



WHAT IS AUTISM?

- Autism is a developmental disability that can cause significant social, communication & behavioral challenges.
- Autism occurs in all racial, ethnic, and socioeconomic groups.
- Autism affects 1 in 68



AUTISM DIAGNOSIS

A diagnosis of **Autism Spectrum Disorder (ASD)** now includes several conditions that used to be diagnosed separately:

- Autistic disorder
- Pervasive developmental disorder - not otherwise specified (pdd-nos)
- Asperger syndrome





autism

AUTISM HAS MANY SYMPTOMS THAT VARY FROM PERSON TO PERSON, BUT THERE ARE CONSISTENT HALLMARKS.

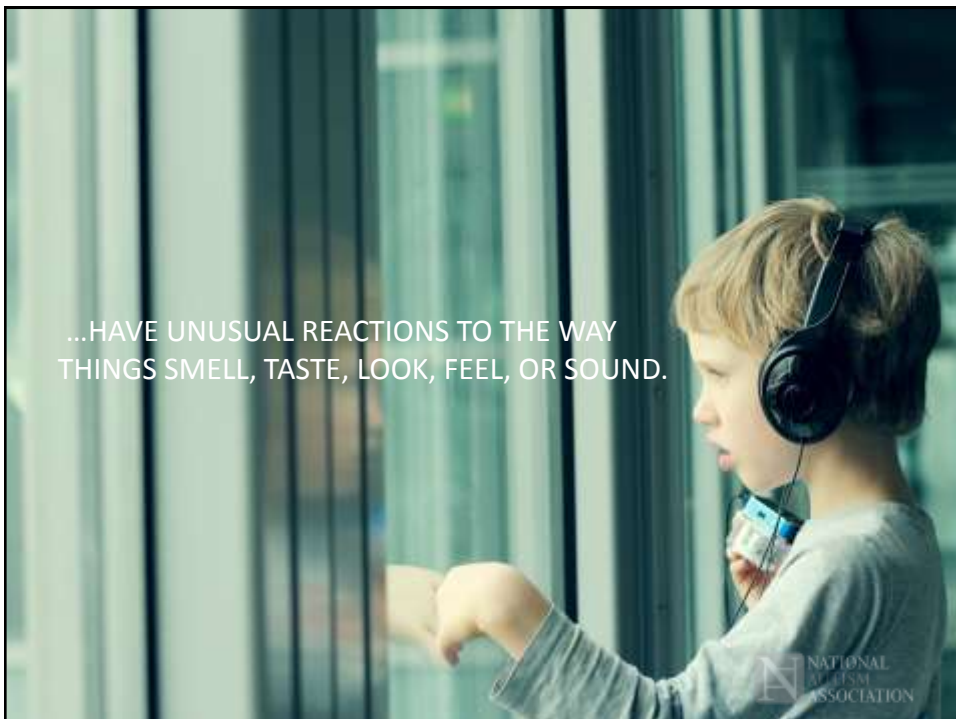
SOMEONE WITH AUTISM MIGHT:

- not speak
- avoid eye contact
- want to be alone
- want to wear no clothing
- appear deaf
- wear a diaper
- repeat or echo words (echolalia)
- repeat actions over and over again
- dislike change

And...



...HAVE UNUSUAL REACTIONS TO THE WAY THINGS SMELL, TASTE, LOOK, FEEL, OR SOUND.





IT'S ESTIMATED THAT
25% to 40% CANNOT SPEAK.

autism

OTHER COMMON TRAITS OF NOTE:



- hyper/hypo sensitivity to pain.
- no fear of danger or understanding of consequences.
- extreme phobias
- may take figurative language in a literal way. *for example, sit down in the chair would be better understood over "take a seat."*



autism

ADDITIONAL TRAITS OF NOTE:

- Fecal smearing
- Head-banging, self injury
- Unusual fascinations
- Narrow food preferences
- Pica
- No interest in toys
- Co-existing conditions: epilepsy, insomnia, allergies, GI issues, asthma



