

Autism Spectrum Disorders and Public Safety Considerations: Guidance for Families and Caregivers

**Parents Of Autistic Children-NoVA
meeting in Burke, VA
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From the Autism Society of Northern Virginia (ASNV) and
Parents Of Autistic Children of Northern Virginia (POAC-NoVA)

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What is an Autism Spectrum Disorder?

- Autism Spectrum Disorder is a developmental disability.
- New category added in the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5 of Social Communication Disorder, which will allow for a diagnosis of disability in social communication without the presence of repetitive behavior.
- Autism impacts the normal development of the brain in the areas of social communication impairment and restricted interests/ repetitive behaviors, including hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.
- Autism is a broad-spectrum neurological disorder that causes the brain to process information differently.
- It is not a mental or psychological disorder.
- Affects persons in varying degrees, symptoms & severity.
- Specific cause is unknown, & there is no definitive cure.

Autism Prevalence



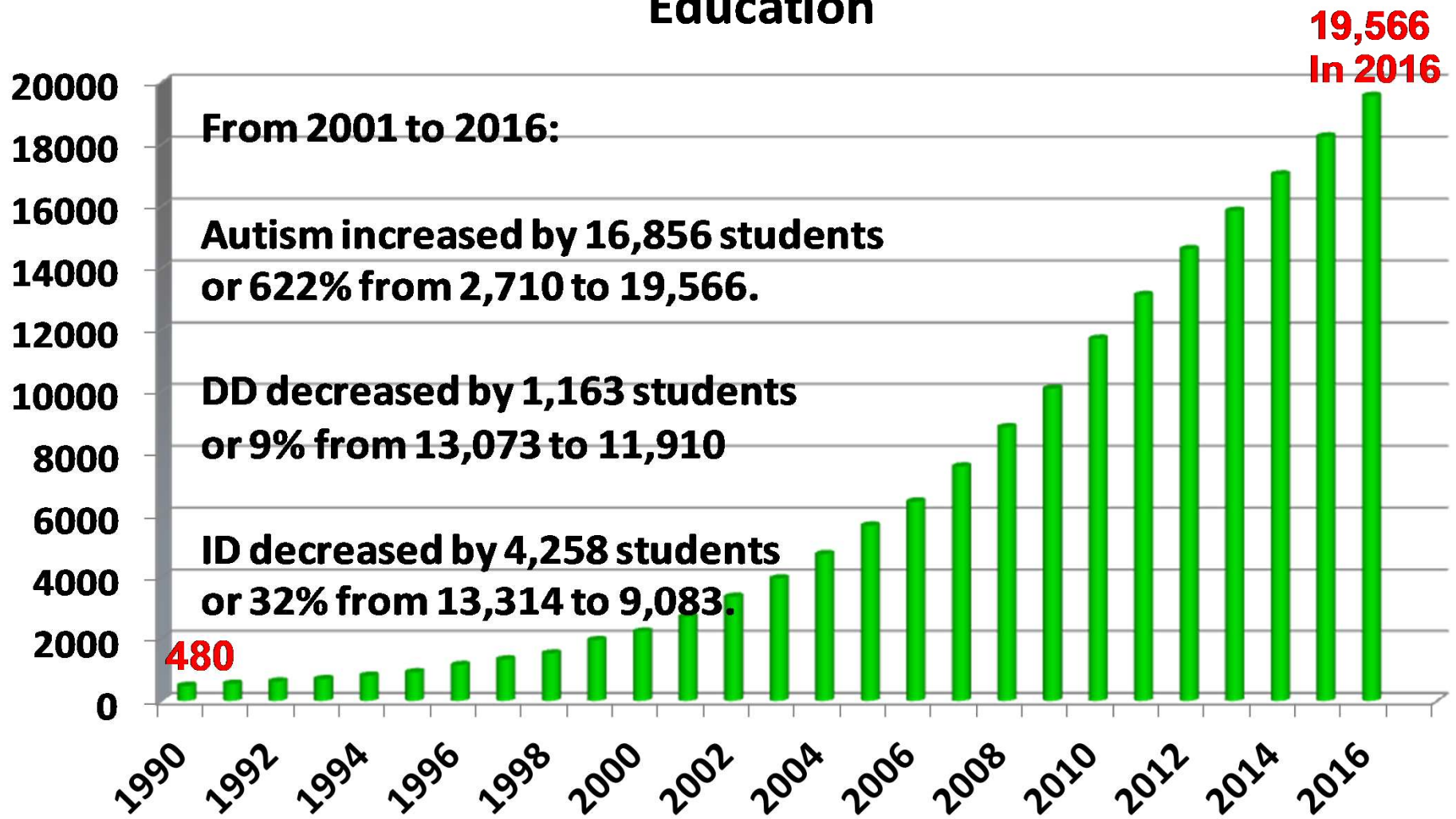
Autisms!

