

Safety Considerations for Parents of Individuals with Autism and Other Cognitive Disabilities

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Presented by Scott Campbell

**From Autism Society of America, Northern Virginia
Chapter (ASA-NV) and Parents Of Autistic Children
of Northern Virginia (POAC-NoVA)**

What are Autism Spectrum Disorders?

- **Definition** - Pervasive Developmental Disorders or Autism Spectrum Disorders are developmental disabilities that typically appears during the first three years of life.
 - Pervasive Developmental Disorders include Autism, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder (CPD), 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, and 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.
- Children and adults 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 over 236,000 individuals (ages 3 to 21) in the U.S as of April 2007. (Over 560K for ages 3 to 22)
- America's fastest growing developmental disability at 1 in 150 births per Feb. 2007 CDC Report.
[1 in 113 in FCPS in FY06]
- More prevalent in boys (1 in 67 to 150 births) versus 1 in 233 to 500 births for girls or male to female ratio of 2.8 to 5.5 to per Feb. 2007 CDC Report.
- 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!

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.
- May have very high tolerance for pain.
- May flail against physical restraint or continue to struggle.
- May have other medical conditions, such as seizure disorder (up to 30-40%), asthma, hypotonia - low muscle tone.
- May react poorly to changes in routine for apparent trivial reasons.
- Some foods make the symptoms and behaviors worse.

Autism Risks, Continued

- May not respond to stop or other commands.
- May inappropriately approach or run towards you.
- May flee when approached due to sensory overload.
- May repeat words or body language of law enforcement officers.
- May answer no or why to all questions.
- May invade your personal space and have little eye contact.
- 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.
- Attracted to water, reflections, shiny objects, or high places.
- 65 to 72% of marriages with special needs children fail.

Autism Risks, Continued

- At risk of misunderstandings by public, increased 911 responses.
- Up to seven times more contacts with law enforcement (Curry, 1993), since 20% of U.S. population are individuals with disabilities. (2001 US Census)
- Rate of crimes and violence against children with disabilities is 3.4 to 7 times higher than for children without disabilities. (Sullivan & Knutson, 2000)
- Violent crime is 5 to 10 times higher for individuals with disabilities. (Sobsey, 1996)
- 5 Million serious crimes are committed annually against individuals with developmental disabilities in the U.S., which is almost five times higher than individuals without disabilities. (Pertersila, 1998)
- Two major studies have found a serious crime rate 9.4 times higher for people with psychiatric disabilities. (Lehman and Linn, 1984).

Autism Risks, Continued

- Study found that the rate of sexual assault was 10.7 times higher and 12.8 times higher for robbery for people with developmental disabilities. (Wilson and Brewer, 1992)
- Two studies found that 80% of women and 32 to 54% of men with developmental disabilities had been sexually assaulted compared to 13% of women in the general. (Hard, 1986)
- Another study found that 80% of victims of sexual assault with disabilities had been assaulted more than once and 50% had been sexually assaulted over 10 times. (Sobsey & Doe, 1991)
- “Children with intellectual disabilities were 4.0 times as likely as children without disabilities to be sexually abused.” (Sullivan & Knutson, 2000)
- “Approximately 61 percent of females and 25 percent of males with developmental disabilities will be sexually molested by age 18. Between 15,000 and 19,000 individuals with developmental disabilities are raped each year in the United States.” (Mitchell, 2006)

Wandering & Autism: the leading reason for first response contact

- Often seek water sources (40% of deaths).
- Attempted entries.
- Run into traffic.
- Go with or run from strangers.
- Alzheimer's parallel.
- May be seeking special treatment.
- Elopement prevention and care may look like abuse.
- Up to 50% non-verbal. (14% unable to talk by age nine and 60% not able to speak fluently per University of Michigan Autism and Communications Dept. Paper, 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 obsessive or compulsive behaviors or suspected of substance abuse.
- Parent or caregiver actions misinterpreted.
- Running into traffic, enter homes of others, or looking into windows of homes.
- Caregiver becomes incapacitated.
- Person is in unsafe location.
- Medical emergency, fire or natural disaster - person is alone and upset at scene.



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

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.
- 100% success rate with average location time of less than 30 minutes.
- As of 5 April 2007, have located 1,474 individuals in 570 locales and 40 states.
- 54 million people in the U.S. now have Project Lifesaver coverage in their area, equating to 18% of the U.S. population.
- 7 of the 41 largest cities in the U.S. now have coverage.
- 65% Project Lifesaver coverage in Virginia and 29% in Maryland.
- 95% located are Alzheimer's adults and 5% are children 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.
- Dress the child in bright colored shirts and coats for a quicker search!