autism

THE VAST MAJORITY OF THOSE WITH AUTISM “STIM,” WHICH COMES FROM THE TERM SELF-STIMULATING

Examples: rocking; spinning; flapping hands; flicking fingers; verbal repetition

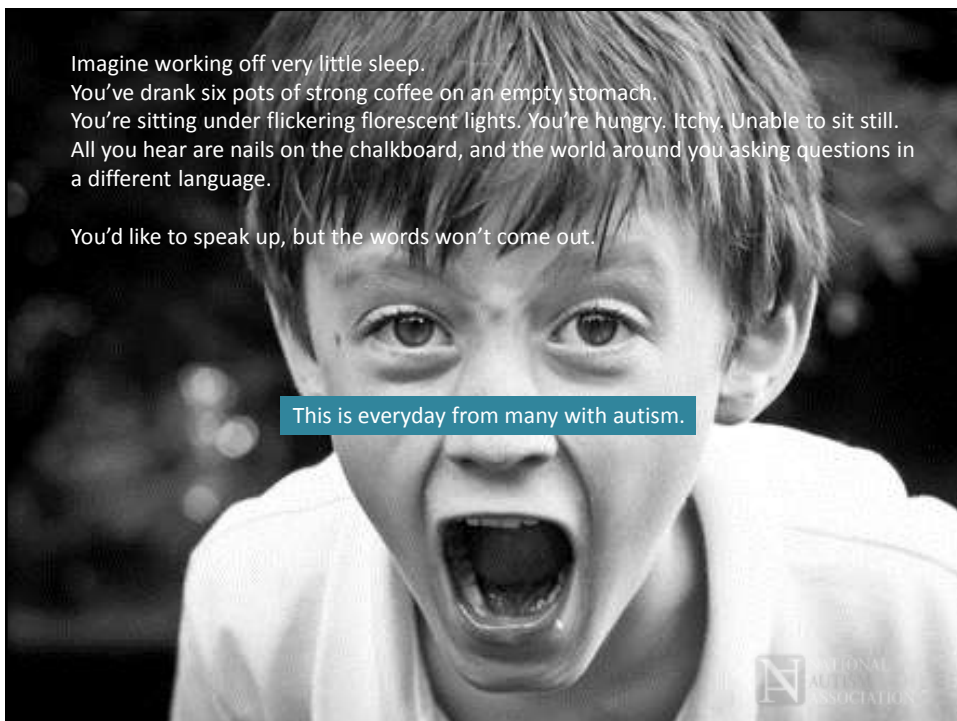
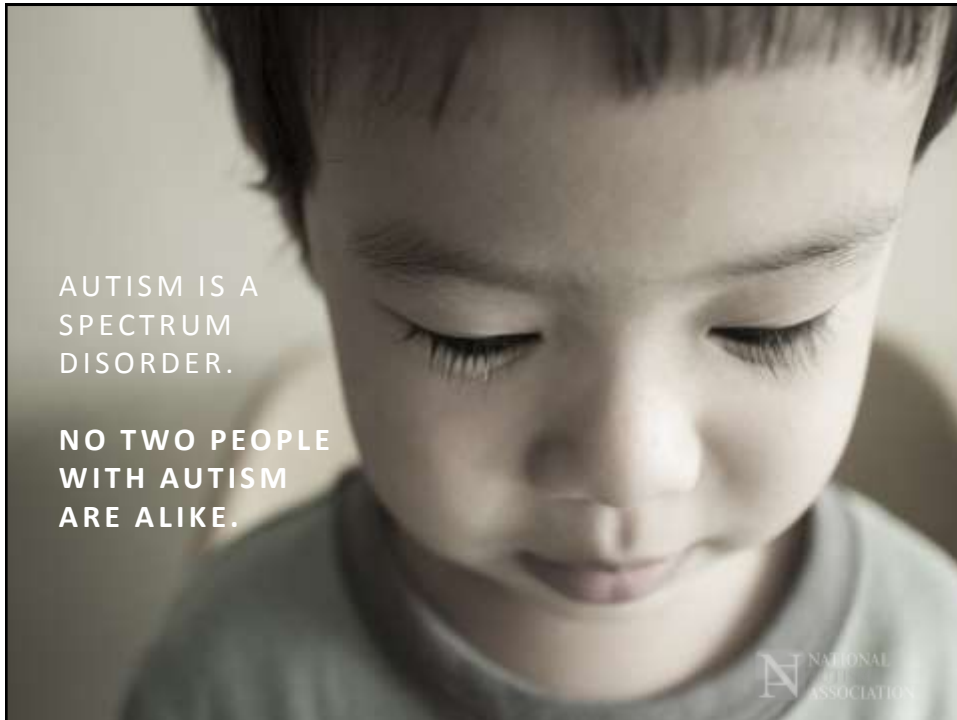
“My child stims on roadway signs.”

“She’s stimming on end credits.”

“She’s doing happy stims right now.”

“He’s angry stimming right now.”





AUTISM & WANDERING



WANDERING DEFINED

Wandering is the tendency for an individual to try to leave the safety of a responsible person's care or a safe area, which can 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 it may persist in children and adults with autism spectrum disorders (ASDs). Children with ASDs have challenges with social and communication skills and safety awareness. This makes wandering a potentially dangerous behavior.

Wandering may also be referred to as elopement, bolting, fleeing, running.



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.