- No racial, ethnic, or social boundaries.
- Income, lifestyle and education levels have no effect.
- Affects over about one million Americans!
- America's fastest growing developmental disability at about 15% each year per the 2018 CDC Report.
- 4 to 5 times more prevalent for boys than for girls!
- Prevalence reports vary from year-to-year and by source.
 - CDC reports on surveys of 8 year olds went from 1 in 150 per 2000 report to 1 in 59 per 2018 report, which varies from 1 in 34 (NJ) to 1 in 77 (AR) in parts of 11 states.
 - 2013 National Health Statistics Report found 1 in 50 rate.
 - 2015 NHSR found 1 in 45 rate, per national phone survey.
- \$265B per year in autism's direct & indirect economic costs per 2015 Autism Speaks report, versus \$35B in 2006.

Student (ages 2 to 22) Autism Totals as of 12/16

Alexandria City	187
Arlington County	513
Clarke County	40
Fairfax County	3,518
Falls Church City	42
Fauquier County	159
Fredericksburg City	35
Loudoun County	1,325
Manassas City	91
Manassas Park City	60
Prince William County	1,365
Spotsylvania County	372
Stafford County	414
Warren County	95

Number of Virginia Public Schools Students Ages 2 to 22+ from Virginia Department of Education



Public Safety Risk Associated with Autism

- 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 or new situations 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.

Public Safety Risk Associated with Autism

- May not respond to stop or other instructions.
- 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 your words or body language. Often trained to be imitators!
- May answer no or why to all questions.
- May not recognize instruments of authority or understand what is expected of them if they do.
- Behaviors draw attention and may limit credibility.
- Elopement: lost and wandering. Trespassing. Stalking!
- Attracted to water, reflections, shiny objects, or high places.
- Some foods make the symptoms and behaviors worse.

Elopement Risk Associated with Autism

- 2012 Kennedy Krieger Institute study: “49% of children with autism wander from a safe setting, a rate nearly four times that of their unaffected siblings”.
- More than one third of children who elope are never or rarely able to communicate contact information.
- Two in three parents report their missing children had a “close call” with a traffic injury.
- 32% of parents report their missing children had a “close call” with a possible drowning.
- Wandering was ranked among the most stressful ASD behaviors by 58% of parents of elopers.
- 62% of families were prevented from attending activities outside the home due to fear of wandering.

Public Safety Risk Associated with Autism

- Three times more likely to have to quit their jobs or reduce work hours to care for their kids. (Kogan, 2008)
- Significantly higher stress levels of 80-90% \neq Divorce!
- 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)

Public Safety Risk Associated with Autism

- “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)
- 83% of the developmentally disabled females and 32% of males are the victims of sexual assault. (Johnson & Sigler, 2000)
- 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)
- 49% of people with developmental disabilities who are victims of sexual violence will experience 10 or more abusive incidents. (Valenti-Heim & Schwartz, 1995)

Public Safety Risk Associated with Autism

- 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)
- 78% of autistic adults reported at least one occurrence of sexual victimization compared to 47.4% of the adults without an ASD . (Brown, 2014)
- 81% of child sexual abuse incidents for all ages occur in one-perpetrator/one-child circumstances. (Snyder, 2000)
- Multiple studies show that approximately 90% of individuals with developmental disabilities know their abusers/ care givers.

