

Safety Issues in Individuals with ASD/IDD

*"And I look down and he is gone."**

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Solomon & Lawler. "And I look down and he is gone": Narrating autism, elopement and wandering in Los Angeles. Social Science & Medicine 2013; 94:106-114



Narrow Focus on Interventions for Individuals with ASD

Some Possible Interventions for ASD

- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Applied Behavioral Analysis [ABA]
- Special Education
- Seizure medications
- Other [unproven] remedies
 - *e.g.*, hyperbaric oxygen, chelation, vitamin therapy, Y-globulin, secretin, gluten-free/ casein-free diets, hippotherapy, stem cells




***A Critical Behavior
is Usually Overlooked in ASD/IDD***

Wandering or Eloping

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 behavior is considered common and short-lived in toddlers, but may persist or re-emerge in children and adults with ASD.

Big Red Safety Box, National Autism Association; Autism Speaks website




Early Research into Higher Mortality in ASD

Comparative mortality of persons with autism in California, 1980-1996
Robert M. Shavelle and David J. Strauss
Journal of Insurance Medicine, 1998; 30(4): 220-225

Causes of Death in Autism
Robert M. Shavelle, David J. Strauss, and Jane Pickett
Journal of Autism and Developmental Disorders, 2001; 31(6): 569-576

**Highest mortality rates for ASD + severe ID
also ↑↑↑ even for ASD + mild ID**

Ages (years)	Standardized Mortality Ratios (SMRs)
2 - 5	2.4
5 - 10	5.4
10 - 20	3.0
20+	2.1
All	2.4




***A Critical Behavior
is Usually Overlooked in ASD/IDD***

**In 2011, the CDC successfully advocated to create an ICD diagnostic code for wandering because it is such a common behavior in ASD/IDDs, with potential deadly consequences.
ICD-10: **Z91.83****

**In 2012, the CDC published a report on wandering:
Wandering Among Children with Special Healthcare Needs from the Pathways Survey
Catherine Rice PhD**

Little was previously known about wandering behaviors and the inherent risks.



***A Critical Behavior
is Usually Overlooked in ASD/IDD***


**December 2017:
American Academy of Pediatrics [AAP] added WANDERING to the list for physicians' "anticipatory guidance" for families living with ASD.**

"To prevent wandering, pediatricians must be aware of the seriousness of the problem and incorporate counseling into anticipatory guidance. Parents, school personnel and first responders also can help prevent wandering in people with ASD."

School personnel need to be aware of wandering as well. IEP [sic] protections may include adequate supervision with aide support and environmental modifications.

Education for first responders about ASD and how to interact with verbal and nonverbal individuals with ASD is a critical aspect of community preparedness for this problem."


<http://www.aappublications.org/news/2017/12/12/ASD121217>



Wandering in ASD/IDD: The Facts

- **HALF** of children with ASD wander away from a safe environment;
- **42%** of wandering cases involving a child aged 9 years and younger **HAVE ENDED IN DEATH**;
- **29%** of wandering happens from a classroom or school;
- **35%** attempt to wander at least once per week;
- **Over 33%** of children who wander are unable to state their name, address, or phone number;
- Wandering was ranked among the **most stressful** behaviors by **58%** of parents of wandering.


Anderson C, et al. Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders. *Pediatrics*. 2012;130(5): 870-877
National Autism Association, *Lethal Outcomes in ASD Wandering/ Elopement (2012)* http://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf



Wandering in ASD/IDD: The Facts

- **Accidental drowning** accounts for **~90%** of lethal outcomes.
- **66%** of parents of wanderers reported their missing child had a **“close call” with a traffic injury**;
- **32%** of parents reported a **“close call” with a near drowning**;
- **62%** of families of children who wander were prevented from attending/enjoying activities outside the home due to fear of wandering;
- **40%** of parents suffered sleep disruption due to fear of elopement.

Anderson C, et al. Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders. *Pediatrics*. 2012;130(5): 870-877
National Autism Association, *Lethal Outcomes in ASD Wandering/ Elopement (2012)* http://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf




Wandering: The Facts

And shockingly,

Half of families with wanderers report they never received advice or guidance about wandering from a professional.