GPS Bracelet Options

- Columba phone-bracelets combine "hands-free" portable telephone, GPS positioning system and intelligent alert system to detect any wandering outside of a specified security zone and is able to quickly locate the person who has strayed from this pre-defined secure zone.
- "Bracelet's GPS keeps track of lost Alzheimer's patients" dated 27 February 2007 from the Times Colonist (Canada) at <http://www.canada.com/victoriatimescolonist/news/life/story.html?id=d3aa7ea6-e965-410c-bec5-4023f8c56c13>.
- "Medical Intelligence announces the expanded distribution of Columba phone-bracelets in France" dated 25 May 2006 in a press release from Medical Intelligence Technologies Inc. at http://www.mirror99.com/20060525/medical_intelligence_announces_the_expanded_distribution_of_columba_phone_bracelets_in_dhfg.jspx.

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.
- **Nextel Mobile Locator** shows real-time location - see where people are either by address or web-based map for \$15/ month.
- **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>.

911 Flags for Local Dispatcher

- 911 flags with key dispatch data to alert first responders.
- Information sheets at 911 data base with name, address, phone numbers and emergency contacts, including:
 - Name of child or adult.
 - Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks.
 - Names, home, cell and pager phone numbers and addresses of parents or caregivers and emergency contact persons.
 - Sensory, medical, or dietary issues, if any.

911 Flags for Local Dispatcher, Continued

- Inclination for elopement and any atypical behaviors or characteristics that may attract attention.
- Favorite attractions and locations where person may be found.
- Likes, dislikes--approach and de-escalation techniques.
- Method of communication, if non-verbal - sign language or picture boards.
- Identification wear - jewelry, tags, info cards, or in their clothes.
- Map and address guide to nearby properties with water sources and dangerous locations highlighted.
- Blueprint or drawing of home, with bedroom of individual highlighted.

(From *Autism, Advocates and Law Enforcement Professionals*,
Dennis Debbaudt, 2003)

Autistic Child in Area Signs



- Traffic signs and signals are maintained by the Virginia Department of Transportation (VDOT). For more information, contact VDOT at 703 383-8368.
- From article titled "Sign of relief" dated 17 March 2006 by Andy Rathbun from The Battle Creek (MI) Enquirer at <http://battlecreekenquirer.com/apps/pbcs.dll/article?AID=/20060317/LIFESTYLE08/603170302/1032>.
- Another article titled "Rochester's 'Autistic Child' signs are among the first in the nation" dated 27 February 2007 from The Associated Press at <http://www.startribune.com/462/story/1027629.html>.

Sex Offender Registries

- <http://www.nsopr.gov> for the U.S. Department of Justice Dru Sjodin National Sex Offender Public Website.
- <http://www.mapsexoffenders.com> for nationwide sex offender mapping and information.
- <http://www.familywatchdog.us> for another sex offender registry and information.
- <http://www.fbi.gov/hq/cid/cac/states.htm> for the FBI's list of State Sex Offender Registry Web Sites.
- <http://www.ice.gov/pi/predator/sexoffenders.htm> for the U.S. Immigration and Customs Enforcement (ICE) sexual offender information by state.
- <http://sex-offender.vsp.virginia.gov/sor/index.htm> for the Virginia State Police Sex Offender and Crimes Against Minors Registry.
- <http://www.dpscs.state.md.us/onlineservs/sor> for the Maryland Department of Public Safety and Correction Services' Sex Offender Registry.
- <http://mpdc.dc.gov/mpdc/cwp/view,a,1241,q,540704,mpdcNav-GID,1523,mpdcNav,1%20,.asp> for the DC Metropolitan Police Department's Sex Offender Registry.

Community Involvement

- Get your neighbors and community involved proactively.
- Ask neighbors to call you immediately if they see your child outside the home; before calling 911.
- Provide 911 information sheets with photo and your contact info to neighbors; explain unusual behaviors.
 - Have a get-to-know-your-kid BBQ or party, so they know you are approachable.
 - Show them your child's ID wear, tags, or info cards.
 - Inform neighborhood watch programs.
- Visit your local police and fire departments.
- Get a “Kismart Vocal Smoke Detector”, if needed.
- In 911 situation, ask to ride with your child.
- Use the child's working dog to the best extent possible.

Sources for Autism Awareness Items

- “*Basic Information About Autism To Carry In The Pocket*” Pocket Slip at <http://hasselbrink.com/Pocketslip1.doc> and <http://hasselbrink.com/Pocketslip2a.doc>.
- “*Contact and Emergency Information To Be Carried In The Pocket*” Pocket Slip at <http://hasselbrink.com/Pocketslip2a.doc>.
- “*Information for Neighbors*” Pocket Slip at <http://hasselbrink.com/Neighbors.doc>.
- Law Enforcement Awareness Network On Us personal autism safety cards for children at http://www.leanonus.org/images/LEAN_On_Us_Child_ID_Safety_Card_7_04.pdf and for adults at http://www.leanonus.org/images/LEAN_On_Us_safety_card_for_adults_7_04.pdf.
- Silent No More Premise Alert Form and Information at <http://www.papremisealert.com>.