DATA



PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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


The online version of this article, along with updated information and services, is
located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0762>


THE DATA

- 49% of children with autism engage in wandering behaviors
- 35% attempt to wander at least once per week
- More than one third of children with autism who wander are never or rarely able to communicate their name, address, or phone number
- 29% of wandering happens from a classroom or school
- 53% of those who exhibited elopement behavior, went missing long enough to cause concern
- 42% of cases involving a child 9 and younger have ended in death

NATIONAL
AUTISM
ASSOCIATION



Half of families report they have never received professional advice or guidance on wandering prevention.



40% of parents report suffering sleep disruption due to fear of their child wandering.





CHILDREN WITH AUTISM ARE HIGHLY
ATTRACTED TO WATER.



91 % of wandering-related
deaths are caused by drowning. (NAA)

Other risks include traffic/train
Injuries & fatalities, exposure,
Encounters with strangers
Secondary risks: restraint

Since 2011, there have been
Close to 500 autism-related missing person
cases serious enough to be reported by the
media (NAA).



But in 2014, we began seeing
A couple of noticeable trends.





wandering

TRENDS IN TEENS & ADULTS

- More deaths in teens & adults
- More minority cases
- More repeat cases



WE ARE ALSO DOCUMENTING
MORE CASES OF BOLTING.



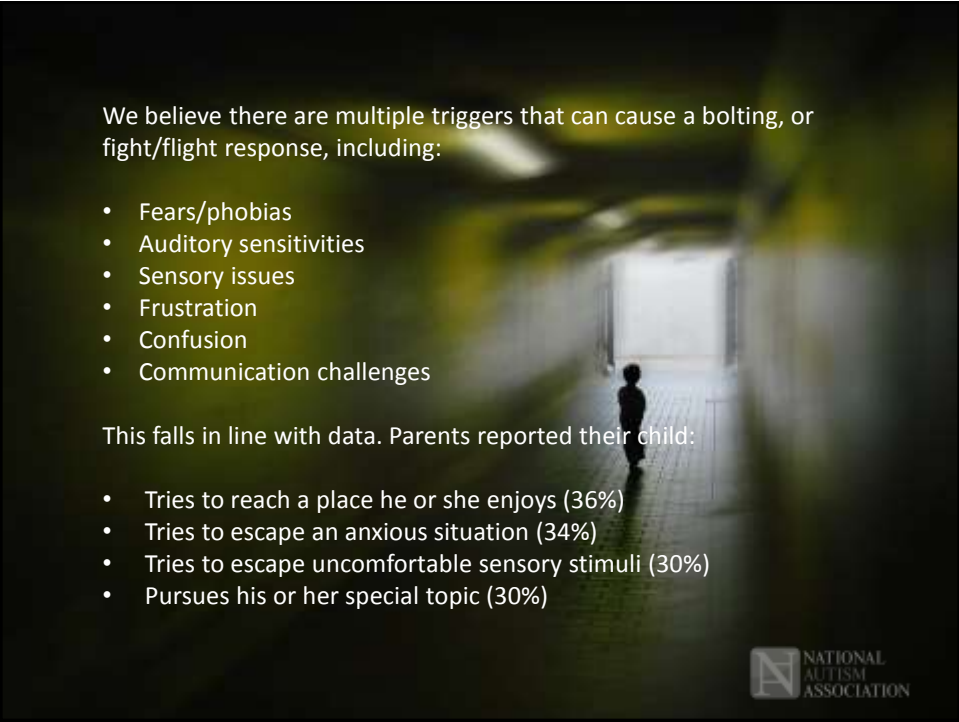
BOLTING

When an individual suddenly becomes frustrated or overwhelmed and quickly leaves his /her environment.



CAUSES





We believe there are multiple triggers that can cause a bolting, or fight/flight response, including:

- Fears/phobias
- Auditory sensitivities
- Sensory issues
- Frustration
- Confusion
- Communication challenges

This falls in line with data. Parents reported their child:

- Tries to reach a place he or she enjoys (36%)
- Tries to escape an anxious situation (34%)
- Tries to escape uncomfortable sensory stimuli (30%)
- Pursues his or her special topic (30%)



CASE STUDIES



Case Study: Prolonged Exposure

- Logan Mitcheltree - Age 9
- South Williamsport, PA
- December 2004
- Slipped out of home unnoticed
- Found deceased in the woods after a 3-day search
- **Tracking device likely would have prevented lethal outcome**



Case Study: Drowning, Creek

- Benjy Heil – Age 7
- Wisconsin Rapids, WI
- June 2007
- Slipped out of his home
- 6-day search ended when Benjy's body was found in a nearby creek
- Benjy had been seen by a neighbor.
- **AMBER Alert could not be issued**



Case Study: Prolonged Exposure

- James Delorey – Age 7
- South Bar, Nova Scotia
- December 2009
- Slipped out of home with his dog
- Found unconscious after 2-day search
- Died that evening in hospital
- **Nova Scotia now has Project Lifesaver Tracking**