Common Reasons for First Response

- Often seek water sources, leading to 91% of deaths children with an ASD (ages 14 and younger) after wandering/elopement. (NAA 2009-2011 Study).
- Person appears to be a threat due to suspected substance abuse or obsessive/ compulsive behaviors.
- Acting out, running into traffic, enter homes of others, looking into windows of homes, or in unsafe position.
- Elopement prevention and care may look like abuse, or actions are misinterpreted.
- Lack of ability to prevent elopement or self-injurious behaviors may lead to criminal charges.
- Injury or death of a disabled individual or by them accidentally. (219 disabled deaths from 2011 to 2015)

Emergency Behavioral Assistance

- **Regional Educational Assessment Crisis Response and Habilitation (REACH)** provides emergency family crisis services and behavioral assistance for individuals with ID/DD of any age in NoVA by calling Easterseals UCP at **855-897-8278 anytime**.
- Get more info on REACH, by contacting Virginia DBHDS at (804) 540-5012 or (804) 786-5850 or <http://23.29.59.140/developmental-services/Crisis-services>.
- Fairfax County Mobile Crisis Unit at **703-573-5679 from 8am to midnight**.
- If requesting police help, ask for CIT-trained officer!
- If arrest occurs, use the Arc's Justice Advocacy Guide at <http://www.thearc.org/document.doc?id=3669>.

Autism and Medications

- 64% had a filled prescription for at least one psychotropic medication.
- 35% had used more than one at a time.
- 15% had used more than three at a time.
- Despite minimal evidence of the effectiveness or appropriateness of multidrug treatment of ASD, psychotropic medications are commonly used, singly and in combination, for ASD. (Spencer, 2013)
- “A higher percentage of children insured by Medicaid or the Children’s Health Insurance Program used prescribed medication for emotional or behavioral difficulties than children with private health insurance or no health insurance.” (Howie, 2014)

Autism and Life Expectancy (Sweden)

- Average life expectancy of only 39 years for those with autism and a learning disability, versus 70 years for the general population.
- “Autistic adults with a learning disability are 40 times more likely to die prematurely due to a neurological condition, with epilepsy the leading cause of death (20 to 40% versus 1% in general population).”
- “Autistic adults without a learning disability are 9 times more likely to die from suicide.”
- “Almost 80% of autistic people experience mental health problems, including anxiety, depression and ADHD.”
- Plus less diet, lack of exercise, and medication problems.

(From 2015 Swedish study published at <https://www.autistica.org.uk>.)

Autism and Life Expectancy (US)

- Study conducted between 2009 and 2014 with 1,367 autism deaths out of over 39 million reviewed.
- Those with an autism diagnosis were three times more likely to die from injuries than the rest of the general population.
- Autistic children are 40 times more likely to die from injuries than the general child population.
- Three causes make up 80 percent of those childhood injuries are suffocation, asphyxiation and drowning.
- Because of this, the average age for those with autism is just 36, compared to 72 for the general population.

(From Joseph Guan and Guohua Li. Injury Mortality in Individuals With Autism. American Journal of Public Health: May 2017, pp. 791-793.)

Why Proactive Preparations!

Survey of 124 police officers of various ranks in Northern California (Modell & Mak, 2008):

- 56% did not know the difference between mental and physical disabilities.
- 80% were unable to describe characteristics of autism.
- 48% indicated that they had received no training on disabilities, and an additional 45% indicated that they had minimal training.
- Finally, 63% of officers indicated that they would like to receive more training on people with disabilities and how to work with them.