Anderson C, et al. Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders. *Pediatrics*. 2012;130(5): 870-877
National Autism Association, *Lethal Outcomes in ASD Wandering/ Elopement (2012)* http://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf



ASD & Wandering Insights

- Usually a form of communication
 - *e.g.*, I need, I want, or I don't want
- Occurs to get to something of interest, or away from something bothersome
- Typically spikes from April to August
- School-related cases spike in the fall and winter
- Triggers include:
 - holidays, vacations, camping trips, transition periods, outdoor gatherings, a recent move to a new home or school, visiting an unfamiliar setting, public outings, etc.

National Autism Association *Big red Safety Tool Box*. <http://nationalautismassociation.org/big-red-safety-box/>

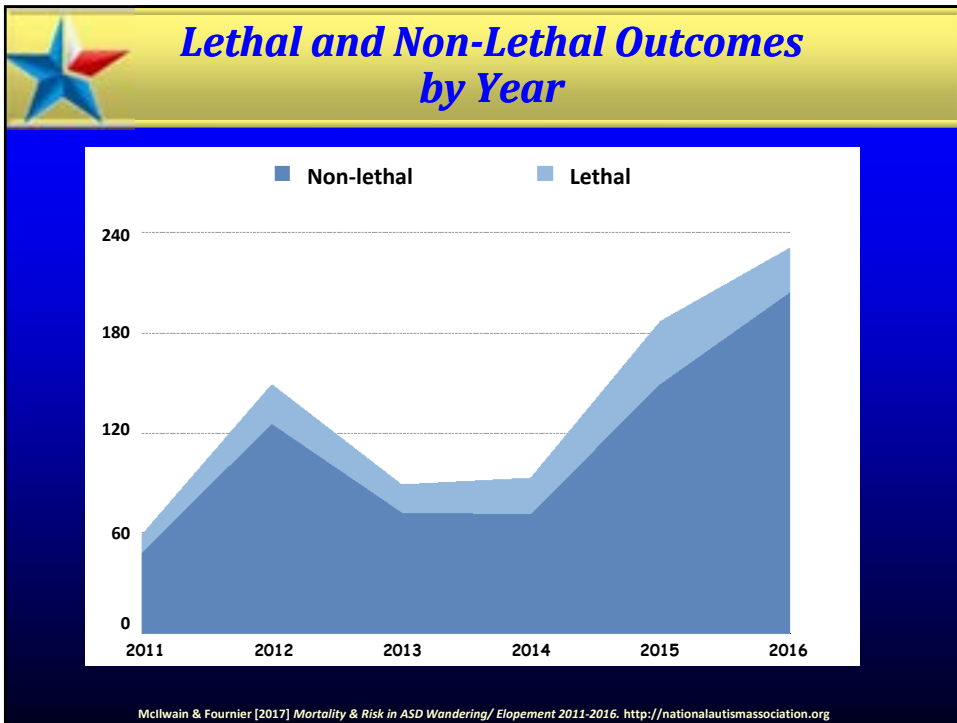
 **Mortality & Risk in ASD
Wandering/ Elopement 2011-2016**