Project Lifesaver “Recent Rescues” Log

Ref #	Date	City or County, State	Diagnosis	Recovery Time
2,203	9/10/2010	Portsmouth, VA	Schizophrenic	2 minutes
2,202	8/27/2010	Rosenhayn, NJ	Alzheimer's	2 minutes
2,201	9/11/10	Chillicothe, OH	Epilepsy	21 minutes
2,200	9/9/2010	Nicholasville, KY	Alzheimer's	2 minutes
2,199	8/31/2010	Nova Scotia, CAN	Autism	9 minutes
2,198	9/8/2010	Quincy, MA	Severe Autism	11 minutes
2,197	9/8/2010	Norfolk, VA	Dementia	1 hour 11 minutes
2,196	9/9/2010	Marion, IN	Dementia	8 minutes
2,195	8/30/2010	Pell City, AL	Alzheimer's	6 minutes
2,194	9/7/2010	Norfolk, VA	Mental Retardation	40 minutes

Case Study: Under Foster Care/Holiday

- Omarion Humphrey – Age 9
- Davison Township, MI
- July 4th holiday, Lake Callis Recreation Complex
- In the care of foster provider
- Wandered off multiple times, foster provider warned
- Wandered final time
- Seven-day search: ground, air and water using the latest technology
- Body recovered in Lake Callis
- **They were confident he was not in the lake**



Case Study: Visiting relatives

- Jayden Morrison, age 4, SC
- Sidney Heidrick, age 4, OH
- Drowning deaths/extensive searches

• **Both wandered away from grandparents' home while visiting**



Case Study: Struck by train, 2015

- Timothy Wallace – Age 9, TN
- Wandered from home at night
- Kaden Lanphear - Age 8, CA
- Wandered from home in morning

(Not pictured)

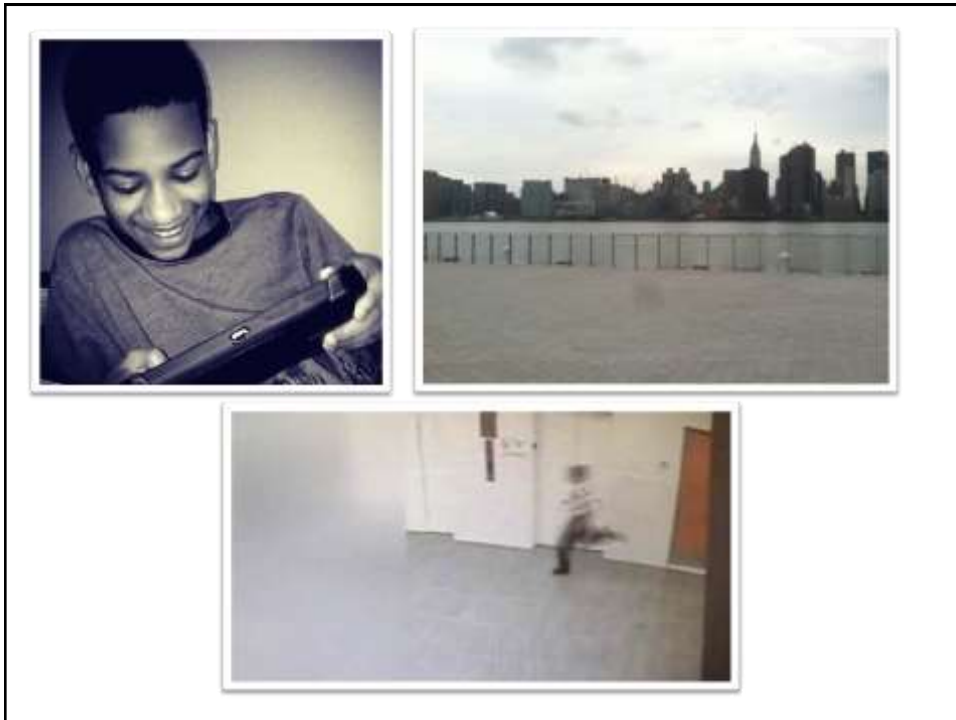
- Andrew Paul Carter – Age 9, AL
- Wandered from home in morning



Case Study: School-related Fatality

- Avonte Oquendo – Age 14, NY
- Left his Queens School in 2013
- Massive search throughout NYC
- Search focus: subway system
- Remains found three months later in the East River





Case Study: Non-Lethal Outcome

- Robbie Wood – Age 8
- Hanover County, VA
- October 2011
- Found alive nearly six days after he wandered away from his family in a wooded park.**
- Found in a fetal position in quarry
- Suffered minor injuries
- Project Lifesaver was available, but child was not enrolled.**



