

**BE  
REDY**  
TO PREVENT WANDERING



Dear Recipient;

If you are receiving this **Big Red Safety Toolkit** 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*
- *Family Wandering Emergency Plan (FWEP)*
- *First-responder profile form. Please fill out and provide a copy to your local law enforcement agencies.*
- *Swimming Lessons Tool*
- *Root-cause Scenario & Strategies Tool*
- *Stop Sign Prompts*
- *Social Stories*
- *Caregiver Log*
- *Sample IEP Letter. (Never allow restraint/seclusion practices into any IEP as this increases associated risks.)*
- *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*

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 kit helpful. For more information on wandering-prevention, visit [awaare.org](http://awaare.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 box. BE SURE TO ADVISE AND CONSULT WITH THE CHILD’S HEALTH CARE PROVIDERS CONCERNING THE USE OF THIS SAFETY TOOLKIT.*



## **ABOUT AUTISM & WANDERING**

The Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 88 individuals in the U.S. have an Autism Spectrum Disorder (ASD) that can cause significant social, communication and behavioral challenges. These challenges often present unique safety risks, including wandering behaviors similarly seen in seniors with dementia or Alzheimer's.

Children with autism typically wander or bolt from a safe setting to get to something of interest, such as water, the park, or train tracks -- or to get away from something, such as loud noises, commotion, or bright lights.

Dangers associated with wandering include drowning, getting struck by a vehicle, falling from a high place, dehydration, hypothermia, abduction, victimization, and assault.

Because children with autism are challenged in areas of language and cognitive function, it may be difficult to search for them, or teach them about dangers and ways to stay safe.

### **WANDERING DEFINED**

*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 such as traffic, open water (drowning), falling from a high place, weather (hypothermia, heat stroke, dehydration) or unintended encounters with potentially predatory strangers.*

**Wandering is also referred to as:** Elopement; Bolting; Running (i.e. "My child is a runner.")

### **WANDERING TYPES**

- **Goal-directed wandering:** wandering with the purpose of getting to something (water, train tracks, park, an item or place of obsession, etc.)
- **Bolting/Fleeing:** the act of suddenly running or bolting, usually to quickly get away from something, a negative reaction to an event, anxiety, fear, excitement, stress or uncomfortable sensory input.
- **Other:** nighttime wandering; wandering due to disorientation, boredom, transition or confusion; or individual simply becomes lost.



## AUTISM-WANDERING STATISTICS

- Roughly half, or 49% of children with an ASD attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings
- In 2009, 2010, and 2011, accidental drowning accounted for 91% total U.S. deaths reported in children with an ASD ages 14 and younger subsequent to wandering/elopement
- More than one third of children with ASD who wander/elope are never or rarely able to communicate their name, address, or phone number
- Two in three parents of elopers reported their missing children had a “close call” with a traffic injury
- 32% of parents reported 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 of children who elope were prevented from attending/enjoying activities outside the home due to fear of wandering
- 40% of parents had suffered sleep disruption due to fear of elopement
- Children with ASD are eight times more likely to elope between the ages of 7 and 10 than their typically-developing siblings
- Half of families with elopers report they had never received advice or guidance about elopement from a professional
- Only 19% had received such support from a psychologist or mental health professional
- Only 14% had received guidance from their pediatrician or another physician

*Source: Interactive Autism Network Research Report: Elopement and Wandering (2011)*

*Source: National Autism Association, Lethal Outcomes in ASD Wandering (2012)*



## CAREGIVER CHECKLIST TOOL

- \_\_\_\_\_ I Have Secured My Home
- \_\_\_\_\_ I've Identified Reasons Why My Child Elopes, & Am Teaching My Child About Elopement Dangers
- \_\_\_\_\_ I Have Enrolled My Child Into Swimming Lessons (*YMCA listing of special needs lessons @ [nationalautism.org](http://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 -- [achild dismissing.org](http://achild dismissing.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 (*included in this kit*)
- \_\_\_\_\_ 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, 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
- \_\_\_\_\_ I Continue To Document Actions Taken To Protect My Loved One

# family wandering emergency plan

awaare.org



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 to remember

**MY CHILD'S TRANSMITTER TRACKING NUMBER (if applicable)** \_\_\_\_\_

**MY CHILD'S OFFICIAL DIAGNOSIS** \_\_\_\_\_

**MY CHILD'S IDENTIFYING MARKS, BEHAVIORS, MEDICATIONS & MEDICAL NEEDS** \_\_\_\_\_

\_\_\_\_\_

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## emergency steps:

