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Love, equity, and access for young people with disabilities

WANDERING AND SAFETY



According to the National Autism Association, "wandering is the tendency of an individual to leave the safety of a responsible person's care or safe area, which may result in potential harm or injury." Other names for wandering are running, bolting, or elopement.

Ways to keep your children safe

1. Supervise your child at all times.
2. Get your child a tracking device and/or wearable identification.
3. Secure your home. You can install alarms, door chimes, and/or deadbolts.
4. Learn what triggers your child to wander and devise strategies to minimize these triggers.
5. Be conscious of what your child is wearing when they go out into the community.
6. Create a family emergency plan.
7. Have a recent photo of your child with you at all times.
8. Teach your child skills to stay safe, including learning how to swim. (Remember that this does not guarantee safety but it helps.)
9. Create social stories for your child that can help them understand how to be safe at home and in the community.
10. Notify first responders and trusted neighbors of your child's tendency to wander.
11. Inform school and program staff (including non-school programs) that your child wanders. You can include this information on their Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP). This keeps school and program staff accountable and aware.

Please visit www.awaare.org for more information and resources.

AUTISM & WANDERING

In 2008, Danish researchers found that the mortality rate among the autism spectrum disorder (ASD) population is twice as high as the general population. In 2001, a California research team found that elevated death rates among those with ASD were in large part attributed to drowning.

Drowning often occurs as a result of wandering off. **Drowning, along with prolonged exposure and other factors, remain among the top causes of death within the autism population.** Although there is no known data that recognizes whether deaths associated with wandering are on the rise within the autism population, anecdotal reports suggest an increase.

There are various reasons someone with ASD may wander. Many parents report their child gravitates towards water, so nearby lakes, ponds and creeks may continue to be a desired destination. Too, someone with ASD is likely aware when attention has shifted away from them and will take the opportunity to slip out quickly in order to reach a desired area or item of interest.

Family gatherings or other events may give a false impression of “all eyes on” someone with ASD. However, heavy distractions can present opportunities to leave unnoticed. Visiting relatives or episodes of distress also may increase the risk for wandering. This also holds true in warmer months when persons with ASD are more likely to play outside or attend summer or day camps.

WANDERING CAN OCCUR ANYWHERE AT ANYTIME. THE FIRST TIME IS OFTEN THE WORST TIME.

Join Autism Wandering Prevention on Facebook



CAREGIVER RESOURCES

AWAARE COLLABORATION

awaare.org

NAA/UA AUTISM SAFETY TOOLKIT

nationalautismassociation.org/safetytoolkit

AUTISM SPEAKS AUTISM SAFETY PROJECT

autismsafetyproject.org

ASA SAFE & SOUND SAFETY INITIATIVE

autism-society.org

CHILD SAFETY PRODUCTS

mypreciouskid.com

SelectAutismMerchandise.com

tattooswithapurpose.com

SERVICE DOGS

autismservicedogsofamerica.com

4pawsforability.org

TRACKING SYSTEMS & MEDICAL DEVICES

Project Lifesaver: projectlifesaver.org

LoJack SafetyNet: lojacksafetynet.com

EmFinders: emfinders.com

Caretrak Systems: caretrak.com

Alzheimer's Comfort Zone: alz.org/comfortzone

Medicalert: medicalert.com

A Child is Missing: achildissing.org

FOR FIRST RESPONDERS & CAREGIVERS

National Center for Missing and Exploited Children:

missingkids.com | 1-800-THE-LOST

Autism Risk Management:

autismriskmanagement.com

The Autism & Law Enforcement Education Coalition:

sncarc.org/alec.htm

The Law Enforcement Awareness Network

leanonus.org

Autism Alliance for Local Emergency Responder

Training: AutismAlert.org

SUPPORTING ORGANIZATIONS:

Designed & Printed by: National Autism

Association & Talk About Curing Autism

Supported By: Age of Autism | Autism One | Autism

Research Institute | Autism Speaks | Doug Flutie Jr.

Foundation for Autism | HollyRod Foundation |

National Autism Association | Safeminds | Talk About

Curing Autism



prevention | safety tips | resources

SECURE YOUR HOME

Consider contacting a professional locksmith, security company or home improvement professional to promote safety and prevention in your home. **You may find it is necessary to prevent your loved one from slipping away unnoticed by:**

- ✓ Installing secure dead bolt locks that require keys on both sides.
- ✓ Installing a home security alarm system.
- ✓ Installing inexpensive battery-operated alarms on doors and windows to alert you when opened (available at stores like Walmart and Radio Shack).
- ✓ Placing hook and eye locks on all doors, above your child's reach.
- ✓ Fencing your yard.
- ✓ Adhering printable STOP SIGNS to doors, windows and other exits, such as gates.

CONSIDER A TRACKING DEVICE

Check with local law enforcement for Project Lifesaver or LoJack SafetyNet services. These tracking devices are worn on the wrist or ankle and locate the individual through radio frequency. Various GPS tracking systems are also available. See the **RESOURCES** section within this pamphlet for more information.

CONSIDER AN ID BRACELET

Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is non-verbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information. See the **RESOURCES** section within this pamphlet for more information.

TEACH YOUR CHILD TO SWIM

Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on. **REMEMBER:**

- ✓ Teaching your child how to swim DOES NOT mean your child is safe in water.
- ✓ If you own a pool, fence your pool. Use gates that self-close and self-latch higher than your children's reach.
- ✓ Remove all toys or items of interest from the pool when not in use.
- ✓ Neighbors with pools should be made aware of these safety precautions and your child's tendency to wander.

The American Academy of Pediatrics does not recommend swimming classes as the primary means of drowning prevention. Constant, careful supervision and barriers such as pool fencing are necessary even when children have completed swimming classes. All families are encouraged to seek training in swimming, lifesaving, first aid and cardiopulmonary resuscitation.

ALERT YOUR NEIGHBORS

It is recommended that caregivers plan a brief visit with neighbors to introduce their loved one or provide a photograph. **Knowing your neighbors can help reduce the risks associated with wandering.**

- ✓ Give your neighbor a simple handout with your name, address, and phone number.
- ✓ Ask them to call you immediately if they see your child outside the home.
- ✓ Decide what other information to present to neighbors.
- ✓ Does your child have a fear of cars and animals or is he/she drawn to them?
- ✓ Does your child gravitate towards pools or nearby ponds or creeks?
- ✓ Does he/she respond to their name or would a stranger think they are deaf?
- ✓ Are there sensory issues or meltdown triggers your neighbors should know about?

ALERT FIRST RESPONDERS

Providing first responders with key information before an incident occurs may improve response. **Informational handouts should include all pertinent information, and be copied and carried with caregivers at all times.** Circulate the handout to family, neighbors, friends and co-workers, as well as first responders.

- ✓ Name of child or adult, current photograph and physical description including any scars or other identifying marks
- ✓ Identify your child's favorite song, toy or character
- ✓ Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- ✓ Sensory, medical, or dietary issues and requirements
- ✓ Favorite attractions and locations where the person may be found
- ✓ Likes, dislikes, fears, triggers, and de-escalation techniques
- ✓ Method of communication: note if nonverbal, uses sign language, picture boards, or written words
- ✓ ID wear, jewelry, tags on clothes
- ✓ Map and address guide to nearby properties with water sources and dangerous locations highlighted

Additional tips can be found at autismriskmanagement.com (above information courtesy of Dennis Debbaudt)

For a generic form that can be used by any caregiver, regardless of city or state, visit AWAARE.org.

SEARCH & RESCUE CHECKLIST | MISSING PERSONS WITH AUTISM

- ✓ Treat each case as CRITICAL. Children with autism have an impaired sense of danger and face immediate risk
 - ✓ Interview and listen to caregivers, they know best the areas their child may be seeking
 - ✓ Ask if the child wears a personal tracking device. If so, immediately initiate tracking measures
 - ✓ SEARCH WATER FIRST. Immediately dispatch personnel to nearby bodies of water. Ask about any pools, rivers, ponds, etc. in the area to which the child may be especially drawn.
 - ✓ Ask about other dangers that the child may be attracted to; busy roads/highways/construction sites, etc. and immediately dispatch personnel to secure those areas
 - ✓ Ask about child's likes that may assist in search efforts – will they be drawn to certain music, favorite characters, fire trucks, etc.
 - ✓ Ask about child's dislikes and fears or sensory issues that may hinder search efforts (Dogs, Sirens, Aircraft, Lights, Shouting)
 - ✓ Ask if the child will respond to his/her name when called
-
- ✓ Immediately implement Reverse 9-1-1 (A Child is Missing)
 - ✓ Issue an Endangered Missing Advisory (EMA)
 - ✓ Continue search efforts even when all hope is lost. Past cases have shown that children/adults with autism can survive a long time.