Proactive Community Involvement

- DISCLOSE - Display autism notification and safety items!
- Get Virginia “Unlocking Autism” license plates.
- 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.
- Invite your school safety officer to an IEP meeting (BIP?).
- Autism and an IEP are not a get-out-of-jail free card!
- Get a “Kismart Vocal Smoke Detector”, if needed.
- In 911 situation, ask to ride with your child.

Examples of Autism Safety Items

Safe and Sound Personal Information Record for Caregivers and Emergency Responders - Includes Static Cling label for posting in residence, vehicle or workplace and Information Record to be filled out for caregivers or emergency personnel.



The image shows a 'Safe and Sound' form and a corresponding static cling label. The label is yellow with a black border and features a large exclamation mark inside a triangle. Text on the label includes 'IN CASE OF EMERGENCY', 'OCCUPANT WITH AUTISM MAY', and 'AUTISM SOCIETY'. The form below is a detailed record for caregivers and emergency responders, with sections for personal information, medical history, and emergency contacts. It includes a 'Safe and Sound' logo at the bottom left.

This individual has autism.

Autistic individuals may experience difficulty in certain situations that may cause them to exhibit undesirable behaviors. These outbursts often happen for no apparent reason and may be due to their inability to tolerate the present environment. The occurrence of these tantrums is a symptom of this condition and is not due to a lack of appropriate parenting skills.

For more information on autism and safety, please visit the Autism Society of Northern Virginia web site at www.asnv.org or call (703) 495-8444.

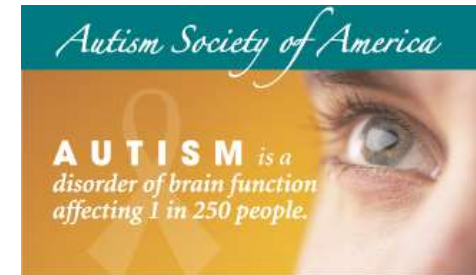
Thank you for your understanding

I have Autism.

My medical condition impairs my ability to communicate with others. As a result, I may have significant difficulty understanding your directions, and may not be able to quickly respond to your questions. I may also become physically agitated if you touch or move too close to me. I may have considerable sensory sensitivities and physical, self-stimulatory behaviors that may complicate the situation.

Please do not interpret my behaviors as a refusal to cooperate. I am not intentionally defying your instructions.

Over Please →



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



I am requesting that you immediately contact the person noted below on my behalf. They will confirm my medical diagnosis and provide crucial information on my identity and how to safely and effectively interact with me to better ease the situation.

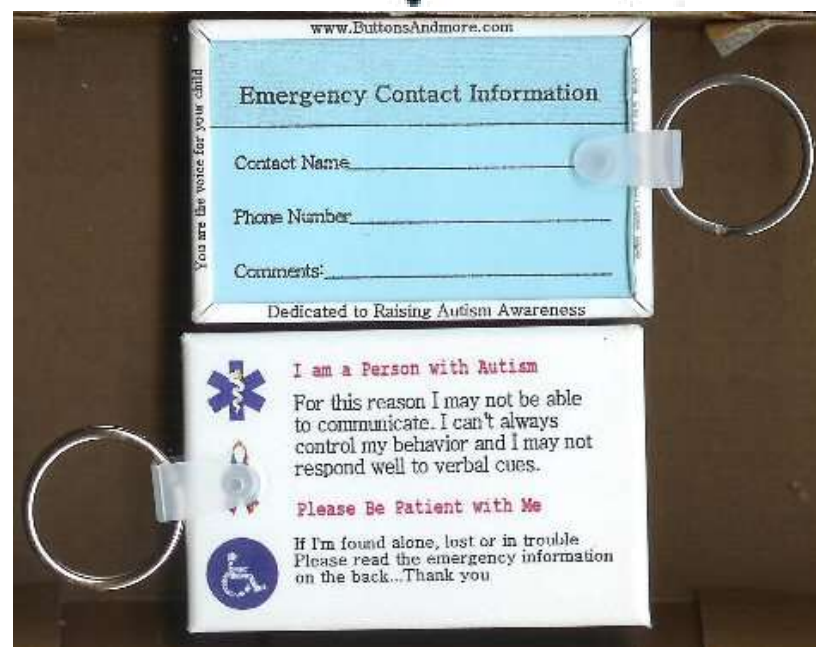
Thank you for your understanding!