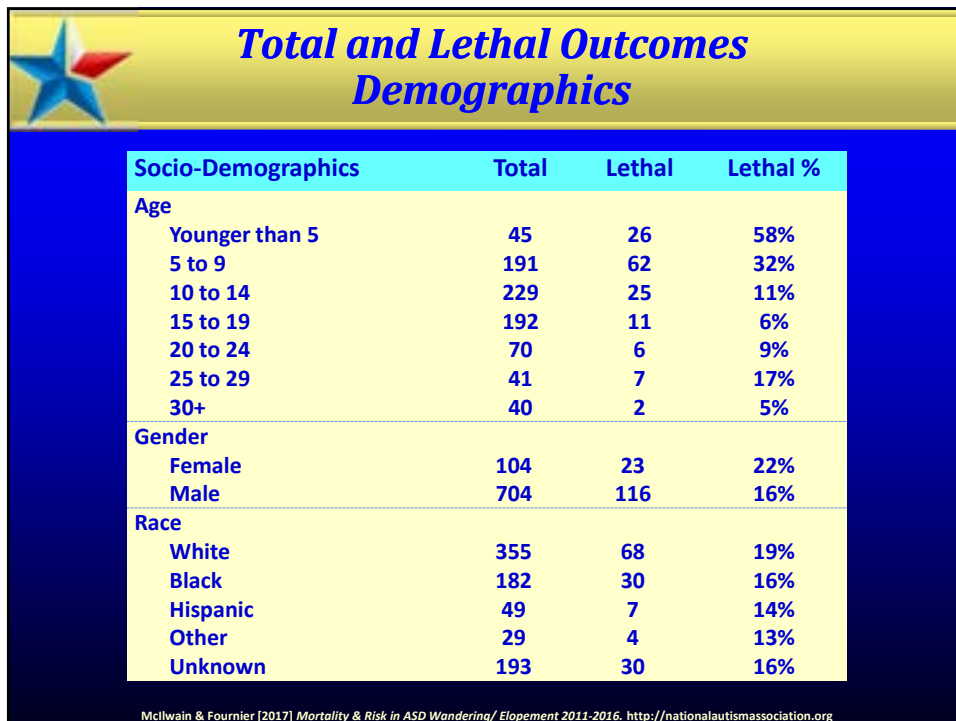
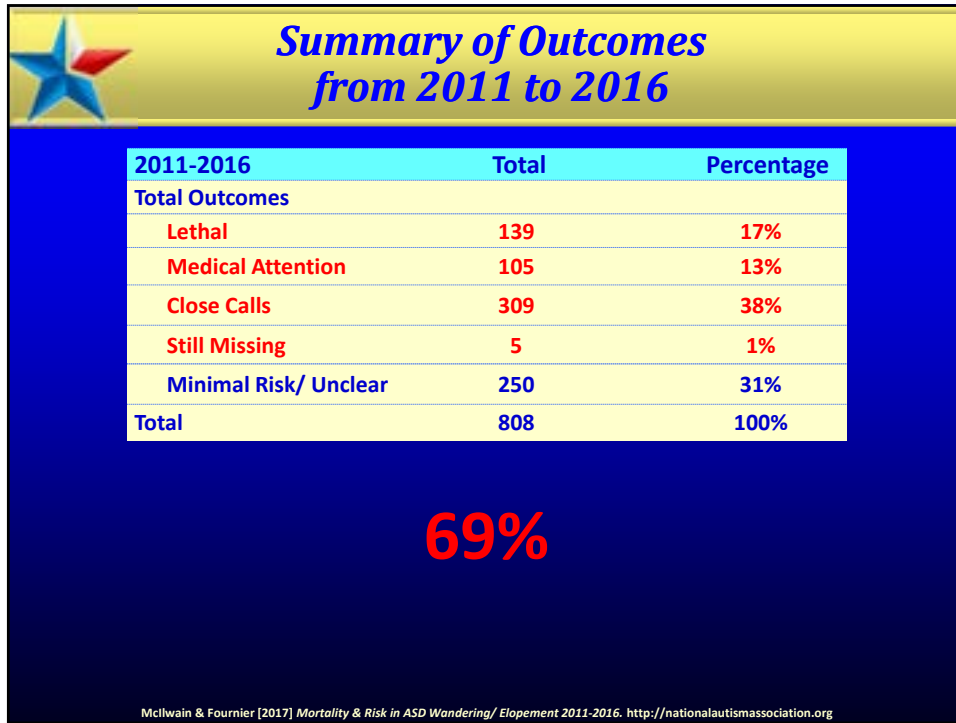
**Lori McIlwain & Wendy Fournier
National Autism Association, 2017**