Once the child/adult is found:

- ✓ Maintain a calm and relaxed environment
- ✓ Speak in a normal tone of voice using simple phrases
- ✓ Bring caregiver to the recovery site as quickly as possible
- ✓ Avoid the use of dangerous restraints

For more information visit awaare.org/lawenforcement.htm

LAW ENFORCEMENT & MISSING PERSONS WITH AUTISM

If you work in law enforcement, chances are you will encounter a child or adult with autism, or be involved in searching for an individual with autism who has wandered away. An increase in autism cases (up from one in 10,000 in the 80's to one in 88 today) is likely the reason for more wandering cases and deaths, and first responders play a critical role in preventing these deaths.

Individuals with autism are often attracted to water, yet have little to no sense of danger. **Drowning is a leading cause of death in children with autism.**

There are four important tools that can be used to improve response time and prevent fatalities including: **1) Having readily available information about an individual with autism; 2) Technology, such as tracking technology or Reverse 911; 3) Alert Systems, such as Endangered Missing Advisories; 4) Training on how to properly interact with a person who has autism.**

GATHERING INFORMATION ABOUT A PERSON WITH AUTISM WHO MAY WANDER:

Having detailed information on file about someone with autism can be very effective in locating them quickly. If your agency does not have a program in place specific to autism wandering, consider distributing a First Responder Form through your web site or grassroots initiatives. Forms may also be found in multiple languages at autismriskmanagement.com. Having caregivers fill out this information **before** their child with autism wanders could give your agency a headstart in properly responding to an emergency situation. **A database software called "Take Me Home" is free and available to agencies.** To learn more about Take Me Home, contact **Officer Jimmy Donohoe at 850.436.5416 or Jdonohoe@ci.pensacola.fl.us**.

TAKING A 5W "JUST ADD WATER" APPROACH TO PREVENTION & RESPONSE

When asking a caregiver questions about their child with autism, be sure to take a 5W approach: **Who, What, Where, When, Water.**

WHO: this would include the basic details about the child/adult, as well as the official diagnosis, cognitive age, and any identifiable mannerisms or unique behaviors.

WHAT: what are the child's likes or dislikes? For example, if the child likes Elmo's voice, this may be a valuable tool during search-and-rescue efforts, while understanding their dislikes may help prevent complications during a search.

WHERE: where does the caregiver think the child might go, or be? Listen to caregivers for clues, they know the child best.

WHEN: when has the child wandered before and how were they located?

WATER: ask about, and document, nearby water sources. **Always search water sources first.** Sixty-eight percent of children with autism who died between 2009 & 2011 were found in either a pond, creek, lake or river.

TRACKING TECHNOLOGY & REVERSE 911 FOR AGENCIES

There are various resources to help law enforcement agencies. The cost to implement tracking programs is extremely low compared to one search-and-rescue effort. To learn more about tracking programs, please visit ProjectLifesaver.org or LoJackSafetyNet.com. You can also enroll your agency into **A Child Is Missing Program**. This **Reverse 911 is FREE to agencies**, and will send an automated call to neighborhoods where a missing child was last seen. Visit achildissing.org or call **954.763.1288**.

ENDANGERED MISSING ADVISORIES

Because there have been numerous cases where a child with autism was found by a member of the public, it's important to review alert guidelines within your state and **issue an Endangered Missing Advisory (EMA)**. Many children with autism who appear old enough to walk alone are often at great risk, especially those that are nonverbal, cannot ask for help, or are unable to respond to their name. **For EMA GUIDELINES (Free Service) visit ncjrs.gov**

COMPREHENSIVE AUTISM TRAINING

To review these options, please visit: autismriskmanagement.com | sncarc.org/alec.htm | leanonus.org | AutismAlert.org. For information on wandering, please visit AWAARE.ORG. For specific questions, please contact the National Autism Association at **877-622-2884, or 877 NAA AUTISM.**

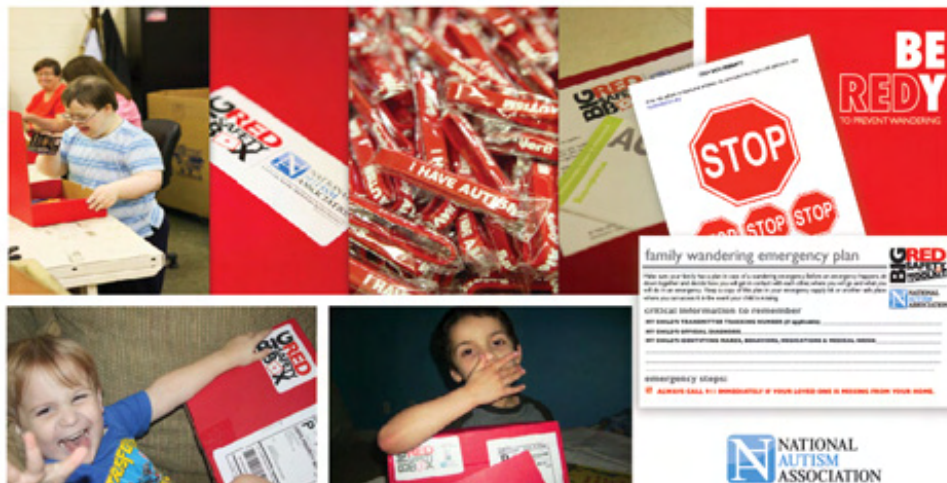


The **National Autism Association** is committed to those with an Autism Spectrum Disorder (ASD) who may be prone to wandering off or eloping from a safe environment, and may be unable to recognize danger and/or stay safe. Wandering, elopement, “running” or fleeing behaviors among those within our community not only present unique safety risks, but also create extraordinary worry and stress among caregivers. Drowning fatalities following wandering incidents remain a leading cause of death among those with ASD. The Big Red Safety Box is a free-of-charge toolkit given to autism families in need as a means to educate, raise awareness and share simple tools that may assist them in preventing, and responding to, wandering-related emergencies. For more information, or to request a Big Red Safety Box, visit <http://nationalautismassociation.org>.

NAA’s Big Red Safety Box includes the following resources:

- 1) Our Be REDy Booklet containing the following educational materials and tools:
 - A caregiver checklist
 - A Family Wandering Emergency Plan
 - A first-responder profile form
 - A wandering-prevention brochure
 - A sample IEP Letter
 - A Student Profile Form
- 2) Two (2) GE Wireless Door/Window Alarms with batteries
- 3) One (1) RoadID Personalized, Engraved Shoe ID Tag
- 4) Five (5) Adhesive Stop Sign Visual Prompts for doors and windows
- 5) Two (2) Safety Alert Window Clings for car or home windows
- 6) One (1) Red Safety Alert Wristband

Regardless of any tools caregivers may have in place, if a loved one’s medical condition interferes with their ability to recognize danger or stay safe, it is critical that caregivers maintain close supervision and security in all settings.



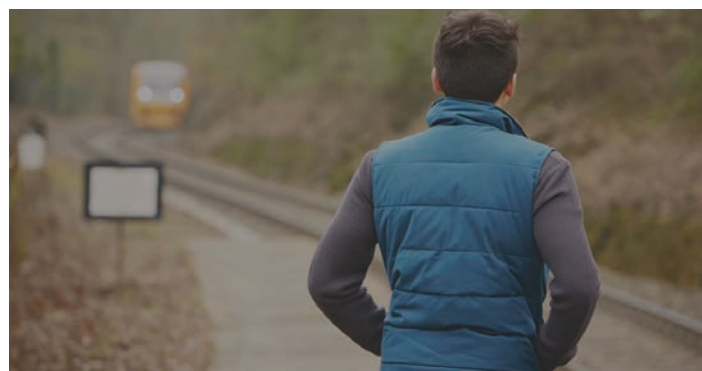


NEARLY HALF OF CHILDREN WITH AUTISM WANDER AWAY FROM SAFE SETTINGS.

The Big Red Safety Box is designed to help prevent a wandering incident.



awareness



safety tools

education



Part of the Big Red Safety Box Program brought to you by the National Autism Association



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

Dear Recipient;

If you are receiving this **Big Red Safety Box** it means you are a caregiver for someone with an Autism Spectrum Disorder (ASD) who is prone to wandering off from a safe environment, and whose diagnosis may interfere with their ability to recognize danger and/or stay safe.