My Name _____ Contact Person's Name _____
Contact Person's Phone Number: _____

Examples of Autism Safety Items



Examples of Autism Safety Items



911 Flags for Local Dispatchers

- 911 flags with key dispatch data to alert first responders for your “**location of interest**”.
- Understand and consider risks of autism for all first responder professionals - police, fire, EMT and ER.
- Information sheets at 911 data base with name, address, phone numbers and emergency contacts, including:
 - Name of individual with autism.
 - Current photograph and physical description including height, weight, eye and hair color, and any ID marks.
 - Names, home and cell phone numbers and addresses of parents or caregivers and emergency contact persons.
 - Sensory, medical, or dietary issues, if any.
 - Inclination for elopement and any atypical behaviors or characteristics that may attract attention.
 - Possible compulsive activity.

911 Flags for Local Dispatchers, Continued

- Favorite attractions and locations where may be found.
- Likes, dislikes - approach and de-escalation techniques.
- Method of communication, if non-verbal iPad, sign language, or picture boards (PECS).
- ID wear jewelry, tags, info cards, or in their clothing.
- Map and address guide to nearby properties with water sources and dangerous locations highlighted.
- Blueprint or drawing of home, with bedroom of individual highlighted for fire-fighting purposes.

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

- “Yellow Dot Program” from Fairfax County Fire and Rescue Department for ID in a vehicle. Call for more information at 703 246-3801.

Sources for Autism Safety Information

At the “Autism Spectrum Disorders and Public Safety Considerations References and Websites” list.

- “Section A: Recommended autism safety references web sites for families”- information articles on many safety topics.
- “Section B: Recommended autism safety web sites for families in Virginia’ – VA specific information.
- “Section C: Recommended web sites for autism safety items for families”, including ID forms and cards.
- “Section E: Recommended Sex Offender Registry web sites for families “, including <http://sex-offender.vsp.virginia.gov/sor> for the Virginia State Police Sex Offender and Crimes Against Minors Registry.

Autistic Child in Area Signs



- Traffic signs and signals are maintained by the Virginia Department of Transportation (VDOT). For more info, contact VDOT at 703 383-8368.
- Photo from article titled "Sign of relief" dated 17 March 2006 by Andy Rathbun from The Battle Creek (MI) Enquirer.
- Another Associated Press article titled "Rochester's 'Autistic Child' signs are among the first in the nation" dated 27 February 2007.

Child Abduction Information

Key Findings from 2006 Child Abduction Murder Study from Washington State Attorney General's Office:

- In 74 percent of nearly 800 solved missing children homicide cases studied, the child murder victim was female and the average age was 11 years old.
- In 44 percent of the cases studied, the victims and killers were strangers, but in 42 percent of the cases, the victims and killers were friends or acquaintances.
- The primary motive for the child abduction killer in the cases studied was sexual assault.
- In nearly 60 percent of the cases studied, more than two hours passed between the time someone realized the child was missing and the time police were notified.

Child Abduction Information

	Time Period Reports for Missing Children	When Abducted Child is Killed
Immediately	19.6%	
Within 1 Hour	27.5%	46.8%
Within 2 Hours	42.9%	
Within 3 Hours		76.2%
Within 4.5 Hrs	68.4%	
Within 24 Hrs	86.6%	88.5%
Over 24 Hours	99.0%	
Within 7 Days		97.9%
Within 30 Days		100%

Child Abduction Information

- Key recommendations to protect children from 2006 Child Abduction Murder Study:
- Be aware that children are not immune from abduction because they are close to home. More than half of abductions took place within three blocks of the home.
- Be certain that your children are supervised – even if they are in their own front yard or neighborhood street. Approximately one-third of the abductions occurred within one-half block of the victim's home.
- Teach your children not to ever approach a car– whether the occupant is a stranger or not– no matter what the occupant the tells them or asks them.
- If your child is ever missing, **CALL POLICE NOW!**