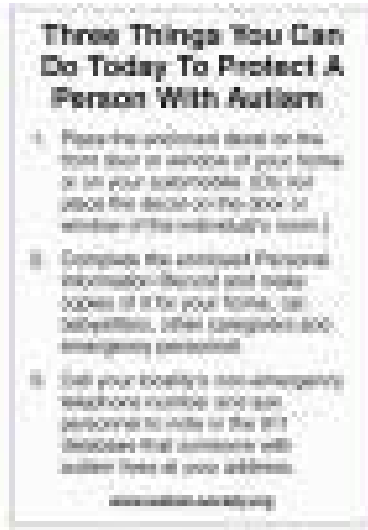
Sources for Autism Awareness Items

- <http://www.911life.com> sells an assortment of medical and alert cards, bracelets, shoe tags and necklaces.
- <http://www.americanmedical-id.com/home/> sells personalized medical identification jewelry.
- <http://www.asaphilly.org> sells emergency alert decals.
- <http://www.autismlink.com/store> sells “child with autism” safety tags, cards, bracelets, decals, lanyards and shirts.
- https://secure2.convio.net/asa/site/Ecommerce?store_id=2001 has an assortment of autism awareness and safety/ ID cards and decals.
- <http://www.autismva.org> to buy autism awareness window cling, please contact Didi Zaryczny at dzaryczny947@cs.com.
- <http://www.buttonsandmore.com> sells a large number of autism awareness and safety/ ID cards, decals and magnets.
- Dennis Debbaudt’s 911 Handout - [http://www.poac-nova.org/pdfs/Debbaudt 911 Handout.doc](http://www.poac-nova.org/pdfs/Debbaudt%20911%20Handout.doc) -- Sample Handout for Ian Campbell - [Ian Campbell's Sample 911 Handout.doc](http://www.poac-nova.org/pdfs/Ian%20Campbell's%20Sample%20911%20Handout.doc).
- POAC-NoVA personal autism safety cards at [http://www.poac-nova.org/pdfs/Autism Cards from POAC-NoVA.pdf](http://www.poac-nova.org/pdfs/Autism%20Cards%20from%20POAC-NoVA.pdf).

Sources for Autism Awareness Items

- http://www.labelsthatlast.com/allergy_labels.asp for allergy labels.
- Medic Alert sells bracelet and medallions at <http://www.medicalert.org>.
- <http://www.medicalmedallion.com> sells a recorder that carries up to 80 words of the person's vital medical or other information.
- Guide to Good Care sells USB devices with a digital memory chip containing all medical and other information at <http://www.gcpublishers.com/Catalog.aspx?ProductId=1>.
- Medic Tag also sells USB devices at <http://www.medictag.com>.
- <http://www.rescuealert.com> sells medical alarm systems bracelets and medical alert system service with a 24 hour response center.
- <https://shopping.webformix.net/lifeline/child.htm> for child ID bracelets.
- www.stitches4autism.com sells autism awareness youth-size bracelets.
- <http://tattooswithapurpose.com> for temporary tattoos.
- <http://www.unlockingautism.org> sells autism awareness stickers too, but they are made of paper and do not last very well.

Examples of Autism Awareness Items



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

 **WHAT YOU ARE WITNESSING IS A CHILD WITH AUTISM**

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

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

To learn more about autism, please visit www.autism.org

www.BoutonsAndmore.com

Emergency Contact Information

Contact Name: _____

Phone Number: _____

Comments: _____

You are the voice for your child

Dedicated to Raising Autism Awareness

 **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



Students with autism need education to help them respond well during an emergency

- How to call for help and safely show identification and info cards.
- How to recognize and respond to first responders as a safe “go-to” stranger.
- How to go to safe places and persons.
- Reduce fear of uniform, badge and police vehicles.
- How to interact with law enforcement officers (next slide).
- Do not make sudden movements or run.
- Keep appropriate distance when interacting with police.
- How to remain calm.
- Recognize inappropriate touching or sexual come-ons.
- How to report bullying, teasing and taunting incidents.
- When to invoke the right to remain silent and ask to speak to an attorney.

Students with autism need education to react safely in law enforcement encounters

- Do not attempt to flee.
- Do not make sudden movements.
- Keep appropriate distance when interacting with police.
- Try to remain calm.
- Tell, sign, or write officer that person has autism.
- Get prior permission before reaching in pocket or a car glove box.
- Show medical alert bracelet or necklace, or identification and info cards.
- Carry phone numbers of autism advocacy organizations.
- Ask officer to contact a family member or advocate, if necessary and possible. Particularly before the interview process.
- Use the Arc's Justice Advocacy Guide at <http://www.thearc.org/AAdvocacyGuide.pdf>.