Wandering, elopement, “running” or bolting behaviors among those within our community present unique safety risks, and create extraordinary worry and stress among caregivers. **Drowning fatalities following wandering incidents remain a leading cause of death among those with ASD.**

The National Autism Association is committed to providing direct aid and support to those at risk. As such, we are pleased to provide you with this toolkit. To follow, you’ll find the following tools and resources:

- *Caregiver Checklist*
- *Swimming Lessons Tool*
- *Root-cause Scenario & Strategies Tool*
- *Stop Sign Prompts*
- *Social Story: “Staying in my house”*
- *Sample IEP Letter (Never allow restraint/seclusion practices into any IEP as this increases associated risks.)*
- *Sample Physician’s Letter*
- *How To Get Tracking Technology In Your Town*
- *General Awareness Letter: share with schools, homeowner’s association, law enforcement agencies, physicians, etc.*
- *Five Affordable Safety Tools*
- *Caregiver Resources One-sheeter*
- *Family Wandering Emergency Plan*
- *First-responder Alert Form (Please fill out and provide a copy to your local law enforcement agencies.)*
- *Calming Cards Sheet*
- *Student Profile Sheet*
- *Wandering-prevention One-Sheet*

Regardless of any tools you may have in place, if your loved one’s diagnosis interferes with their ability to recognize danger or stay safe, it is critical that you maintain close supervision and security in your home.

We hope you’ll find this safety box helpful. For more information on wandering-prevention, visit nationalautism.org.

Sincerely,

The National Autism Association

All materials in this safety TOOLKIT are provided for your INFORMATION only and do not constitute medical advice or an endorsement of any clinical or therapeutic method, treatment, service, safety device, safety product, organization or vendor. National Autism Association is not responsible for the content produced by, or the services rendered by, any third party that is referenced, or to which access may be provided via this safety toolkit



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ABOUT AUTISM & WANDERING

Autism Spectrum Disorder (ASD) is a developmental disability that may range from mild to severe and presents with social, communication, and behavioral challenges, as well as unique safety risks. According to Centers for Disease Control (CDC), 1 in every 68 individuals is diagnosed with an ASD.¹ CDC also estimates that 40% of those with an ASD are unable to speak.²

AUTISM & WANDERING

Wandering – also referred to as elopement, bolting, fleeing, or running – is the tendency for an individual to leave the safety of a responsible person’s care or safe area, which may result in potential harm or injury. This might include running off from adults at school or in the community, leaving the classroom without permission, or leaving the house when the family is not looking. This behavior is considered common and short-lived in toddlers, but may persist or re-emerge in children and adults with an ASD.

Because individuals with an ASD are often attracted to water, yet have little to no sense of danger, drowning fatalities following wandering incidents remain a leading cause of death. Other causes include traffic-related & and train-related incidents, and hyper/hypothermia.

AUTISM & WANDERING FACTS

- 49% of children with autism engage in wandering behaviors³
- 35% attempt to wander at least once per week³
- More than one third of children with autism who wander are never or rarely able to communicate their name, address, or phone number³
- 29% of wandering happens from a classroom or school³
- Accidental drowning accounts for approximately 90% of lethal outcomes⁴
- 42% of autism-related wandering cases involving a child 9 and younger have ended in death⁵

AUTISM & WANDERING INSIGHTS

- ASD wandering is usually a form of communication — an I need, I want, or I don’t want
- Individuals with ASD will wander or bolt to get to something of interest, or away from something bothersome
- Wandering incidents typically spike from April through August; however, school-related cases increase through the fall and winter months
- Trigger times for wandering may include: holidays, vacations, camping trips, transition periods, outdoor gatherings, a recent move to a new home or school, visiting an unfamiliar setting, public outings

SOURCES

1. [Centers for Disease Control](#) Facts About ASD
2. [Centers for Disease Control](#); Johnson, C.P. Early Clinical Characteristics of Children with Autism. In: Gupta, V.B. ed: *Autistic Spectrum Disorders in Children*. New York: Marcel Dekker, Inc., 2004:85-123
3. *Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders*: Connie Anderson, J. Kiely Law, Amy Daniels, Catherine Rice, David S. Mandell, Louis Hagopian and Paul A. Law Pediatrics; originally published online October 8, 2012; DOI: 10.1542/peds.2012-0762
4. *Lethal Outcomes in Autism Elopement*, National Autism Association, 2012
5. *National Autism Association Data Analysis 2011-2015*



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CAREGIVER CHECKLIST TOOL

- ✓ I have secured my home
- ✓ I've identified reasons why my child or adult elopes, & I am addressing those reasons
- ✓ I have enrolled my child or adult into swimming lessons (***YMCA listing of special Needs lessons @ nationalautism.org***)
- ✓ I have looked into tracking devices
- ✓ I have alerted my trusted neighbors
- ✓ I have alerted my local first responders about my child, nearby water sources, & reverse 911 (free for law enforcement -- achildmissing.org)
- ✓ I have talked to my child's doctor about the wandering diagnostic code V40.31 (***use code only if necessary***)
- ✓ I have obtained a wearable id for my child that contains all of my contact information
- ✓ I have completed my family wandering emergency plan (***download @ awaare.org***)
- ✓ I will initiate a "tag, you're it" system during family gatherings, commotion, transitions
- ✓ I will monitor any changes in my home's security, especially when warmer weather or seasonal transitions affect my home's layout
- ✓ I will remain on **high alert** after moving to a new home or school, on summer holidays such as memorial day, labor day, 4th of July, & during visits to friends/family's homes, public places, parks, other non-home settings
- ✓ I have addressed wandering at school, summer camp, and other external settings
- ✓ I continue to reassess as my child grows and/or learns new ways to possibly exit
- ✓ If my child or adult is ever missing, I will remain calm, call 911, and search nearby water and busy streets first
- ✓ I continue to document actions taken to protect my loved one



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STOP SIGN PROMPTS

Print, cut, adhere to doors and windows. For additional laminated Stop Signs with adhesives, visit nationalautism.org



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ROOT-CAUSE SCENARIOS

It's critical to seek out the root cause of a child's wandering behavior – WHY is the child wandering/bolting? What do they want/not want? Wandering behaviors usually have a reason. Once you find the reason, you can create strategies to prevent wandering incidents and teach your child about dangers.

SAMPLE SCENARIO: CHILD IS DRAWN TO WATER

Emily loves playing in water. She loves splashing water, watching it pour out of a cup, swimming in it, and she loves bathtime. On walks, she often wants to go look at the pond, water fountain, or cries for these things when passing them in the car.

STRATEGY: Allow the child to enjoy water time in an adult-supervised, controlled setting. For any child who wants to reach water for any given reason, try scheduling consistent “water play” times each day, or at the same time each week. Schedule around times easily recognized, such as after dinner or before bathtime. Make sure the child sees that each water-play activity has an end time and is “all done.” Swimming lessons are a must. Swimming lessons each week can also act as way for the child to reach their goal of playing in water. Be sure to take a picture of the swim instructor and place this into the schedule. *Knowing what to expect may satisfy your child's desire to reach water, as well as give him/her a tool to communicate their desire with a trusted adult before attempting to reach a destination on their own.*



PICTURE SCHEDULE TIPS: take pictures of your child doing a water-play activity, or in a water-play setting that is safe.

For more tips, visit awaare.org.



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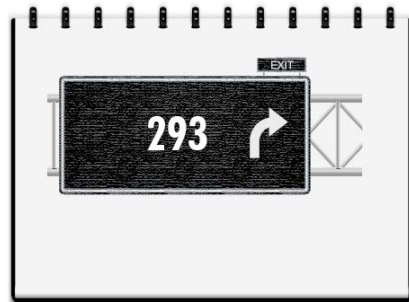
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SAMPLE SCENARIO: CHILD HAS A UNIQUE FASCINATION

Alex loves road signs, especially highway exit signs. He often cries or reacts to signs when passing them on the highway. He verbally stims on highway exit numbers. He will leave home or school to find his item of interest.

STRATEGY: Allow the child to explore fascinations in an adult-supervised, controlled setting. Try to find ways to incorporate the focus/fascination into daily activities so the child knows when to expect it. Use drawing, pictures, games and other creative ways to satisfy the child's need to touch or explore items of obsession.