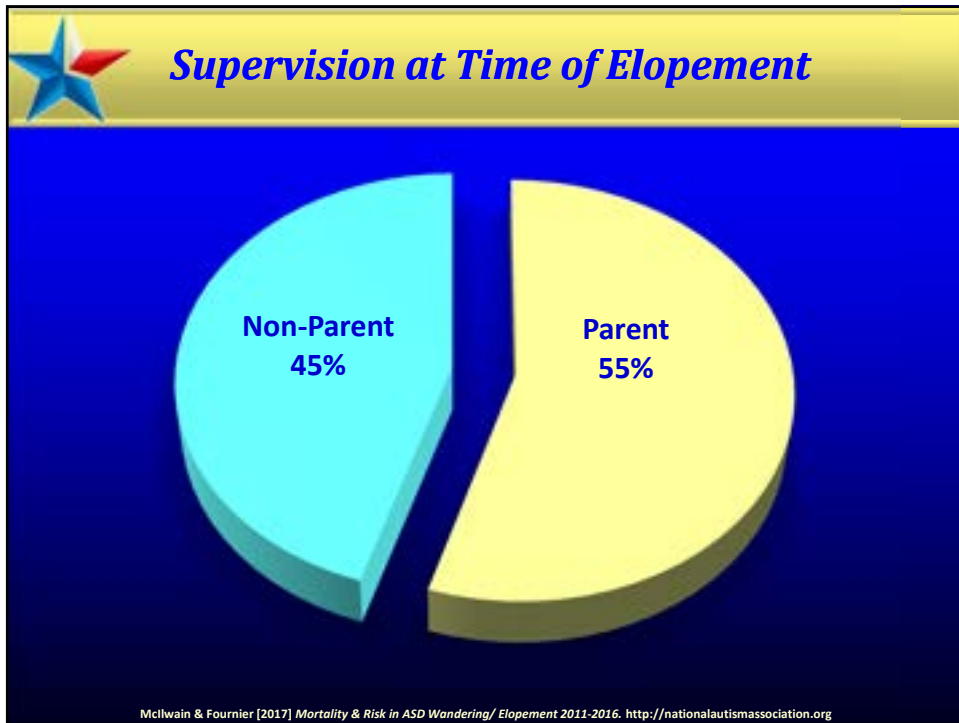
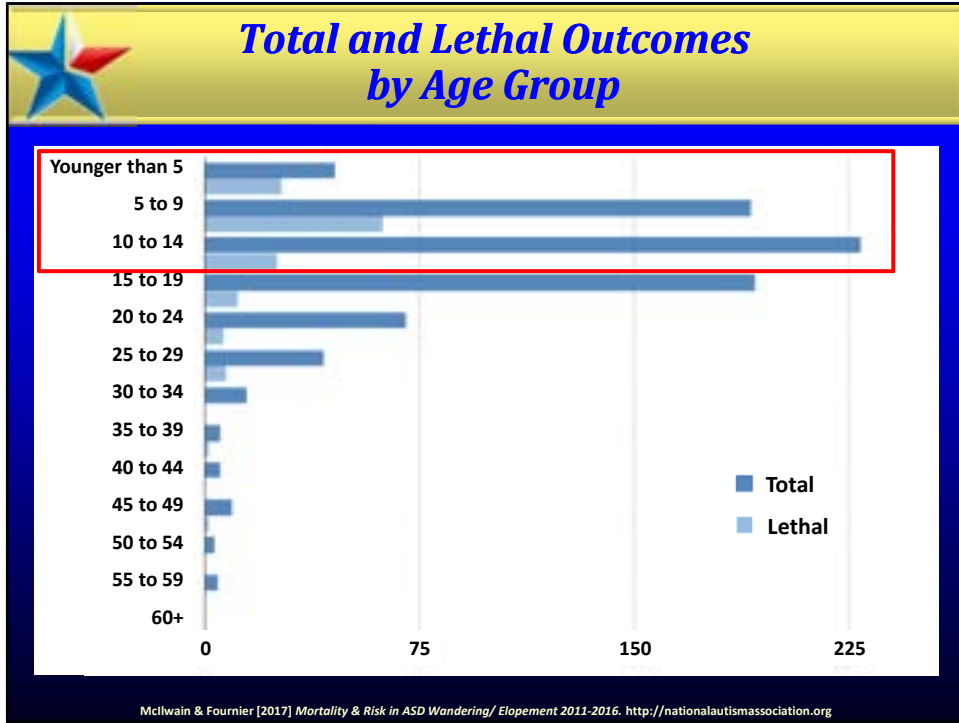
808 cases of wandering/ eloping:


- **Individuals with ASD in the US**
 - **1/1/2011 -- 12/31/2016**
- **Missing long enough for media attention or first responders**