- ALWAYS CALL 911 IMMEDIATELY IF YOUR LOVED ONE IS MISSING FROM YOUR HOME.**
- IF YOUR CHILD IS ATTRACTED TO WATER, SEARCH NEARBY WATER SOURCES FIRST.**
- Clearly state your child's name for the 911 operator.
- 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).
- Provide your child's date of birth, height, weight, and other unique identifiers (eyeglasses, braces, hand-flapping, etc.)
- If your child is attracted to water, tell them to **immediately** dispatch personnel to nearby water sources (lakes, ponds, pools)
- Tell them when you noticed that your child was missing and what clothing he or she was wearing.
- Request an AMBER Alert be issued, or Endangered Missing Advisory.
- Request that your child's name and identifying information be immediately entered into the National Crime Information Center (NCIC) Missing Person File.

*Search known areas your child would likely be or attracted to. 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 you 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, as well as the most dangerous areas nearby, such as 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), willing, and understand which search location is assigned to them.

NAME	NUMBER	NUMBER	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.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**TIPS:** JOIN “NAA AUTISM & SAFETY: WANDERING PREVENTION” ON FACEBOOK so that social media tools are readily available. 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:

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

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

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

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

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

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

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- 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 [achildsmissing.org](http://achildsmissing.org).



## SWIMMING LESSONS

From 2009 to 2011, accidental drowning accounted for 91% of reported 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 swimming lessons should be with clothes and shoes on.*

### Step 1:

To find swimming lessons in your area, click [special needs swimming lessons](#) or visit [our web site](#) click Autism & Safety, 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 "wandering awareness letter" 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, consider contacting this service: [Lessons With Julie](#)

**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.**

## 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 bath time. 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 bath time. 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 water-play setting that is safe.

For more tips, visit [awaare.org](http://awaare.org).

## ROOT-CAUSE SCENARIOS

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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](http://awaare.org).



## STOP SIGN PROMPTS

Print, cut, adhere to doors and windows. For laminated Stop Signs with adhesives, visit [nationalautism.org](http://nationalautism.org)





## SOCIAL STORIES

The following pages contain two social stories,  
one for pictures, and the other for text only.

For additional Social Stories, please visit [awaare.org](http://awaare.org)

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

**This is my house**

*Picture of house or apartment*

**I live in my house with my family.**

*Picture of child with family by house*

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

*Picture of child in house.*

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

*Picture of family.*

**Staying in my house will keep me safe.**

**Mom and Dad will be happy that I am safe.**

## Staying in My House

My name is \_\_\_\_\_ . I live in a house with my Mom and Dad. Lots of kids live in a house. It's important for me to stay in my house with my family. When I stay in the house, my parents will know where I am. They will know where to find me when they need me. My parents will also know that I am safe if I stay in the house. I will try to stay in my house. This will keep me safe.



# CAREGIVER LOG

awaare.org



CAREGIVER & CHILD'S NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

## my child's wandering history:



DATE	WANDERED FROM WHERE/WHOM	WAS FOUND AT

CIRCUMSTANCES OF NOTE

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

ACTIONS/STEPS TAKEN TO PREVENT WANDERING

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# CAREGIVER LOG

awaare.org



CAREGIVER & CHILD'S NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

## RESOURCES AND CONTACTS



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### NUMBERS:

#### LAW ENFORCEMENT & PHYSICIAN

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

#### OTHER CONTACT NUMBERS:

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### OTHER NOTES:

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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) [LEARN MORE](#)***

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 premises have 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 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)



**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 [click here](#).

**- Check to see if Project Lifesaver is in your area:**

1. First [click here](#)
2. Type in your zip code.
3. Scroll down to see results.

**- Check to see if LoJack SafetyNet is in your area:**

1. First [click here](#)
2. Type in your zip code.

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

1. Call Project Lifesaver International at 877-580-LIFE (5433) and request that informational materials about Project Lifesaver be sent to your address.
2. 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 [click & print](#)
  - any news stories or documented cases in your area involving a missing child/adult with autism, or other cognitive impairment, including Alzheimer's.
  - a customized **LETTER OF INTENT** (use template below\*\*)
  - any signed petitions or letters from other members of your community in need of this service. It's helpful to illustrate the need.

## **FIRST-RESPONDER FACILITATED TRACKING PROGRAM CONT'D**

3. If your local agency cannot or will not implement Project Lifesaver because of budgetary constraints, consider holding a community fundraiser through:
  - Local churches, civic groups, autism support groups or organizations
  - Car washes, chili cook offs, spaghetti dinners can be great ways to raise this money.Typically to implement Project Lifesaver, a county will need around \$4000 to \$5000.

