AUTISM SAFETY:
Essential steps to prevent & respond to wandering

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AUTISM BASICS
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

**WHAT IS AUTISM?**

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 occurs in all racial, ethnic, and socioeconomic groups, but autism is 5 times more common among boys.

There is often nothing about how people with autism look that sets them apart from other people.
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 stimulating on end credits.”
“She’s doing happy stims right now.”
“He’s angry stimming right now.”
AUTISM IS A SPECTRUM DISORDER.

NO TWO PEOPLE WITH AUTISM ARE ALIKE.

Imagine working off very little sleep.
You’ve drank six pots of strong coffee on an empty stomach.
You’re sitting under flickering florescent lights. You’re hungry. Itchy. Unable to sit still.
All you hear are nails on the chalkboard, and the world around you asking questions in a different language.

You’d like to speak up, but the words won’t come out.

This is everyday from many with autism.
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.
CHILDREN WITH AUTISM ARE HIGHLY ATTRACTED TO WATER.

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
CHILDREN WITH AUTISM ARE HIGHLY ATTRACTION TO WATER.

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
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 ATTRACTION 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.
| Year | Case | Location | Age | Gender | Race | Education Level | Employment Status | Disability | Cause of Death | Wandering
|------|------|----------|-----|--------|------|-----------------|-------------------|-----------|----------------|---------|
| 2011 | Case 1 | Rural Town | 12 | Male | White | High School | Full-time | Yes | Suicide | Yes
| 2011 | Case 2 | Urban City | 15 | Female | Black | College | Part-time | No | Accidental | No
| 2012 | Case 3 | Rural Town | 18 | Male | Hispanic | High School | Unemployed | Yes | Suicide | Yes
| 2012 | Case 4 | Urban City | 20 | Female | White | Bachelor | Full-time | No | Accidental | No
| 2013 | Case 5 | Rural Town | 22 | Male | Black | High School | Unemployed | Yes | Suicide | Yes
| 2013 | Case 6 | Urban City | 25 | Female | Hispanic | Bachelor | Full-time | No | Accidental | No
| 2014 | Case 7 | Rural Town | 28 | Male | White | High School | Unemployed | Yes | Suicide | Yes
| 2014 | Case 8 | Urban City | 30 | Female | Black | Bachelor | Full-time | No | Accidental | No

**Diagram: Wandering - All Cases**

- 2014
- 2013
- 2012
- 2011

- **10 & Under Non-Lethal**: Red
- **10 & Under Deaths**: Orange
- **11 & Up Non-Lethal**: Light Blue
- **11 & Up Deaths**: Dark Blue
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

<table>
<thead>
<tr>
<th>Ref #</th>
<th>Date</th>
<th>City or County, State</th>
<th>Diagnosis</th>
<th>Recovery Time</th>
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<tr>
<td>2,203</td>
<td>9/10/2010</td>
<td>Portsmouth, VA</td>
<td>Schizophrenic</td>
<td>2 minutes</td>
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<tr>
<td>2,201</td>
<td>9/11/10</td>
<td>Chillicothe, OH</td>
<td>Epilepsy</td>
<td>21 minutes</td>
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<tr>
<td>2,200</td>
<td>9/9/2010</td>
<td>Nicholasville, KY</td>
<td>Alzheimer’s</td>
<td>2 minutes</td>
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<tr>
<td>2,199</td>
<td>8/31/2010</td>
<td>Nova Scotia, CAN</td>
<td>Autism</td>
<td>3 minutes</td>
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<tr>
<td>2,198</td>
<td>9/9/2010</td>
<td>Quincy, MA</td>
<td>Severe Autism</td>
<td>11 minutes</td>
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<tr>
<td>2,197</td>
<td>9/6/2010</td>
<td>Norfolk, VA</td>
<td>Dementia</td>
<td>1 hour 11 minutes</td>
</tr>
<tr>
<td>2,196</td>
<td>9/6/2010</td>
<td>Marion, IN</td>
<td>Dementia</td>
<td>8 minutes</td>
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<tr>
<td>2,195</td>
<td>8/30/2010</td>
<td>Pel City, AL</td>
<td>Alzheimer’s</td>
<td>6 minutes</td>
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<tr>
<td>2,194</td>
<td>9/7/2010</td>
<td>Norfolk, VA</td>
<td>Mental Retardation</td>
<td>40 minutes</td>
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</tbody>
</table>
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
CHILDREN WITH AUTISM ARE HIGHLY ATTRACTED TO WATER.

PREVENTION
prevention tools

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

ESSENTIAL ITEMS

Safety Alert!

STOP

AUTISM IF LOST CALL

ESSENTIAL ITEMS
SWIMMING LESSONS ARE CRITICAL.
YMCA LIST AT NATIONALAUTISM.ORG.

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

SAFEY 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.
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.
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.

- 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.
BE ON HIGH ALERT

- After a new move (e.g., home, new school)
- During vacations
- Holidays/Family gatherings
- Warm weather onset
- Outdoor activities
- School and other transitions
- Times of commotion/stress
CHILDREN WITH AUTISM ARE HIGHLY ATTRACTED TO WATER.

- 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
BULLYING
PHYSICAL ASSAULT
SEXUAL ABUSE
SUICIDE
DEATH

WATER (EVEN IF...)

ROADWAYS, TRAIN TRACKS & TRANSIT SYSTEMS
BULLYING

PHYSICAL ASSAULT

SEXUAL ABUSE

SUICIDE

FAVORITE PLACES
ENCLOSED SPACES
OPEN AREAS – BARNs, FIELDS, WOODs, PARKs

IF YOU’VE MET ONE PERSON WITH AUTISM, YOU’VE MET ONE PERSON WITH AUTISM.

LOW

FUNCTION LEVEL

LOW

Nonverbal
Low to no self-help skills
Low to no socials skills
Intellectual disability

MODERATE

Minimal to limited language
Limited self-help skills
Limited social skills
Wide gap IQ

HIGH

Moderate to high language function
Higher self-help skills
Higher social skills
Higher IQ

HIGH

LOW
 REGARDLESS OF FUNCTION LEVEL, MOST PEOPLE WITH AUTISM FACE SAFETY RISKS.

RISK LEVEL

MORE LIKELY TO WANDER/BOLT HIGH

HIGH

MORE LIKELY TO BE LOST HIGH

SEARCHING FOR A PERSON WITH AUTISM MAY GREATLY DIFFER FROM THAT OF A TYPICAL SEARCH.

DIFFERENCES IN A SEARCH

TYPICAL MISSING PERSON

will answer to name
may call out for help
can approach a trusted person for help
understands danger
understands verbal commands
will not hide from police
normal response to search aids and k9s

MISSING PERSON WITH AUTISM

May not answer to name
May be unable to call out for help
May not approach a trusted person for help
May not understand danger
May not respond to verbal commands
May hide from police
Atypical response to search aids and k9s
CHILDREN WITH AUTISM ARE HIGHLY ATTRACTED TO WATER.

DIFFERENT OPTIONS
Go to ProjectLifesaver.org and enter your zip code.

Go to SafetyNetbyLoJack.com and enter your zip code.
• 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: achilddismissing.org
- EMA Guidelines: ncjrs.gov

Be REDy Booklet

- 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?
Visit autismsafetycoaltion.org
THANK YOU!

NAA offers extensive resources at:
AWAARE.org
NationalAutism.org

CONTACT US:
e-mail: naa@nationalautism.org
phone: 877-622-2884