Case Study: Non-Lethal Outcome

- Joshua Robb – Age 8
- San Bernardino County, CA
- September 2011
- Squeezed through the metal bars of his school playground and ran into a nearby forest.
- Missing overnight during lightning storms.
- Dehydration was noted.
- **The boy's favorite music was played to draw him to safety.**



Case Study: Stranger and Police Encounter

- Connor – Age 15
- Cary, NC
- Multiple goal-directed and bolting incidents from three different schools
- Will flee following certain triggers
- Two identical school incidents involving unescorted transitions from speech therapy to classroom (fire code prohibits locked doors)
- Picked up by a man in a car after wandering from school playground
- School did not contact police
- Police had to search for where he belonged, did not recognize his autism, or note autism in police report
- **ID would have spared the additional trauma**



PREVENTION



WORKING TO PREVENT WANDERING INCIDENTS AND DEATHS WITHIN THE AUTISM COMMUNITY

AWAARE

COLLABORATION

contact us | promote this initiative 

SHARE   

HOME :: AUTISM & WANDERING :: FAQs :: SAFETY MATERIALS :: ABOUT US :: RESOURCES

AUTISM
WANDERING
AWARENESS
ALERTS
RESPONSE
EDUCATION



BECOME AWAARE

With little public understanding about autism-related wandering, coupled with a lack of resources to combat occurrences, drowning deaths associated with autism elopement remain a leading cause of fatalities among children and adults on the autism spectrum. Although no formal data exists about the number of wandering incidents per year, cases are becoming increasingly common and awareness alone can play a major role in reducing occurrences. To learn more, [click here](#).

RESEARCH

Autism is a diagnosis that represents many symptoms, some of which can lead to serious health and safety risks, including death. 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 attributed elevated death rates in large part to drowning. Drowning, prolonged exposure, and other wandering-related factors remain among the top causes of death within the autism population. Currently, no estimates exist and no formal methods are in place to track how many children and adults wander per year, but in a 2007 online poll through the National Autism Association, 92% of parents reported that their child/ren with autism have a tendency to wander.

DOWNLOAD & SHARE

WHAT TO DO IF SOMEONE WANDERS

- Call 911
- Implement your [Family Wandering Emergency Plan \(FWEP\)](#)
- [Click here for more information](#)

QUICK LINKS

- [Autism Risk Management](#)
- [Project Lifesaver](#)
- [A Child Is Missing](#)
- [AWAARE Brochure](#)
- [Social Stories](#)

NEWS, ALERTS, BLOGS

- [News Stories](#)
- [Join our Facebook Group](#)

:: FREQUENTLY ASKED QUESTIONS
 :: HELPFUL MATERIALS
 :: TRACKING TECHNOLOGY
 :: WHERE TO FIND SWIMMING LESSONS
 :: PARENT STORIES
 :: FOR LAW ENFORCEMENT OFFICIALS
 :: FOR PHYSICIANS AND THERAPISTS
 :: FOR SCHOOL ADMINISTRATORS

prevention tools



A wandering prevention resource
for the autism community



HOME SECURITY

- Deadbolt locks
- Hook and eye locks above child's reach
- Home security alarm system
- Door chimes/alarms
- Fencing
- Safeguard pools – self-latching gates, motion sensors
- Baby monitor



prevention tools



prevention tools





SAFETY STRATEGIES

- What type of wandering best describes your child?
- What triggers may cause your child to flee?
- Work on calming/de-escalation methods to help your child cope with triggers and provide alternatives to running/fleeing
- Address known triggers with other caregivers and advocate for de-escalation techniques to be implemented in all settings
- Understand your child's goal – water, trains, park, favorite food, etc.
- Allow safe exploration of obsessions in supervised, safe environment



SAFETY STRATEGIES

- Use a “Tag, You’re It” System: Many incidents occur during a family gathering, camping trip, school function or transition. Encourage parents to establish a “tag” strategy to identify the adult who is primary supervisor during a period of time. Use physical tag prompt, eye contact and verbal acknowledgment. Make sure tagged caregiver understands responsibilities and expectations.
- Use a “Bookends” Approach: If hiking or walking outdoors, make sure two responsible adults act as bookends – one adult on each side of the child, or one in front and one behind.
- Use a Double Shoulder or Arm Lock: Maintain physical contact when walking through parking lots or other busy public places.



wandering

Free family wandering emergency plan at 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:


- ☒ **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).
- ☒ Provide your child's date of birth, height, weight, and any other unique identifiers such as eyeglasses and braces.
- ☒ Tell them when you noticed that your child was missing and what clothing he or she was wearing.
- ☒ 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'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 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: _____



wandering



AUTISM ELOPEMENT ALERT FORM Date Submitted: _____

PERSON-SPECIFIC INFORMATION FOR FIRST RESPONDERS

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
 ___ Prone to Seizures ___ Cognitive Impairment ___ Other _____