PICTURE SCHEDULE TIPS: create ways for your child to explore an item of focus through their own creativity, or use the item in a social story.

Teach your child about the dangers of trying to reach an item of focus. For more tips, visit awaare.org.



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SOCIAL STORY: "STAYING IN MY HOUSE"

My name is _____

Picture of house or apartment

This is my house.

Picture of child with family by house

I live in my house with my family.

Picture of child in house.

It's important for me to stay in my house.

Picture of child with parents.

When I stay in my house, my parents will know where I am.

Picture of child in house with family.

Staying in my house will keep me safe.

Picture of happy parents.

Mom and dad will be happy that I am safe.



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SAMPLE WANDERING-PREVENTION IEP LETTER

This is provided as an example only. Please incorporate details as they apply to your personal situation. You may approach your child's physician to help with writing any letter concerning your child's wandering tendencies, and discuss the medical diagnostic code V40.31 (Wandering in Diseases Classified Elsewhere)

Dear (List School Administrator's Name) and IEP Team;

Our child, (full name and DOB), attends (list name of school) and has a diagnosis of autism. He/she is susceptible to wandering, elopement and fleeing incidents.

(Name) is extremely interested in (include any outside attractions, such as areas of water, pools, lakes, ponds and creeks). He/she will wander off to get to these areas and all measures must be taken to ensure his/her safety. Due to (name)'s tendency to wandering, including (list any past incidents) his/her physician has drafted the attached letter strongly urging close one-on-one adult supervision.

Should (name) wander, 911 should be called IMMEDIATELY. We also request immediate parental notification of ANY wandering incident, including incidents where he/she may have wandered within the building. All incidents should be well documented, and include when and how the occurrence took place.

Please know that failure to address known, preventable escape patterns and security breaches puts our child at great risk. We ask for your cooperation in working with us to report all incidents, to make sure the school's premises has proper architectural barriers in place, to ensure all school staff members are aware of his/her tendency to wander or flee, to ensure fences are gated at all times and exterior doors are always be shut, and to ensure that our child is never left unattended no matter what the circumstance.

(NOTE: If your child's school does not have fencing or other architectural barriers, this should be noted in detail.)

Incidents that may trigger fleeing include (list triggers or other pertinent information). De-escalation methods are best in preventing self-injurious behavior (SIB) or fleeing the premises. As the attached physician letter also strongly recommends, calming methods should be facilitated by the staff member most familiar with (name), and aversive methods and escalation triggers should be avoided.

Sincerely,

(your name and signature)



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PHYSICIAN SAMPLE LETTER: AUTISM ELOPEMENT

This is provided as an example only for your child's physician.

NAME OF CHILD (DOB XX/XX/XX) carries a diagnosis of Autism, which poses certain cognitive challenges and safety risks. NAME currently attends NAME OF SCHOOL in NAME OF TOWN.

NAME has a history of wandering from safe environments, including a YEAR incident where NAME wandered from LIST INCIDENT. According to Centers for Disease Control (CDC), Wandering places children and adults with autism spectrum disorders (ASDs) in harmful and potentially life-threatening situations—making this an important safety issue for individuals affected and their families and caregivers.

If given the opportunity, NAME will wander from safe environments. NAME'S wandering tendencies include goal-directed elopement, which means NAME will seek out items of interest, specifically roads and bodies of water. NAME'S history also includes fleeing incidents following a meltdown or escalation trigger.

It is for these reasons, and NAME'S history of elopement, that NAME now has a medical diagnosis of **Wandering In Diseases Classified Elsewhere (ICD-9 V40.31)**. To ensure NAME's safety, it is medically necessary that NAME have close and constant adult supervision at all times, and that proper safeguards are in place. Safeguards may include architectural barriers, door alarms, visual prompts, and a school-wide response protocol.

A Functional Behavioral Assessment should be done to help identify root causes of NAME's elopement behaviors. NAME must never be left unattended by any adult for any reason. Leaving NAME unattended poses serious safety and health risks.

Sincerely,

For more information on the wandering diagnostic code, visit <http://www.cdc.gov/ncbddd/autism/code.html>



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

ABOUT TRACKING TECHNOLOGY

There is a wide range of tracking devices available. However, there is not one solution that is appropriate for everyone. Some children will wear a wristband, some will not. Some need a waterproof device, some do not. Some areas do not have reliable cellular service, which is vital for many of these units. For some children, who are at risk only in certain situations, it may be okay for them to be frequently unprotected while their unit is sitting on a charger, others are at risk around the clock. There are simply too many variables in products, and a wide scope of individual needs for our children for us to make specific recommendations.

Families should thoroughly research the features of personal locating devices before deciding on which is best for their child. We suggest the following considerations:

- ✓ *Battery Life - does the unit have to be charged? If so, how often? Is your loved one unprotected during the charging process?*
- ✓ *Water Resistance - can the unit be worn when bathing, showering, swimming?*
- ✓ *Efficacy in water – will the unit transmit a signal under water?*
- ✓ *Is the unit removable by the wearer?*
- ✓ *Is geofencing/perimeter notification available?*
- ✓ *Cellular service in your area - will the unit work in the area of your home, school, etc?*
- ✓ *Does the system involve trained emergency response personnel?*
- ✓ *Is the manufacturer accessible in case you have critical questions or challenges? Are they interested in your child's specific needs? Do they support a multi-layered approach to safety?*
- ✓ *What are the costs involved, are there monthly fees?*

Lastly, if parents choose to use a personal locating device, they should be sure to field test the equipment in different locations, terrain and various types of weather as if it were a real-life situation. For more, please visit awaare.org.



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

**STEPS FOR AUTISM PARENTS/CAREGIVERS:
GETTING A FIRST-RESPONDER FACILITATED TRACKING PROGRAM IN YOUR COMMUNITY**

If you're the caregiver of a child/adult with autism, and your loved one demonstrates wandering/ elopement tendencies and is at serious risk, you may be interested in obtaining a personal locating device, or "tracking device." While many options are available, National Autism Association prefers programs implemented by professionally trained emergency response personnel such as Project Lifesaver and LoJack SafetyNet. Below are steps you can take to identify any existing programs in your area, or start the process of implementing these services through your appropriate local agency.

For more information about tracking technology, visit awaare.org.

Check to see if Project Lifesaver is in your area:

1. First visit projectlifesaver.org.
2. Go to "where we are" link.
3. Type in your zip code.
4. Scroll down to see results.

If no first-responder tracking program is available in your area, follow these steps:

- ✓ Call Project Lifesaver International at 877-580-LIFE (5433) and request that informational materials about Project Lifesaver be sent to your address.
- ✓ Present the materials to your local agency, along with other helpful information that may include:
 - a documented history of your child's wandering/elopement patterns/incidents
 - information about autism and wandering
 - any news stories or documented cases in your area involving a missing child/adult with autism, or other cognitive impairment, including Alzheimer's.
 - any signed petitions or letters from other members of your community in need of this service. It's helpful to illustrate the need.



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

AWARENESS LETTER

Subject: Wandering Deaths In Children With Autism

To Whom It May Concern:

Similar to wandering behaviors in seniors with dementia or Alzheimer's, children with an Autism Spectrum Disorder (ASD) are prone to wandering away/elope from a safe environment. Unfortunately, many cases end in tragedy.

According to a 2012 study in *Pediatrics*, 49% of children with an ASD wander/elope from safe supervision. This is at a rate nearly four times higher than their unaffected siblings, indicating it is not an issue of bad parenting. It is, however, a growing crisis in need of awareness, understanding and hyper vigilance.

From 2009 to 2011, accidental drowning accounted for 91% of total U.S. deaths reported in children with an ASD ages 14 and younger subsequent to wandering/elopement. Many children and teenagers with ASD have little understanding of danger and are unable to respond to their name when called. Dangers associated with wandering/elopement include drowning, getting struck by a vehicle, falling from a high place, and hyperthermia.

Children with ASD often leave a safe environment to get to something of interest, or away from something, such as loud noises or bright lights. In 2008, Danish researchers found that the mortality rate among the autism population is twice as high as the general population. In 2001, a California research team found that elevated death rates were attributed in large part to drowning. Wandering in ASD has become so common, it was assigned a medical diagnostic code [V40.31], which went into effect in October of 2011.