Project Lifesaver




<http://www.projectlifesaver.org>

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 October 2018, have located 3,484 individuals in over 1,500 locales in all 50 states and 6 provinces.
- Initially, 95% located are Alzheimer's adults and 5% are individuals with autism or other developmental delay.
- Put "In Case of Emergency" (ICE) emergency contact information into the person's cell phone or iPad at <http://icecontact.com> or <http://www.ice4autism.com>.

GPS Tracking Systems Options

- “Section D: Recommended web sites for tracking and locator systems for families” has a wide variety of tracking and locator system options are available using GPS devices in cell phones and clothing.
- Of note, is the FREE Safelink Wireless cell phone and service at
<https://www.safelinkwireless.com/Enrollment/Safelink/en/Public/NewHome.html>.
- Qualification criteria for Virginia residents is at
http://www.autismva.org/sites/default/files/4-24-12_safelink_wireless.pdf.
- <https://www.autismfyi.org> for Autism FYI, which
 operates a national 24-hour autism registry hotline connected to local 911 systems.

Other Locator Options

- Amber Alert programs do not apply, but ask about alert procedures in stores you go to frequently.
- Free DNA kit at <http://someoneismissing.com/dna-kits>.
- “Walker” or “Non-Driving ID” cards from Virginia DMV <https://www.dmv.virginia.gov/webdoc/pdf/dl1p.pdf>.
- <http://www.autismdailynewscast.com/free-individualized-wallet-card-individuals-autism/24662/snapshot> for a free wallet card from the Disability Independence Group.
- Parking placards for Virginia disabilities application at <https://www.dmv.virginia.gov/webdoc/pdf/med10.pdf>.

Elopement Prevention

- Place slide or dead bolt locks out of reach or out of sight.
- Use double-bolt locks, but make sure a key is readily available in case of an emergency.
- Reverse door knobs to be able to lock them in a room.
- Cover door knobs to make turning more difficult. Add child safe plastic covers or socks, so that only the cover turns and not the knob.
- Use “Do Not Enter”, “No!”, or “STOP!” signs or labels to explain purpose of each room or discourage entry to particular rooms.
- Place Plexiglass or bars on exterior windows.
- Place locks on all exterior fences. High fences common.

Elopement Prevention

- Disengage garage door openers.
- Place warning bells above doors or on door knobs.
- Place a pressure-sensitive mat at doors or person's bedside that sounds an alarm to alert you to movement.
- Install video monitors or a security system to check movement in certain rooms or exterior doors.
- Engage the child safety lock or have the inside door handle removed on your car's back seat door.
- Use seat belt buckle guards to reduce removal.
- Dress the person in bright colored shirts and coats for a quicker, positive search results!

Students with autism need education to help them respond when bullied/ disability harassed

- Kennedy Krieger Institute study: “children with ASD (39%) were bullied at a rate more than three times higher than that of their unaffected siblings (12%)” in past month. (Anderson, 2012)
- “Children with ASD attending regular public schools are bullied at a rate of nearly 50% more than children in private school or special education settings.”
- Do not understand that other people have their own points of view.
- Have difficulty understanding the emotions, beliefs, and attitudes of others. Do not have the social skills to avoid bullies.

Students with autism need education to help them respond when bullied/ disability harassed

- Cannot anticipate what others will do or say in many situations.
 - Engage in behaviors that are “odd”.
 - Do not realize they are being bullied.
 - Want friends at any cost.
 - If they do report, they do not explain it well.
 - Potential risk of suicide!
-
- More information at “Section H: Recommended web sites for information on bullying and disability harassment prevention”.