If Other, Please explain: _____

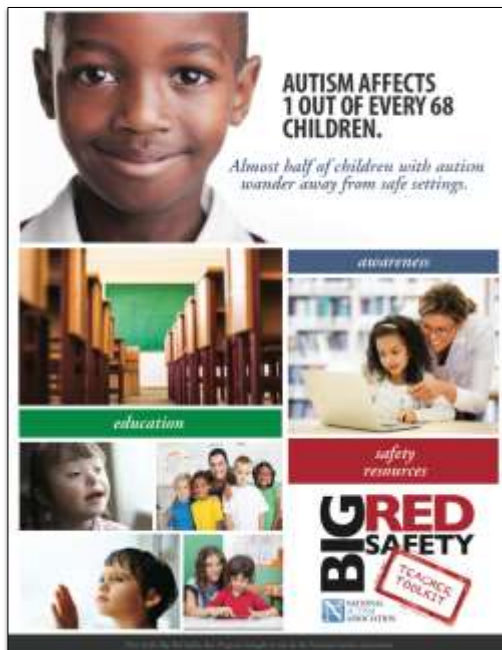
Prescription Medications needed: _____

Attach current
photo here

SAFETY AT SCHOOL

- Ask what protocols are in place to prevent and respond to wandering incidents and other emergencies
- “Has my child ever wandered outside school building?”
- “Has my child ever fled from a teacher or been left unattended during transitions?”
- Take a tour of the school/facility and note possible areas of concern, ask for each area to be addressed
- Write a letter requesting that you immediately be informed of any wandering incident, prevention and response protocols – include this information in IEP
- Consider asking physician about wandering diagnosis code **V40.31** (Wandering in Diseases Classified Elsewhere) went into effect in October 2011.





**NAA BIG RED
SAFETY
TEACHER TOOLKITS
AVAILABLE SOON!**



BOLTING

- While wandering behaviors are typically a form of communication, bolting can have the added elements of impulsivity and unpredictability.
- It can be a type of trigger that sets a child or adult in motion – a noise, a fear, a desire. The abruptness and speed of bolting makes it especially dangerous, particularly in open public environments.



BOLTING

- If your child tends to bolt, ask his/her school for a functional behavioral assessment. Based on its findings, a behavioral intervention plan should be developed and used consistently between home and school. If you're going out in a public place, communicate safety rules beforehand.



BOLTING

- Use a picture schedule or social story to help your child understand expectations.
- Arm Lock. Walking arm-in-arm helps prevent bolting incidents in areas like a parking lot.
- For walking or hiking, use a bookends approach with one adult on each side of the child.
- A school 1:1 should be assigned to any child or teen with autism at risk of bolting or wandering off.
- Reducing or eliminating triggers while creating ways for your child to deescalate will help prevent bolting incidents and the need for emergency restraint.



<p>1</p>  <p>HAPPY!</p> <p>Everything's Okay</p>	<p>2</p>  <p>WORRIED</p> <p>First I can try:</p> <ul style="list-style-type: none"> - Take 5 deep breaths - Sing a song in my head - Squeeze a squishy ball - Put my worry in my pocket - Tell my teacher why I am worried 
<p>3</p>  <p>SAD</p> <p>First I can try:</p> <ul style="list-style-type: none"> - Take 5 deep breaths - Sing a song in my head - Squeeze a squishy ball - Put my sadness in my pocket! - Do a little dancing - Ask for a break - Tell my teacher why I am sad 	<p>4</p>  <p>ANGRY</p> <p>First I can try:</p> <ul style="list-style-type: none"> - Take 10 deep breaths - Sing a song in my head - Squeeze a squishy ball - Put my anger in my pocket! - Do a little dancing - Ask for a break - Tell my teacher why I am angry 

BE ON HIGH ALERT

- After a new move (new home, new school)
- During vacations
- Holidays/Family gatherings
- Warm weather onset
- Outdoor activities
- School and other transitions
- Times of commotion/stress