Because children with ASD are challenged in areas of language and cognitive function, it can be difficult to teach them about dangers and ways to stay safe. As such, our organization respectfully requests your help in allowing, or providing, resources and safeguards that could potentially save a child's life. This may include offering swimming lessons to special-needs children, allowing fencing to go around an at-risk child's home, tightening security around nearby water and pools, informing parents of any wandering incidents on school grounds or other non-home settings, and providing close and constant adult supervision.

We are grateful for your commitment to child safety. Should you have questions, you may reach us at 877.622.2884 or naa@nationalautism.org.

Sincerely,

A handwritten signature in black ink that reads "Lori McIlwain".

Lori McIlwain
Chair
National Autism Association



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

SWIMMING LESSONS

From 2009 to 2011, accidental drowning accounted for 91% of wandering-related deaths in children with autism. Swimming lessons are a crucial component to your child's safety.

REMEMBER:

- ✓ *Teaching your child how to swim DOES NOT mean your child is safe in water.*
- ✓ *If you own a pool, fence your pool. Use gates that self-close and self-latch higher than your children's reach. Remove all toys or items of interest from the pool when not in use.*
- ✓ *Neighbors with pools should be made aware of these safety precautions and your child's tendency to wander.*
- ✓ *Final lessons should be with clothes and shoes on.*

Step 1: To find swimming lessons in your area, visit nationalautism.org, click Autism & Safety, then choose "Swimming Instructions."

Step 2: If you do not see swimming lessons in your area, Google **Special Needs Swimming Lessons + (Your City, State)**. You may have a non-YMCA facility, or specialty service in your area.

Step 3: If you cannot find special-needs swimming lessons in your area, ask a local swimming facility, such as YMCA, to provide this service. The "parent resource sheet" located within this toolkit can be used to demonstrate the need for lessons specific to children with special needs.

Step 4: If you are still unable to find lessons, considering contacting swimwithmrblue.com.

NOTE: 68% OF DROWNING DEATHS HAPPENED IN A NEARBY POND, CREEK, LAKE OR RIVER. LIFE VESTS ON CAMPING AND BOATING TRIPS SHOULD ALWAYS BE WORN.



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

FIVE AFFORDABLE SAFETY TOOLS

Through our work to address Autism Wandering over the last few years, we've discovered some effective and inexpensive ways to help keep our kids safe. Please review this information and share with other caregivers who may benefit from it. For additional items, please visit nationalautism.org.

- 1.) [Door/Window Alarms](#)** These battery-operated alarms are super easy to install and can be found at many retail outlets including Home Depot, Walmart and Radio Shack.

- 2.) [Shoe ID Tags](#)** These are especially good for our kids who can't tolerate wearing an ID bracelet. They're water-resistant and attach easily to shoes with velcro. Using a Sharpie, you can write your emergency contact information and medical conditions onto the inside of the tags.

- 3.) [Stop Signs](#)** A visual prompt that makes your child stop – or even pause for a moment – can be critical to preventing a tragedy. To create your own, see the **Stop Signs Page** in this toolkit.

- 4.) [Guardian Lock](#)** The Guardian Lock is a portable lock you can use on any exterior door – and you can take it with you when you travel. This lock is difficult for even our most talented little escape artists to get through.

- 5.) [Temporary Tattoos](#)** We love these colorful and fun temporary tattoos, especially for vacations or even a quick outing in your local community. Each kit contains six Lost and Found Autism Temporary Tattoos, one Tattoos With A Purpose Marker, six Moisture Towelettes (for applying) and six On-The-Go Alcohol Wipes (for removing). These tattoos last for several days.

For additional resources, please visit nationalautism.org.

Disclaimer: NAA is not affiliated with the manufacturers of these products. The above is posted for informational purposes only. NAA offers no guarantee and accepts no liability on product performance.



The Big Red Safety Box Program is a wandering prevention initiative brought to you by the National Autism Association.

RESOURCE SHEET

GENERAL RESOURCES

National Autism Association: nationalautism.org
AWAARE Collaboration: awaare.org
Autism Safety Coalition: autismsafetycoalition.org

SWIMMING LESSONS

YMCA Listing nationalautism.org
Super Swimmers superswimmersfoundation.org

CHILD SAFETY PRODUCTS

NAA's Big Red Safety Shop: nationalautism.org

TRACKING SYSTEMS & ID PRODUCTS

Project Lifesaver projectlifesaver.org
LoJack SafetyNet lojacksafetynet.com
Caretrak Systems: caretrak.com
Alzheimer's Comfort Zone: alz.org
Road ID roadid.com

PLEASE NOTE

A multi-layered approach to prevent, and respond to, wandering emergencies is necessary to achieve optimal safety for your child. This includes making every attempt to educate your child on self-help skills including swimming, making every attempt to educate them about safety and potential dangers by using social stories, language, prompts, or any communication mechanism best suited for their individual needs. It's important that caregivers work to understand what is causing, or contributing to, the wandering or bolting behaviors so that any triggers may be addressed or eliminated.

The most important thing is that the at-risk child or adult is learning to keep themselves safe, while proper safeguards and adult supervision are also in place to help ensure their safety.

No matter what prevention strategies are put into place, parents should never allow themselves to feel a false sense of security. Although certain safety-product retailers may market their items with words like "relaxation" and "peace of mind," please know that these benefits are secondary to the overall goal of safety. For more, please visit awaare.org.

FAMILY WANDERING EMERGENCY PLAN



Make sure your family has a plan in case of a wandering emergency. Before an emergency happens, sit down together and decide how you will get in contact with each other, where you will go and what you will do in an emergency. Keep a copy of this plan in your emergency supply kit or another safe place where you can access it in the event your child is missing.

CRITICAL INFORMATION

CHILD'S NAME _____

CHILD'S TRANSMITTER TRACKING NUMBER (if applicable) _____

CHILD'S OFFICIAL DIAGNOSIS _____

CHILD'S IDENTIFYING MARKS, MEDICATIONS & MEDICAL NEEDS _____

EMERGENCY STEPS:

- STAY CALM AND ALWAYS CALL 911 IMMEDIATELY IF YOUR LOVED ONE IS MISSING FROM YOUR HOME.*
- Clearly state your child's name.
- State that they have a cognitive impairment, provide the diagnosis, state they are endangered and have no sense of danger.
- Provide your child's radio frequency tracking number (if applicable).
- Request an AMBER Alert be issued (if your child is a minor) or a Silver Alert be issued (if your child is an adult)
- Request that your child be immediately entered into the National Crime Information Center (NCIC) Missing Person File.
- Always search high-threat areas first, such as nearby water and busy roads.

*While calling, search areas of immediate threat first, such as nearby water and busy roads. If you have an emergency point person assigned to contact neighbors, pick up your other children from school, watch your children, etc., alert them while searching known areas your child would likely be. If you have other small children, never leave them unattended.

TIP: Create an emergency point person who can contact neighbors, fax your alert form to local law enforcement, and assist in making arrangements for your other children. Should your child go missing, make sure this contact has a cell phone, knows what your child is wearing, any identifying features, where your child was last seen, how long your child may have been gone, any medical needs or allergies your child may have, your child's likes and dislikes and main attractions. Ideally, the emergency contact will be a relative or close friend. Provide your emergency contact with a copy of this plan and ask them to keep it in a safe, accessible place.

EMERGENCY CONTACT NAME: _____

EMERGENCY CONTACT NUMBER: _____

TIP: List the main places your child may likely go within the neighborhood, especially nearby ponds, lakes, pools, etc. Search these areas first. If you have assigned “search angels” ahead of time, make sure they know which location is assigned to them. Draw maps of these locations, or physically show the volunteers the location to which they are assigned before an emergency happens.

LOCATION NAME	LOCATION DESCRIPTION
1.	
2.	
3.	
4.	
5.	

TIP: Before an emergency happens, assign at least five (5) willing “search angels” who will commit to searching for your child in the event of an emergency. Make sure they would be immediately available (are typically home) are willing, and know and understand which search location is assigned to them.

NAME	NUMBER	ADDRESS	ASSIGNED LOCATION

OTHER NUMBERS:

LAW ENFORCEMENT FAX NUMBERS: (in case local law enforcement does not have your child’s information on file, have your assigned emergency point person fax it.)

National Center for Missing & Exploited Children (NCMEC): 1-800-THE-LOST (1-800-843-5678)

LOCAL MEDIA CONTACT NUMBERS:

OTHER NOTES: (make any notes you feel may be important in case of a wandering emergency.)

Keep this document with you at all times. Keep a copy in a safe, accessible place within the home. Keep this with your child’s first responder alert form, documentation of diagnosis, medical papers and any other important information.



