.fireflymobile.com](http://www.fireflymobile.com).
- **Nextel Mobile Locator** shows real-time location - see where people are either by address or web-based map for \$15/ month.
- **Wherifone** is another GPS locator phone option. More info is at <http://www.wherify.com/wherifone/kids.html?page=kids>.
- **Quantum Satellite Technology's GPS sneakers** should be available soon, but will also require a \$19.95 monthly subscription. More info is at <http://www.msnbc.msn.com/id/17063608>.
- **Jacket includes GPS tracker"** dated 25 October 2007 on CNN.com at <http://www.cnn.com/2007/TECH/ptech/10/25/gps.jacket.ap/index.html>.

# Community Involvement

- Get their neighbors and community involved proactively.
- Ask neighbors to call the parents immediately if they see their child outside the home; before calling 911.
- Provide 911 information sheets with photo and their contact info to neighbors; explain unusual behaviors.
  - Have a get-to-know-their-kid BBQ or party, so they know that the parents are approachable.
  - Show them their child's ID wear, tags, or info cards.
  - Inform neighborhood watch programs.
- Get “Unlocking Autism” license plates. Tackle box!
- Visit their local police and fire departments.
- In 911 situation, have parent ride with their child.
- Parking placards for Virginians with disabilities application at [http://www.dmv.state.va.us/webdoc/citizen/disability/plates\\_assist.asp](http://www.dmv.state.va.us/webdoc/citizen/disability/plates_assist.asp) and “Walker” or “Non-Driving ID” from DMV.

# Summary

- First responder professionals can enhance safety and reduce exposure to liability when they:
  - Recognize the risks associated with individuals who have autism.
  - Learn response options.
  - Use this and additional training.
  - Apply tolerance and public relation skills in situations with people that have autism.

**For more information, contact:**

**Scott Campbell**

**703 241-2640 (Home)**

**[campbellsservices@gmail.com](mailto:campbellsservices@gmail.com)**

Autism Awareness and Home Safety web links at

**<http://www.autism->**

**[society.org/site/DocServer/Autism Awareness and Home](http://www.autism-society.org/site/DocServer/Autism_Awareness_and_Home)**

**[Safety3 1 .doc?docID=9261](http://www.autism-society.org/site/DocServer/Autism_Awareness_and_Home_Safety3_1.doc?docID=9261) and <http://www.poac->**

**[nova.org/base.cgim?template=autism awareness](http://www.poac-nova.org/base.cgim?template=autism_awareness)**