*\* Your local agency for search and rescue will likely be the Sheriff's office, which you can Google using your county's name. Google: (Your County & Your State) + Sheriff's Office. You may also try searching (Your County) + Search and Rescue. When calling, request to speak to the person who handles search and rescue, or the Sheriff.*

### **\*\*PROJECT LIFESAVER LETTER OF INTENT**

Date

Dear (Put Prospective Agency name here);

On behalf of the community from (Community/County) we wanted to take a moment to describe a community relations program that would be a wonderful addition to our local agency. It's called Project Lifesaver.

Project Lifesaver is a not for profit organization that offers a public safety program that trains and certifies local law enforcement and first responders to search for loved ones with cognitive conditions such as Alzheimer's, dementia, Autism, and Down syndrome. The program includes two days of training on cognitive conditions, how to communicate effectively with those who have a cognitive condition, and how to use radio technology to track at-risk individuals that wander. **This technology has proven to be successful for many years and a helpful tool in search in rescue, which without tracking technology can cost significant man-hours, money, and usually produce negative outcomes, especially for those who have cognitive conditions and are more prone to wandering.**

After review of this informational packet, DVD, and material, you will see why your local residents have brought this program to your attention. We have grants available for those agencies that are unable to afford starting the program. If your agency would like to move forward please feel free to contact Chief Tommy Carter at [tcarter@projectlifesaver.org](mailto:tcarter@projectlifesaver.org) or at 757-435-8494 with any questions you may have.

We thank you for your time and consideration and we all can work hard to keep our communities a safer place.

Sincerely,

Chief Gene Saunders

CEO & Founder

Project Lifesaver International



## **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](http://awaare.org).



## TYPES OF TRACKING TECHNOLOGY

There are various types of tracking technology, though pricing, coverage, efficacy, battery life and other features vary greatly between locating devices. Please feel free to [contact us](#) with specific questions.

**Global Positioning System (GPS)** Many location management services rely on GPS technology. GPS depends on satellites to provide positioning and navigation information. The device communicates with satellites and figures out the distance to each and then uses this information to deduce its own location. In order for GPS to work, there must be a clear line of sight between the device and the satellites. **Advantages:** GPS is not dependent on the availability of a network and can provide very precise, worldwide outdoor positioning information at any time of day. Users can set up Geofencing and receive notifications when their loved one steps outside of a designated perimeter. **Limitations:** Natural barriers, such as mountains, thick foliage or clouds, and artificial obstructions, such as large buildings and dense communities, can hinder satellite signals. For this reason, GPS tracking inside buildings is seldom possible. Also, GPS tracking in large cities is not always reliable. Like a cell phone, these units require frequent charging, leaving the user unprotected during those times. GPS units are not waterproof.

**Network Assisted GPS (A-GPS)** A-GPS technology works in conjunction with GPS by using cell towers to triangulate locations. **Advantages:** A-GPS can provide indoor positioning information with greater accuracy and is usually faster than unassisted GPS. Users can set up Geofencing and receive notifications when their loved one steps outside of a designated perimeter. **Limitations:** A drawback to A-GPS is the availability and reach of the cellular network it gets its boost from. If you travel out of the network's reach, your device won't be able to pick up the signals. Before choosing a device, find out if the network the device depends upon is reliable where the person with Autism lives and in the areas he or she is likely to travel. Like a cell phone, these units require frequent charging, leaving the user unprotected during those times. A-GPS units are not waterproof.

**Radio Frequency (RF)** RF works through the transmission of radio waves between a transponder, an antenna and a receiver. The RF chip transmits a signal to the receiver through the antenna and provides data on a person's location. **Advantages:** The device does not have to be removed for charging. RF transmitters typically use small watch batteries. Batteries are replaced once per month. RF transmitters do not need to be removed when bathing or swimming. **Limitations:** Key limitations of RF are the need for multiple pieces of equipment and a limited signal range. Additionally, most systems using RF technology offer the service through local law enforcement so it is necessary to determine whether your community supports a RF location system. RF technology does not allow the option of perimeter notifications or Geofencing.

**Uplink Time Difference of Arrival (U-TDOA)** U-TDOA is a position-location technology for mobile phone networks. It uses advanced triangulation techniques to determine the precise location of a mobile phone. U-TDOA has been widely embraced by major U.S. GSM carriers to meet the government's E-911 requirements. **Advantages:** A small, single-purpose wireless device that upon remote activation dials 9-1-1 and reports its location directly to emergency responders. **Limitations:** Must call 911 and open missing person's case before system can be activated and signal given to emergency response personnel.