AUTISM ELOPEMENT ALERT FORM
PERSON-SPECIFIC INFORMATION for FIRST RESPONDERS

Date Submitted: _____

Individual's Name _____
(First) (M.I.) (Last)

Address: _____
(Street) (City) (State) (Zip)

Date of Birth _____ Age _____ Preferred Name _____

Does the Individual live alone? _____

Individual's Physical Description:

___ Male ___ Female Height: _____ Weight: _____ Eye color: _____ Hair color: _____

Scars or other identifying marks: _____

Other Relevant Medical Conditions in addition to Autism (check all that apply):

___ No Sense of Danger ___ Blind ___ Deaf ___ Non-Verbal ___ Mental Retardation

___ Attracted to Water ___ Prone to Seizures ___ Cognitive Impairment ___ Other

If Other, Please explain: _____

Prescription Medications needed:

Sensory or dietary issues, if any:

Calming methods, and any additional information First Resonders may need:

EMERGENCY CONTACT INFORMATION

Name of Emergency Contact (Parents/Guardians, Head of Household/Residence, or Care Providers):

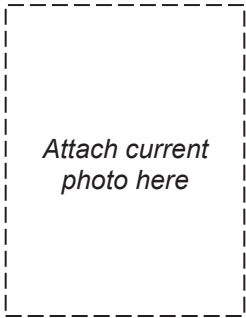
Emergency Contact's Address: _____
(Street) (City) (State) (Zip)

Emergency Contact's Phone Numbers:

Home: _____ Work: _____ Cell Phone: _____

Name of Alternative Emergency Contact: _____

Home: _____ Work: _____ Cell Phone: _____



INFORMATION SPECIFIC TO THE INDIVIDUAL

Nearby water sources & favorite attractions or locations where the individual may be found:

Atypical behaviors or characteristics of the Individual that may attract the attention of Responders:

Individual's favorite toys, objects, music, discussion topics, likes, or dislikes:

Method of Preferred Communication. (If nonverbal: Sign language, picture boards, written words, etc.):

Method of Preferred Communication II. (If verbal: preferred words, sounds, songs, phrases they may respond to):

Identification Information. (i.e. Does the individual carry or wear jewelry, tags, ID card, medical alert bracelets, etc.?):

Tracking Information. (Does the individual have a Project Lifesaver or LoJack SafetyNet Transmitter Number?):

- MANY CHILDREN WITH AUTISM ARE DRAWN TO WATER. SEARCH & SECURE NEARBY WATER SOURCES FIRST.
- REVERSE 911 IS AN EFFECTIVE TOOL FOR FINDING A MISSING CHILD AND FREE TO AGENCIES. VISIT achildmissing.org.

1



HAPPY!

Everything's Okay

2



WORRIED

I can try:

- Take 5 deep breaths
- Sing a song in my head
- Squeeze a squishy ball
- Put my worry in my pocket
- Tell my mom or dad why I am worried

3



SAD

I can try:

- Take 5 deep breaths
- Sing a song in my head
- Squeeze a squishy ball
- Put my sadness in my pocket!
- Do a little drawing
- Ask for a break
- Tell my mom or dad why I am sad

4



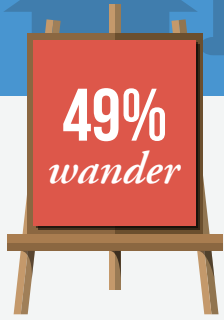
ANGRY

I can try:

- Take 10 deep breaths
- Sing a song in my head
- Squeeze a squishy ball
- Put my anger in my pocket!
- Do a little drawing
- Ask for a break
- Tell my mom or dad why I am angry

AUTISM & WANDERING PREVENTION TIPS

promoting safety in the home & community



Similar to the wandering behaviors in seniors with dementia or Alzheimer's, children and adults with autism spectrum disorder (ASD) are prone to wandering away from a safe environment. Because many children with ASD have challenges in areas of language and cognitive function, it is critical for parents to understand ways to keep their child or adult with autism safe.

 *prevention*
 *education*
 *response*

Install Home Safeguards



Install secure locks (exterior doors), door/window chimes; fence yard; secure gates; keep garage opener out of reach; use baby monitors and visual prompts like simple stop signs

Identify Triggers/Teach Self-help



Be aware of any known triggers that could prompt fleeing (loud noises, bright lights, fears, etc.) and work towards teaching your child safe alternative ways to respond

For an individual who demonstrates bolting behaviors due to fear or stress, etc., use aids, such as noise-cancelling headphones, and teach calming techniques using favorites topics or items

Secure Personal Safeguards



Have wearable identification on your child (RoadID.com); Temporary Tattoos are great for field trips and other outings; Check with local law enforcement to see if they offer Project Lifesaver Tracking Devices (ProjectLifesaver.org)

Teach Safety Skills



Enroll your child into swimming lessons. Final lessons should be with clothes and shoes on. (YMCA listing, nationalautism.org) Use social stories to teach individuals with autism ways to stay safe, and use favorite objects or tools to demonstrate when it's outside time versus inside time (social stories at awaare.org)

Create Community Awareness



Alert trusted neighbors, and introduce them to your child; fill out an alert form for local police, include a current photo and unique characteristics, likes, fears, and behaviors; alert the school, and bus drivers

Call 911



Remain calm and always call 911 immediately if an individual with ASD is missing; law enforcement should treat each case as "critical"

Law enforcement agencies are encouraged to contact the National Center for Missing & Exploited Children at 1-800-THE-LOST (1-800-843-5678) for additional assistance

Remain Hyper Vigilant



Stay on extra high alert during warmer months, holidays, vacations, camping trips, transition periods, outdoor gatherings, a recent move to a new home or school, visiting an unfamiliar setting, public outings

Initiate a "tag, you're it" system during family gatherings and transitions. Tag one responsible adult to closely supervise your child for an agreed-upon period of time

Search Water First



Immediately search areas that pose the highest threat first, such as nearby water, busy streets, train tracks, and parked cars



For more tips and resources, visit nationalautism.org.

Missing Children With Special Needs

Finding and safely recovering a missing child with special needs often presents a unique and difficult challenge for families, law enforcement, first responders, and search teams. The behaviors and actions of a missing child with special needs are often much different than those of a missing nonaffected child. While the behaviors will differ from child-to-child, missing children with certain special needs may

- Wander away, run away, or bolt from a safe environment
- Exhibit a diminished sense of fear causing them to engage in high-risk behavior such as seeking water or active roadways
- Elude or hide from search teams
- Seek small or tightly enclosed spaces concealing themselves from search teams
- Be unable to respond to rescuers

A special-needs condition may be characterized by debilitating physical impairments, social impairments, cognitive impairments, or communication challenges.

Heightened Risk Factors Associated with Autism Spectrum Disorders

One such cause for these types of impairments and challenges is autism. Generally speaking, no two children with autism are alike — each child is unique. The symptoms vary from the most severely affected child who may be nonverbal and low functioning, to those with milder forms, such as Asperger’s Syndrome or Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS), who may be higher-functioning. This does not suggest all missing children diagnosed with Asperger’s Syndrome or PDD-NOS are not at risk — the risk factors must be weighed for each individual child regardless of the diagnosis. It is also important to note the chronological age of individuals with autism is often irrelevant to their level of functioning. For example a 15-year-old may have the cognitive function of a much younger child.

For reasons not entirely clear, missing children with autism, especially those who are severely affected, have a tendency to wander or elope from a safe environment and will often seek bodies of water such as streams, ponds, lakes, rivers, creeks, storm-water retention/detention basins, and backyard and public swimming pools. According to the National Autism Association, in the United States between 2009 and 2011, accidental drowning accounted for 91% of the total deaths reported in children with autism ages 14 and younger subsequent to wandering or elopement.¹ Children with autism may also exhibit other interests or fascinations posing similar dangers such as going to active roadways/highways, trains, heavy equipment, fire trucks, roadway signs, bright lights, and traffic signals.

In the event of an extended missing episode the children are also at risk of exposure to weather and environmental hazards; dehydration; lack of adequate nutrition such as food and medication; traffic-related injuries/accidents; falls, especially down steep terrain; and even potential encounters with child molesters or others who would intentionally try to take advantage of or harm them.