RESPONSE

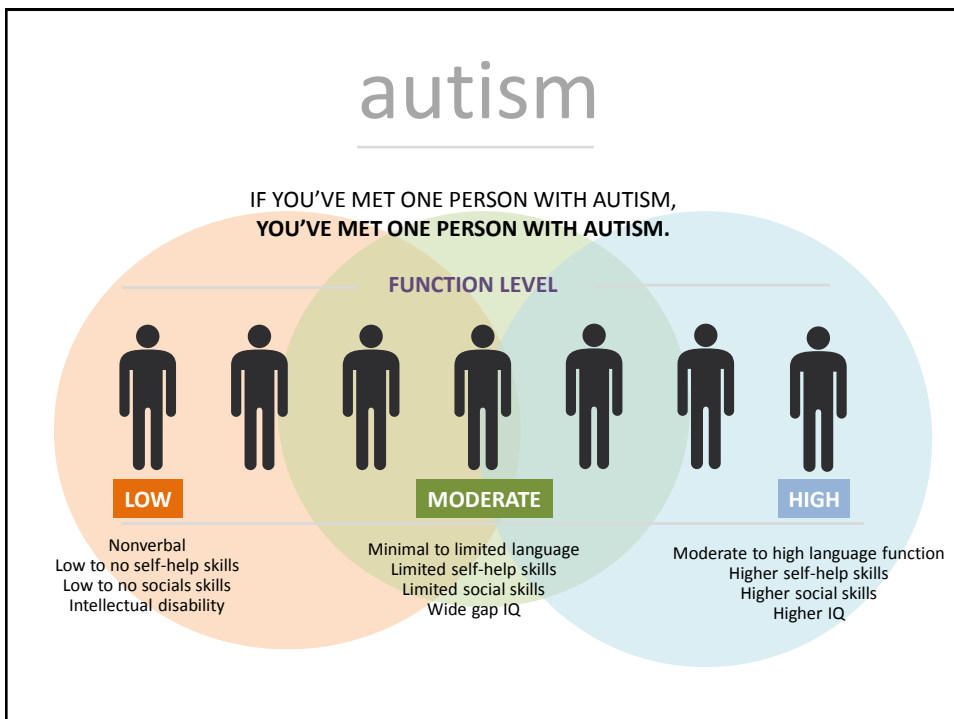
- Call 911 immediately
- Ask Police to activate Reverse 911 system to alert everyone in the local area
- Implement your Family Wandering Emergency Plan
- Provide Profile Form to Police
- Search areas that pose the highest threat first
- Use favorite things to safely attract child

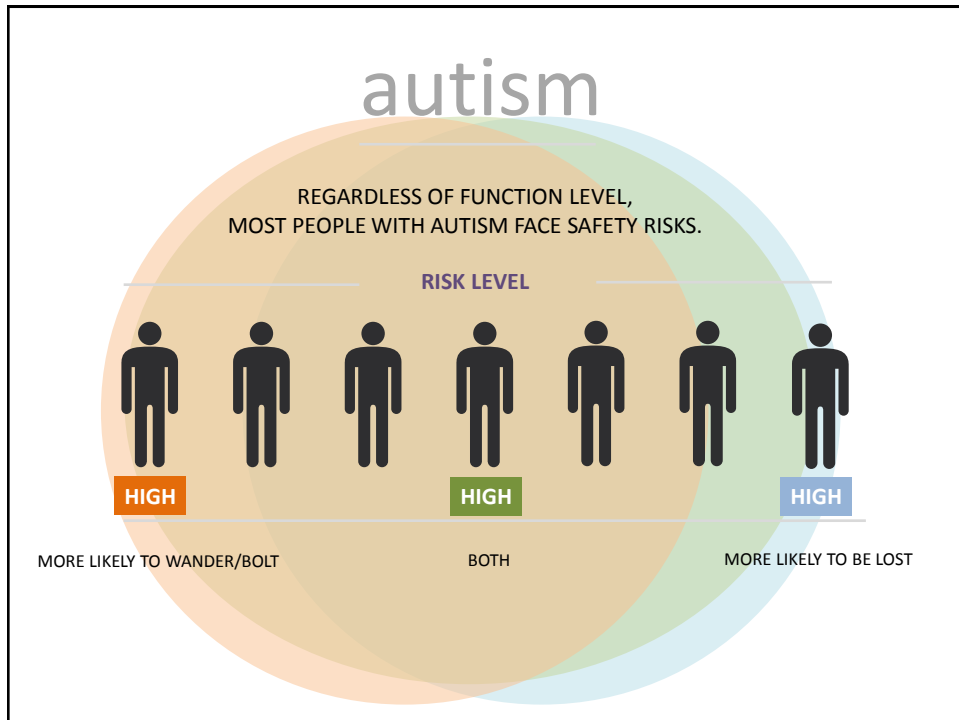


WHERE TO SEARCH









TRACKING DEVICES



Water resistant for 24/7 protection

Unique digital ID verification for each client

Transmits within dedicated radio frequency band

FCC and Industry Canada certified


Lightweight ergonomic design

SafetyWear

DIFFERENT OPTIONS

Zip Code Search By City:

Radius




Map Satellite

Info data ©2014 Google Terms of Use Report a map error

Location	Address	Distance	Directions
National Autism Association	429 Warren Avenue Cary, NC 27511 919-741-1840	1.0 miles	Directions
Wake County Sheriff's Office	330 South Salisbury Street Raleigh, NC 27602 919-856-6400	7.9 miles	Directions
Durham County Sheriff's Office	310 S. Grand Street Durham, NC 27701 919-360-5871	16.7 miles	Directions
Chapel Hill Police Department	808 MLK Blvd. Chapel Hill, NC 27514 919-853-2917	18.7 miles	Directions

GO TO
PROJECTLIFESAVER.ORG
AND ENTER YOUR
ZIP CODE.