<http://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf>





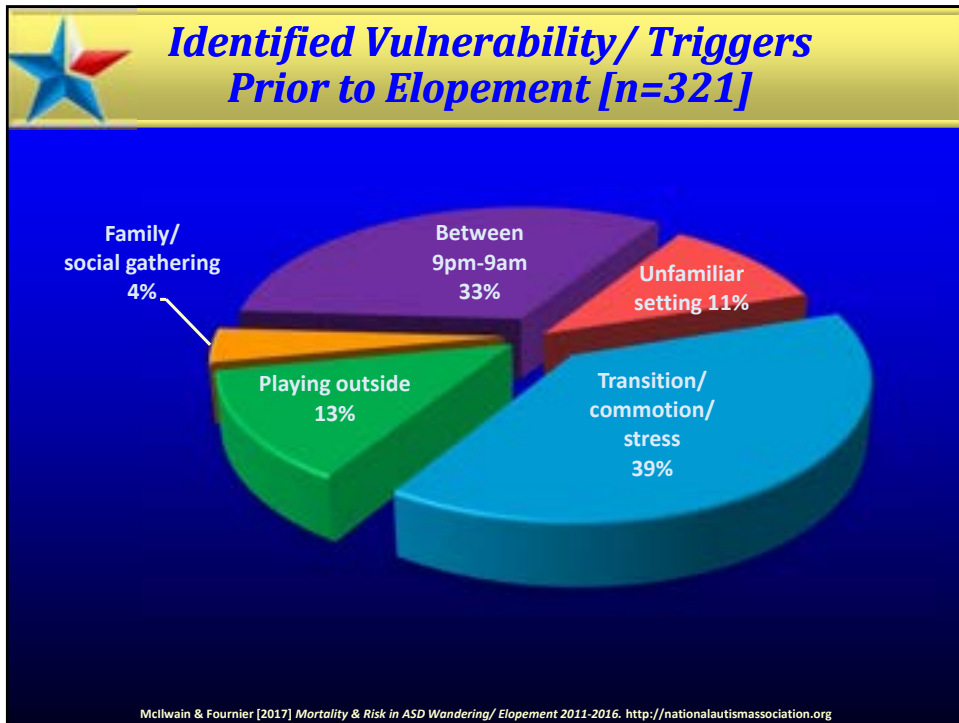


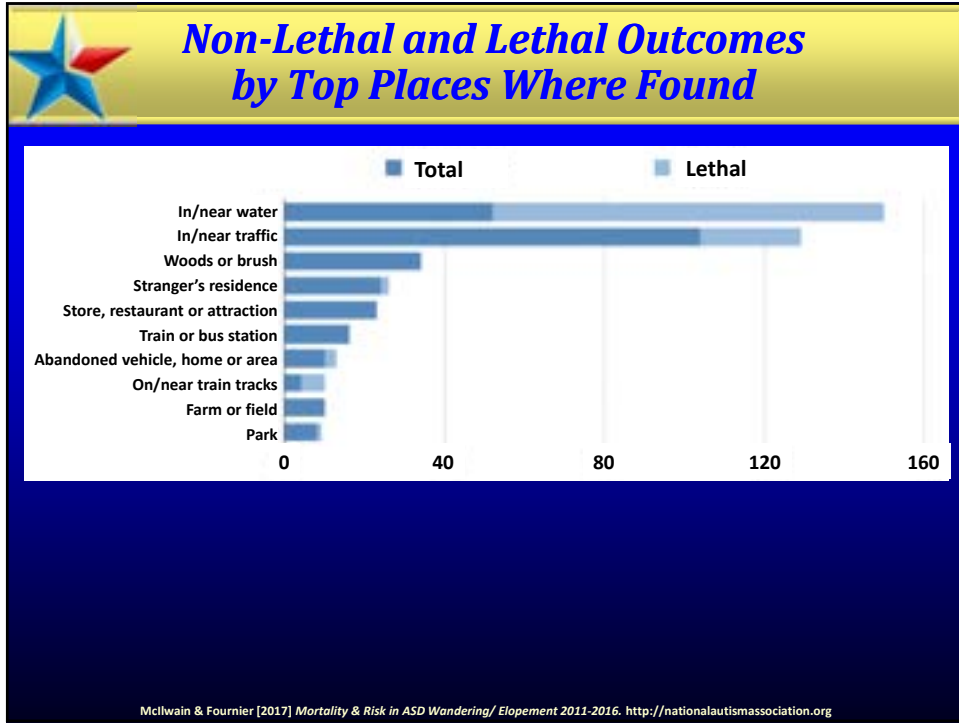


Total and Lethal Outcomes by Origin of Incident

Setting Type	Total	Lethal	Percentage
Home	383	72	19%
School or School Bus	81	4	5%
Relative or Friend's Home	53	23	43%
Outdoor Recreation/ Field Trip/ Camp	49	14	29%
Group Home or Residential Facility	35	9	26%