Because of the tendency for children with autism to wander or elope it is vitally important to quickly identify the unique interests of the child and create

¹*Autism & Safety Facts*. Attleboro Falls, Massachusetts: National Autism Association, accessed on July 24, 2012, at nationalautismassociation.org/resources/autism-safety-facts.

a list of their favorite places. It is imperative first responders talk to the parents, siblings, relatives, caregivers, and others who know the child well to ask for information about interests, fascinations, stimulations, or obsessions when developing search plans and determining where the child may go. This information could provide key clues leading to a speedy recovery.

Wandering and Elopement

The National Autism Association describes wandering and elopement as a situation when a person who requires some level of supervision to be safe leaves a supervised, safe space and/or the care of a responsible person and is exposed to potential dangers. These dangers can include traffic; drowning in open water; falling from a high place; harmful weather or environmental conditions such as hypothermia, heat stroke, or dehydration; or unintended encounters with individuals who could try to intentionally harm them. Wandering is also referred to as elopement, bolting, fleeing, and running.²

Children with autism wander or elope for a variety of reasons. They may hide from parents, caregivers, or teachers. They may seek places of special interest to them such as water, active roadways, train tracks, a favorite place, or possibly to escape an environment because of overwhelming stimulus such as sights, sounds, surroundings, or activities of others. First responders must quickly gather information about why the child may have wandered and places the child may go. **Interviewing parents, siblings, caregivers, and others who know the child well is vital, since these people may know about the child's activities, behaviors, and interests, both past and present.**

It is estimated nearly half of children with autism will wander or elope, a rate nearly four times higher than nonaffected children.³ More than one-third of children with autism who wander or elope are considered nonverbal and are unable or rarely able to communicate their name, address, or phone number.⁴

Because of the unique circumstances often associated in cases of missing children with special needs, the guidance noted below is provided to assist law enforcement, first responders, and search teams in the event of a reported incident.

Missing Children With Special Needs: Response Recommendations

While cases of missing children with special needs should be treated as critical incidents requiring elevated responses by law enforcement and first responders, children with autism have an unusually high mortality rate and are especially at risk. Certain exceptions may apply for those special-needs children who are considered high functioning and therefore should be assessed accordingly weighing all risk factors.

Preliminary Considerations Because children with autism often have an extremely high attraction to water, it is **strongly** recommended first responders and search teams immediately check all nearby bodies of water in an effort to head-off the child. These include but are not limited to streams, ponds, lakes, rivers, creeks, storm-water retention/detention basins, and backyard and public swimming pools.

²For more information about this topic visit www.nationalautismassociation.org, www.autismsafety.org, and www.awaare.org.

³*Autism & Safety Facts*. Attleboro Falls, Massachusetts: National Autism Association, accessed on July 24, 2012, at nationalautismassociation.org/resources/autism-safety-facts.

⁴*Id.*

Children with autism typically have difficulty with verbal and nonverbal communication and in many cases may **not** be able to respond to their name being called. They will often hide to elude searchers, sometimes concealing themselves in small or tight spaces, and may display a diminished sense of fear about dangers in their environmental surroundings.

As with all critically missing children, time is a vitally important factor in a safe recovery. Public-safety telecommunicators are encouraged to obtain the information noted below and **immediately** share it with all first responders. Additionally law-enforcement agencies are encouraged to contact the National Center for Missing & Exploited Children® at 1-800-THE-LOST® (1-800-843-5678) for additional assistance and resources, including search-and-rescue experts who may be able to immediately deploy to help find the child.

Call-Intake Questions The recommendations noted below are offered to help public-safety telecommunicators when taking calls concerning children with special needs. First obtain a full description of the child including height, weight, hair color, and clothing worn. Then ask

- Is the child wearing or carrying any tracking technology device? If so, which one and how is location information accessed?
- Is the child attracted to water? If so, can the child swim?
- Is the child attracted to active roadways/highways?
- Does the child have a fascination with vehicles such as trains, heavy equipment, airplanes, or fire trucks?
- Has the child wandered away before? If so, where was he or she found?
- Does the child have a sibling with special needs? If so, has that sibling wandered away before? If so, where was the sibling found?
- Where does the child like to go? Does the child have a favorite place?
- Is the child nonverbal? How will the child likely react to his or her name being called?
- Will the child respond to a particular voice such as that of his or her mother, father, other relative, caregiver, or family friend?
- Does the child have a favorite song, toy, or character? If so, what or who is it?
- Does the verbal child know his or her parents' names, home address, and phone number?
- Does the child have any specific dislikes, fears, or behavioral triggers?
- How might the child react to sirens, helicopters, airplanes, search dogs, people in uniform, or those participating in a search team?
- How does the child respond to pain or injury?
- What is the child's response to being touched?
- Does the child wear a medical ID tag?
- Does the child have any sensory, medical, or dietary issues and requirements?
- Does the child rely on any life-sustaining medication?
- Does the child become upset easily? If so, what methods are used to calm him or her?

The Initial Response The recommendations noted below are offered to help guide law enforcement and other first responders in the initial response and search for the child.

- [] Identify hazards in the area where the child was last seen and dispatch personnel to those locations to search for the child, paying special attention to any bodies of water and specific locations of interest to the child such as his or her favorite places.
- [] Secure identified hazardous areas near where the child was last seen to prevent the child from entering those areas.
- [] Determine if the child was wearing/carrying a tracking device and, if so, immediately initiate tracking measures to locate the child.
- [] Determine if the child is frightened by aircraft, dogs, ATVs, or any other resources used to assist in searches. Remember using search dogs at the onset of the initial response will better ensure successful tracking.
- [] Determine if the child is sensitive to or frightened by noise and how he or she will typically react to that type of noise.
- [] Establish containment measures of the child's known routes to prevent him or her from wandering further away from the place last seen using all appropriate means such as road, bike, and air patrol.
- [] Contact the National Center for Missing & Exploited Children without delay to request assistance from their search-and-rescue and search-management experts.
- [] Ensure the lead agency is using the services of a reverse 911 system, such as A Child Is Missing Alert at www.achildismissing.org. This service helps alert the local community via a rapid-response, neighborhood-alert program using high-tech phone systems.
- [] Determine if an Endangered Missing Child Alert has been issued.

Use of the National Center for Missing & Exploited Children's *Missing Children With Special Needs Lost-Person Questionnaire* is also highly recommended.

Investigative Measures The recommendations noted below are offered to help guide law enforcement's search and investigative efforts.

- [] Contact the child's parent/guardian to further assess the child's special-needs condition.
- [] Determine if the child has any history of wandering or eloping and, if so, where and what physical features associated with those episodes may have attracted the child.
- [] Identify additional physical features the child may be attracted to such as roadways/highways, trains, heavy equipment, fire trucks, park swings, and road signs.
- [] Determine if the child has any favorite places.
- [] Determine if the child has a favorite song, toy, or character.
- [] Determine if the child has any dislikes, fears, or behavioral triggers and, if so, how he or she will typically react to negative stimuli.
- [] Determine how the child reacts to sirens, dogs, vehicles used in searches, and people of authority/in uniform. Children with autism will sometimes avoid search teams or attempt to hide in small places.
- [] Determine the communication abilities of the child regarding verbal versus nonverbal skills.
- [] Determine if the child will respond to his or her name when being called.
- [] Determine if the child knows his or her parents' names, home address, and phone numbers.

- Determine if the child has any other mental or physical conditions.
- Determine if the child has any dietary issues or requirements.
- Determine if the child is taking any medications, and, if so, the type of medications, risks involved with delayed or missed doses, and potential side effects if the medication is not taken as prescribed.
- Determine if the child wears a medical identification bracelet or tag.
- Determine how the child responds to pain or injury.
- Determine the child's response to being touched.
- Determine what methods are used to calm the child.

Search-and-Rescue Measures The deployment of personnel trained in search-and-rescue protocols is highly recommended to assist in the investigation to safely locate the missing child. Law enforcement should **immediately** provide information to search-and-rescue personnel about the child's special-needs condition and any information about the specific behaviors or interests that may assist in searching for the child.

Law enforcement should consider immediately establishing an Incident Command System (ICS) to help ensure all aspects of the investigative and search functions are properly managed and resources are used to their fullest potential. Additionally a critical component of that ICS is the establishment of a search-and-rescue manager for all aspects of the search-and-rescue operation. The search measures noted below may help in safely locating a missing child with special needs.