GO TO
SAFETYNETBYLOJACK.COM
AND ENTER YOUR
ZIP CODE.


news public safety caregivers enroll now community resources about us

Enroll now!

SafetyNet™
by LO/JACK

Caring for a loved one who wanders is a considerable responsibility. Nothing is more frightening than the thought of a loved one with autism, Alzheimer's, or other cognitive impairment becoming lost. Proven SafetyNet by Lojack™ technology helps public safety agencies quickly find and bring your loved ones home. It provides you with additional protection and peace of mind to keep your loved one safe.

How it Works





FOR ILOC,
GO TO
ILOCTECH.COM.
FOR PAL, GO TO
PROJECTLIFESAVER.ORG




NATIONAL
AUTISM
ASSOCIATION




DISTANCE
MONITORS:
MYBUDDYTAG.COM
ANGEL ALERT AT
AMAZON.COM

NATIONAL
AUTISM
ASSOCIATION

TRACKING DEVICE FUNDING

- Pay out of pocket.
- Seek insurance coverage (get medical code v40.31)
- Seek funding through law enforcement, local groups, or national organizations.
- Encourage law enforcement to seek Byrne Grant.



- Police departments nationwide will be able to make the tracking devices available to children in their communities who are at risk of wandering using money available through the Justice Department's Byrne grant program.
- All applications must go through law enforcement agencies, so organizations and schools should work with local police to put programs in place.
- Police departments that receive money through the federal grant will be responsible for designing and administering their local program and determining how tracking devices are distributed.



OTHER SEARCH RESOURCES

- National Center for Missing and Exploited Children:
1-800-THE-LOST
- Reverse 911: achild dismissing.org
- EMA Guidelines: ncjrs.gov



Be REDy Booklet



**A wandering prevention resource
for the autism community**

- Caregiver Checklist
- Family Wandering Emergency Plan
- First Responder Alert Form
- Social Stories
- Sample IEP Letter ...and more



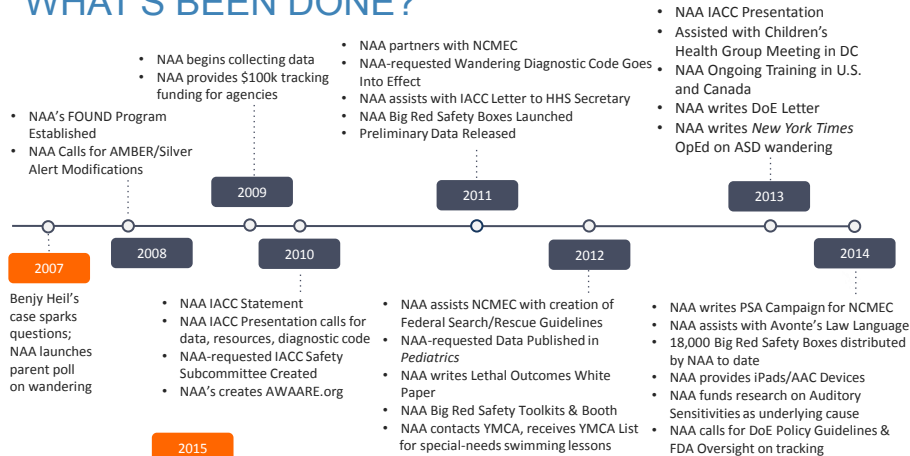
NAA'S Big Red Safety Box



WHAT'S BEEN DONE?

NATIONAL AUTISM ASSOCIATION | AUTISM/WANDERING RESPONSE TIMELINE

WHAT'S BEEN DONE?



WHAT'S STILL NEEDED?

Outreach. We need to reach law enforcement agencies with resources. We also need to reach families, schools, clinicians, and the public. We need programs directed at increasing personal safety and survival skills, and training and emergency protocols for school administrators, staff, and families. We need widespread response tools for law enforcement and search-and-rescue agencies. Avonte's Law!



Autism Safety Coalition

Visit autismsafetycoalition.org

Home About ASC Avonte's Law Take Action Find Resources Blog Contact Us

HALF OF CHILDREN WITH AUTISM WANDER FROM SAFE SETTINGS.

avonte's law will help speak for those who may not be able to speak for themselves.

Avonte's Law would help reduce the risk of injury and death relating to wandering behaviors in individuals with autism and other disabilities.

TAKE ACTION



THANK YOU!

NAA offers extensive resources at:

AWAARE.org

NationalAutism.org

CONTACT US:

e-mail: naa@nationalautism.org

phone: 877-622-2884