Signs Bullying/ Disability Harassment Occurred

- Torn, damaged, missing clothes or belongings.
- Unexplained cuts, bruises, or scratches.
- Frequent headaches, stomach aches, other ailments.
- Change in eating behavior or response to medications.
- Fear of going to bus, school, or participating in peer activities. Increased isolation from friends or siblings.
- Increased moodiness, sadness, depression, trouble sleeping, or frequent bad dreams.
- Increased anxiety or decreased self-esteem.
- Increased self-destructive behaviors, such as running away, self-injurious behaviors, or talking about suicide.

Bullying versus Disability Harassment

- Repeated bullying IS disability harassment and a potential violation of Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act.
- Could apply to any student with an IEP or 504 plan.
- “Harassment of a student based on disability may decrease the student's ability to benefit from his or her education and amount to a denial of a Free and Appropriate Public Education.” (OCR Letter, 2010)
- “Schools should have well-publicized policies prohibiting harassment and procedures for reporting.”
Recommends a prompt, thorough, and impartial investigation usually within 10 days.

Bully Proofing Behaviors to Protect Victims

CALM Approach:

- **C - Cool down.** When you confront the bully, stay calm and always in control. Don't let him think he's getting to you. And most importantly: tell your child to always get help whenever there is a chance she might be injured.
- **A - Assert yourself.**
- **L - Look at the teaser straight in the eye.** Appear confident, hold your head high, and stand tall.
- **M - Mean it!** Use a firm, strong voice. Say what you feel, but don't be insulting, threaten, or tease back.

From Michele Borba, Ed.D. at

<http://www.micheleborba.com/Pages/ArtBMI03.htm>.

Bully Proofing Behaviors to Protect Victims

HA HA SO Approach:

- Help - get help for yourself and others.
- Assert - say “I feel ____ when you _____. Please stop.”
- Humor - about the comment, not the bully.
- Avoid - walk away.
- Self-Talk - say good things about your self.
- Get Out - walk away and tell self it is not true.

From Carol Schall, Ph.D., Director of Virginia Autism Resource Center at <http://128.172.18.193/index.cfm>.

What To Do When Cyber-bullying Occurs

Cyber-bullying- Spreading of harmful information or lies about others through email, online chats or blogs, text messages, cell phones, or cameras.

Steps to take when cyber-bullying occurs:

- Do not respond or forward cyber-bullying messages.
- Document. Print and save any electronic messages.
Keep a record of all incidents.
- Block the person who is cyber-bullying.
- Report cyber-bullying to online services providers and school staff if it occurred at school.

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.
- Recognize inappropriate touching or sexual come-ons.
- How to report bullying, teasing and taunting incidents.
- If problem behaviors, request Functional Behavioral Assessment and Behavioral Intervention Plan.

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

- Do not attempt to flee or 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, backpack, or a car glove box.
- Show medical alert bracelet/ necklace, or ID & info cards.
- Carry phone numbers of autism advocacy organizations.
- When to invoke the right to remain silent and ask to speak to an attorney.
- Ask officer to contact a family member or advocate, if necessary and possible before the interview process.

Other Sources for Autism Safety Information

Also at the “Autism Spectrum Disorders and Public Safety Considerations References and Websites” list.

- “Section F- Recommended autism and sexuality web sites for families”
- “Section G: Recommended autism and air travel web sites for families”
- “Section H: Recommended information on bullying and disability harassment prevention for families and school staff”

Emergency Preparedness Resources

- What to do in local emergency- where do you meet if there is a fire in your house? Who gets the person with the disability out of the house?
- What to do in a regional emergency- where do you go if have to leave and may never come back? What do you take if you only have 15 minutes to pack up what matters? What matters?
- “Section I: Recommended emergency preparedness web sites for families”.

For more information, contact:

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Visit Autism Spectrum Disorders and Public Safety
Considerations References and Websites information from
the Autism Society of Northern Virginia at

<http://www.asnv.org/education>,

or from POAC-NoVA at **<http://poac-nova.org/wp-content/uploads/2017/02/PSWG-ASD-Safety-Training-for-Families-Websites2.5.doc>**