- Preserve the place the child was last seen.
- Use search-and-rescue personnel accustomed to the existing geography whether urban, suburban, or rural.
- Provide a detailed briefing to search-and-rescue personnel arriving on scene about the behaviors of the missing child.
- Consider using the National Center for Missing & Exploited Children's *Missing Children With Special Needs Lost-Person Questionnaire*.
- Initiate search-and-rescue efforts with an emphasis on bodies of water, high-hazard areas, travel corridors, routes to favorite places, previous locations visited, and any other areas of interest suggested by those who know the child.
- Attempt to attract the child by using his or her favorite things such as playing a favorite song or driving a favorite type of vehicle into the search area.
- Use night-search techniques, if appropriate, such as projected lights and patterns, especially spinning patterns, or other types of favorite visuals to attract the missing child. **Note:** Be aware night searches could be hazardous to the child if the terrain includes dangers such as cliffs, drop offs, mine shafts, or bodies of water. Attempting to draw a child into these areas could lead to tragic consequences if these are not identified by searchers and secured prior to using attraction devices.
- Extend search duration because the unique behaviors of some children with special needs may have a protective effect allowing the child to survive longer than what is considered to be a normal survival rate for a child.

Considerations in the Event of a Prolonged Search In the event immediate search efforts have not resulted in the safe recovery of the missing child, begin to plan for the prolonged use of resources in order to sustain search efforts. The search-and-

rescue manager should evaluate the overall effectiveness of the search operations and make necessary adjustments for a prolonged search operation. The recommendations noted below are provided to assist in the planning for a prolonged search-and-rescue effort.

- [] Evaluate the overall effectiveness of the search operations and adjust as necessary for the next operational phase.
- [] Estimate immediate and long-range resources and logistical requirements for deployment of those resources.
- [] Assign new or additional personnel for the prolonged search operation.
- [] Consider expanding the search area, taking into account the distance the child could have walked during the time frame he or she has been missing and his or her resiliency. Children with autism have been known to walk several miles, often exceeding the initially established search containment area.
- [] Determine if there are any gaps in the original search area and make arrangements to search those areas again.
- [] Consider using trained search-and-rescue personnel with volunteer searchers to enhance the search capabilities.

Additional Considerations Unique to Children With Special Needs

The unique behaviors of a child with special needs must be considered by law enforcement and first responders when planning and conducting searches. Past episodes have revealed children with special needs have a natural self-survival instinct and are often resilient, allowing them to survive long periods of time — sometimes longer than a nonaffected child. Additionally the children may have a diminished sense of fear of their surroundings and are highly mobile and thus may cover great distances, necessitating an expanded search parameter. The children may seek shelter or conceal themselves in confined spaces making it more difficult for searchers to locate them. In urban and suburban environments, it is highly recommended searchers focus their efforts on small confining spaces. Missing children with special needs may also have a fascination with or fixation on particular sounds; objects, especially moving or spinning objects; or certain foods. Consider use of attraction tactics, based on the unique behaviors and interests of the child, as a means to draw the missing child to the search party. Take special care, however, to help ensure the missing child is not drawn into a hazardous environment such as water, a cliff or bluff, or an active roadway. Additionally discuss with family members and caregivers techniques that would best work to help bring the child out versus what measures could be detrimental to the search.

Recovery and Reunification Measures

With the understanding children with autism exhibit social and cognitive impairments, communication difficulties, and repetitive behaviors, keep in mind the interaction between law enforcement/search-and-rescue personnel and a child with autism at the time of recovery and subsequent reunification can be a traumatic experience.

The considerations noted below are recommended to deescalate and/or minimize any heightened emotions or anxieties the child may experience at the time of recovery.

- Maintain a calm and relaxed environment.
- Contain the child in a passive way to keep him or her from running or bolting and avoid use of restraints.
- Bring a parent or guardian immediately to the recovery site, whenever possible, and tell the child that person is on the way.
- Approach the child at his or her level, kneeling if necessary, and speak in a normal tone of voice using simple phrases.
- Use a task-and-reward process to ease anxiety and enhance compliance using phrases such as, “First we are going to stay here, and then your father is going to come here.”
- Avoid assuming the child understands everything being said and done at the recovery scene.
- Use communication aids, written instructions, drawings, or prompts if possible.
- Use humor and familiar topics when possible. For instance if the child is wearing a shirt with a cartoon character on it, talk to the child about the character to help lessen any anxiety the child may be feeling and calm the child if upset.
- Check for any identification such as a medical bracelet or tracking device.
- Contact the National Autism Association for further reunification assistance at 1-877-622-2884. For more information about children with autism and resources for families, such as the Big Red Safety Box, visit www.nationalautismassociation.org.
- Visit the National Autism Association’s websites at www.autismsafety.org and www.nationalautismassociation.org and the AWAARE Collaboration at www.awaare.org for additional information about children with autism.
- Consult Robert Koester’s *Lost Person Behavior: A search and rescue guide on where to look - for land, air and water* (2008) for additional general information.

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AUTISM AND WANDERING

Recommended links

- **ARTICLES**

<https://www.autismspeaks.org/advocacy/advocacy-news/critical-safety-legislation-passes-us-senate>

<https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html>

http://www.missingkids.com/en_US/publications/SpecialNeeds_Addendum.pdf

<https://www.disabilityscoop.com/2016/12/13/wandering-bill-falls-short/23127/>

<https://childmind.org/article/autism-plus-wandering/>

<http://www.vox.com/the-big-idea/2016/12/17/13993398/safety-autonomy-avonte-tracking-autism-wandering-schumer>

<https://www.psychologytoday.com/blog/inspectrum/201612/117-autistic-children-and-adults-who-died-deserve-better>

Virtual candlelight vigil for autistic children who lost their lives after wandering. April 1st of every year. Facebook event created by mom of a child on the spectrum

<https://www.facebook.com/events/979863278748923/>

- **RESOURCES**

- Trackers
- Angel sense
- Pocketfinder
- If I Need Help (wearable IDs)



Serving Manhattan, Bronx, Queens, Brooklyn, Staten Island, Nassau, Suffolk, Westchester, Rockland
www.nationalautismny.org

WEBSITES OF INTEREST CONCERNING WANDERING and SAFETY

Information and Resources

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

<http://autismsafetycoalition.org/>

<http://nationalautismassociation.org/resources/awaare-wandering/>

<http://nationalautismassociation.org/store/#!/Big-Red-Safety-Shop/c/2416355/offset=0&sort=normal>

<http://nationalautismassociation.org/resources/autism-safety-facts/swimming-instructions/>

<https://www.autismspeaks.org/wandering-resources>

Tracking/Safety Devices

<https://www.angelsense.com/>

<http://shop.alz.org/Care-and-Safety>

<http://www.autismalert.org/>

<https://www.brooklynautismcenter.org/safety-products>

<http://caretrak.com/>

<https://ifineedhelp.org/>

<http://www.medicalert.org/autism>

<http://www.mypreciouskid.com/special-needs-children.html>

<http://pocketfinder.com/personaltracker/>

<https://www.roadid.com/>

<https://safetynettracking.com/>

<http://selectautismmerchandise.com/>

<http://tattooswithapurpose.com/>

Service Dog Information

<http://autismservicedogsofamerica.com/>

<http://4pawsforability.org/>

For First Responders, Caregivers and Others

<http://www.achildissing.org>

<http://www.arcsouthnorfolk.org/alec-first-responder-training.html>

<http://www.autismriskmanagement.com/>

<http://www.missingkids.org/home>

Is your child **struggling** in school? Does your child have **special needs** or an **IEP** (Individualized Education Program)? Do you have questions about your young person with a **disability**?

WE CAN HELP

CONTACT OUR FREE HELP LINE



CALL US
212•677•4660

TEXT US
646•693•3175

VISIT OUR WEBSITE INCLUDENYC.ORG



**ACCESS FREE RESOURCES
ONLINE**

**ATTEND A FREE WORKSHOP
IN YOUR COMMUNITY**

includenyc

love, equity, & access for young people with disabilities

¿Su hijo **tiene problemas** en la escuela?
¿Su hijo tiene **IEP**
(Plan de Educación Individualizado)?
Como padre, ¿tiene dudas sobre las
necesidades especiales de su hijo?

NOSOTROS LO PODEMOS AYUDAR

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DE AYUDA GRATUITA**

LLÁMENOS

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MÁNDENOS UN TEXTO

646•693•3157

WHATSAPP

212•858•0795

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INCLUYENYC.ORG**

ACCESO A RECURSOS

EN EL INTERNET

ASISTA A UN TALLER GRATUITO

EN SU COMUNIDAD



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amor, equidad, y acceso para jóvenes con discapacidades