Between Settings	34	4	13%
Store, Restaurant/ Indoor Recreation	32	2	6%
Hotel or Vacation Home	12	6	50%
Vehicle	8	2	25%
Hospital or Healthcare Facility	6	0	0%
Train or Bus Station	6	0	0%
Church	5	0	0%
Other/ Unclear	104	3	3%

McIlwain & Fournier [2017] *Mortality & Risk in ASD Wandering/ Elopement 2011-2016*. <http://nationalautismassociation.org>



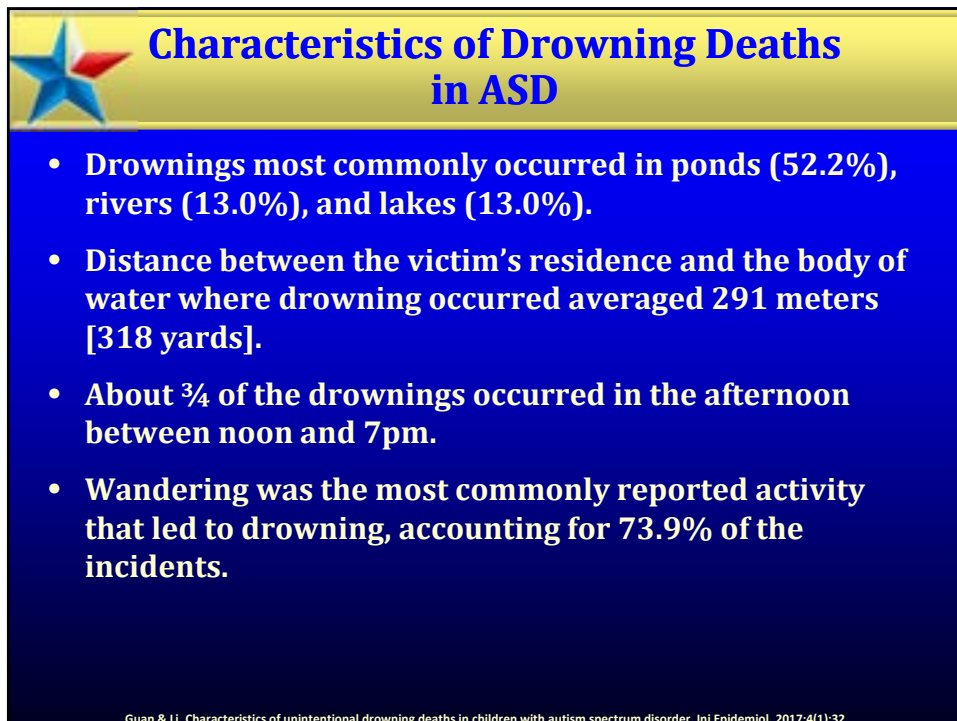
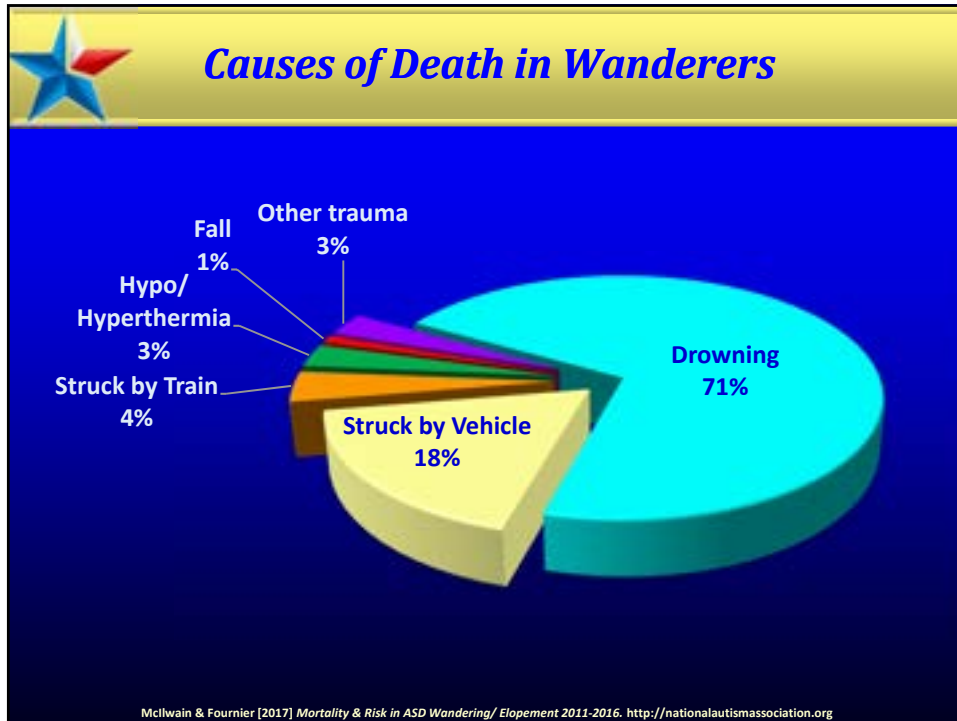