Safety Training Resources

- Electrical and traffic safety training resources at <http://www.johnbald.net/goplay/safety.htm>.
- Autism and Safety - how to be prepared suggestions at <http://www.tacanow.com/autismsafety.htm>.
- Safety in the Home hints at <http://www.autism-society.org/site/PageServer?pagename=livingsafety>.
- Emergency situations training resources at http://www.frsd.k12.nj.us/autistic/Emergency%20Situations/Stories/emergency_situations.htm.
- <http://www.cec.sped.org/osep/database/detailView.html?masterID=387> explains the “Safe Life” program.
- Do2Learn has some good lessons about street safety at <http://www.do2learn.com/games/songs/streetsafety/index.htm>.
- Autism & Airport Travel Safety Tips at <http://www.sath.org/?section=Travel%20Tips%20and%20Access%20Information&id=2371&skip=>.

Safety Training Resources

- “Victimization & Abuse of Persons with Autism” article at <http://www.autism-mi.org/Protecting%20Loved%20Ones%20with%20Autism.pdf>.
- "Tips for Keeping Children on the Autism Spectrum Safe" article at <http://www.bellaonline.com/articles/art40928.asp>
- Protecting the Child or Adult with Autism Information for Parents and Other Caregivers article at <http://www.scautism.org/protect.html>.
- Autism Proof Your Home- Making A Secure Environment suggestions at <http://autism.about.com/cs/familyissues/a/safety.htm>.
- Fire Safety for Autistic Children hints at <http://autism.about.com/cs/parentstrategies/a/firesafety.htm>.
- Child Abduction and Autism- The Unique Problems of ASD concerns and suggested recommendations at <http://autism.about.com/cs/hiddenproblems/l/blabduction.htm>

Transportation Security Administration Guidance

- Guidance for persons with disabilities and medical conditions at <http://www.tsa.gov/travelers/airtravel/specialneeds/index.shtm>.
- * Inform the screener if someone has any special needs or medical devices.
- * Inform the screener if you think someone may become upset during the screening process as a result of their disability.
- * Offer suggestions on how to best accomplish the screening to minimize an outburst for the child.
- * Ask the screener for assistance during the process by helping you put your and the child's carry-on items on the x-ray belt.
- * Know that at no time during the screening process will they be separated from the child.
- * Tell the screener what are the child's abilities are.
- * Know that if a private screening is required, you should escort and remain with the child during the private screening process.

Transportation Security Administration Guidance

- * Know that all no time should the screener remove the child from his wheelchair. You are responsible from removing the child from his equipment at your discretion to accomplish screening.
- * Know that if your child is unable to walk or stand, the screener will conduct a pat-down search of your child while he/she remains in their mobility aid, as well as a visual and physical inspection of the equipment.
- Department of Transportation Information for the Air Traveler with a Disability at <http://airconsumer.ost.dot.gov/publications/horizons.htm>.
- Department of Transportation Information on Nondiscrimination on the Basis of Disability in Air Travel at <http://airconsumer.ost.dot.gov/rules/rules.htm>.
- Lots of Tips for Travelers with Special Needs will be at bottom of chart at http://www.fcps.edu/ss/prc/sports_rec_ops.pdf.

Emergency Preparedness Resources

- <http://www.ready.gov> from the U.S. Department of Homeland Security.
- <http://www.hhs.gov/od/emergencypreparedness.html> from the Department of Health and Human Services.
- <http://www.makeaplana.org> from the National Capital Region.
- <http://www.nod.org> from the National Organization on Disability. They have a “Prepare Yourself: Disaster Readiness Tips for People with Developmental or Cognitive Disabilities” available.
- <http://www.disabilitypreparedness.org> from the National Center on Disaster Readiness Tips for People with Developmental or Cognitive Disabilities.
- http://www.autism-society.org/site/DocServer/disaster_tips.pdf?docID=2881 from the Autism Society of America for disaster tips.

Emergency Preparedness Resources

- Autism Risk & Safety- Are You Prepared for an Autism Emergency? by Dennis Debbaudt at <http://www.autismriskmanagement.com/id1.html>.
- <http://www.cdihp.org/links.html#disaster> and http://www.cdihp.org/products.html#evac_guide from the Center for Disability Issues in the Health Professions and June Isaacson Kailes has a large list of resources in English and Spanish.
- <http://www.fema.gov/library/disprepf.shtm> from the Federal Emergency Management Agency.
- <http://www.redcross.org/services/disaster/beprepared/disability.html> from the Red Cross.

For more information, contact:

Scott Campbell

703 681-9426 (Office)

703 241-2640 (Home)

scott.alan.campbell@us.army.mil

Autism Awareness and Home Safety web link

at **http://www.poac-nova.org/base.cgim?template=autism_awareness**