For more, visit [awaare.org](http://awaare.org).



**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/elopeing from a safe environment. Unfortunately, many cases end in tragedy.

According to a 2011 study by the Interactive Autism Network (IAN) through the Kennedy Krieger Institute (KKI)<sup>1</sup>, 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.<sup>2</sup> 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 hypothermia.

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.<sup>3</sup> In 2001, a California research team found that elevated death rates were attributed in large part to drowning.<sup>4</sup> Wandering in ASD has become so common, it was assigned a medical diagnostic code [V40.31], which went into effect in October of 2011.<sup>5</sup>

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](mailto:naa@nationalautism.org).

Sincerely,

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

Lori McIlwain  
Executive Director  
National Autism Association

1. Interactive Autism Network Research Report ASD Elopement, 2011 2. McIlwain, L. National Autism Association – Lethal Outcomes In ASD Wandering. January 2012. 3. Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. Department of Child and Adolescent Psychiatry, Bispebjerg University Hospital, Copenhagen, Denmark. July 2008 4. Shavelle RM, Strauss DJ, Pickett J. - Life Expectancy Project, San Francisco, California, USA. December 2001 5. ICD-9 Code for Wandering, Centers for Disease Control. October 2011 [cdc.gov](http://cdc.gov).





## **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 [NAA's Big Red Safety Shop](#).

- 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 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. Watch this [YouTube video](#) for a demonstration.
- 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 our [AWAARE](#) website, or [click here](#) to join our Wandering Prevention Facebook group.

*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.*



## **RESOURCES**

### **GENERAL RESOURCES**

National Autism Association: [nationalautism.org](http://nationalautism.org)

AWAARE Collaboration: [awaare.org](http://awaare.org)

NAA Autism Safety: [autismsafety.org](http://autismsafety.org)

Autism Speaks Safety Project: [autismsafetyproject.org](http://autismsafetyproject.org)

### **SWIMMING LESSONS**

YMCA Listing [nationalautism.org](http://nationalautism.org)

Super Swimmers [superswimmersfoundation.org](http://superswimmersfoundation.org)

### **CHILD SAFETY PRODUCTS**

NAA's Big Red Safety Shop: [nationalautism.org](http://nationalautism.org)

### **TRACKING SYSTEMS & ID PRODUCTS**

Project Lifesaver [projectlifesaver.org](http://projectlifesaver.org)

LoJack SafetyNet [lojacksafetynet.com](http://lojacksafetynet.com)

Caretrak Systems: [caretrak.com](http://caretrak.com)

Alzheimer's Comfort Zone: [alz.org](http://alz.org)

Medic Alert [medicalert.org](http://medicalert.org)

Road ID [roadid.com](http://roadid.com)

### **SERVICE DOGS**

Blessings Unleashed [blessingsunleashed.org](http://blessingsunleashed.org)

4 Paws for Ability [4pawsforability.org](http://4pawsforability.org)

### **FOR FIRST RESPONDERS & CAREGIVERS**

Reverse 911 [achildsmissing.org](http://achildsmissing.org)

National Center For Missing And Exploited Children [missingkids.com](http://missingkids.com) 1-800-THE-LOST

Autism Risk Management [autismriskmanagement.com](http://autismriskmanagement.com)

The Law Enforcement Awareness Network [leanonus.org](http://leanonus.org)

Autism Alliance for Local Emergency Responder Training [autismalert.org](http://autismalert.org)

Take Me Home [autism-society.org](http://autism-society.org)



A NATIONAL AUTISM ASSOCIATION SAFETY INITIATIVE

## **A MULTI-LAYERED APPROACH IS BEST**

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](http://awaare.org).

## ABOUT THIS TOOLKIT

This Big Red Safety Toolkit is part of NAA's FOUND Program, dedicated to wandering prevention and bringing children and adults with autism home safely. Other Big Red Safety initiatives include:

- *The Big Red Safety Box*
- *The Big Safety Booth*
- *The Big Red Safety Shop*
- *The Big Red Safety Toolkit for Caregivers*
- *The Big Red Safety Toolkit for First Responders*



*NAA's Big Red Safety Box initiative ships critical resources to at-risk children and adults with autism. The initiative also helps provide employment for adults with autism and other disabilities.*

For more information on autism-related wandering, please visit [awaare.org](http://awaare.org). For specific questions, please contact the National Autism Association at 877-622-2884, or 877-NAA-AUTISM.