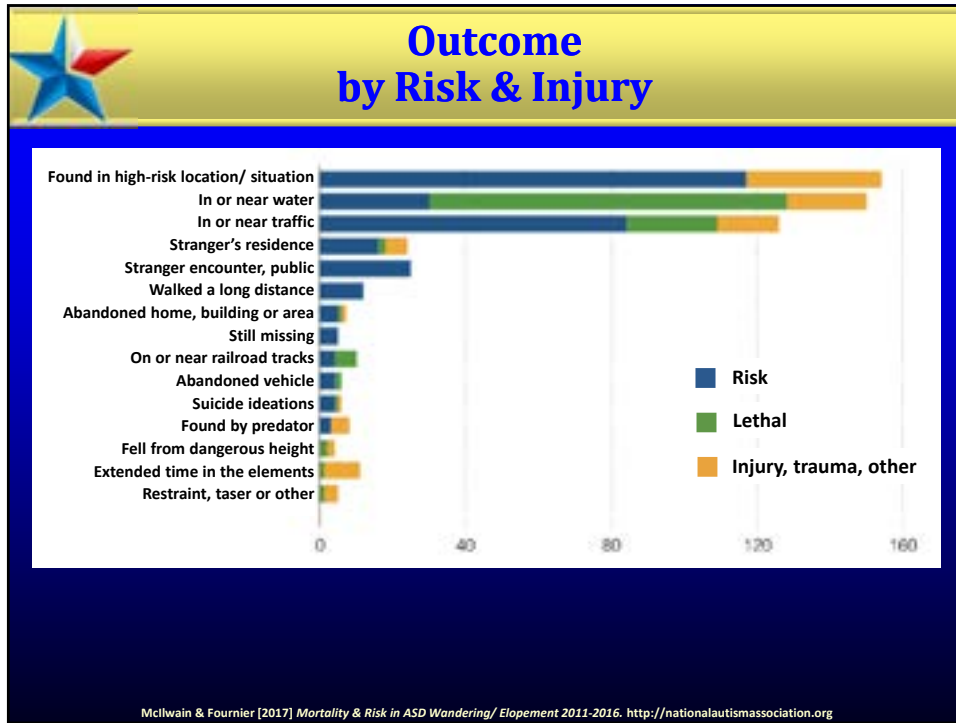
Causes of Death in Wanderers

2011-2016	Total	Percentage
Lethal Outcomes		
Drowning	98	71%
Struck by vehicle	25	18%
Struck by train	6	4%
Hyper/ Hypothermia	4	3%
Fall	2	1%
Trauma, other	4	3%
Total	139	100%

89%

McIlwain & Fournier [2017] *Mortality & Risk in ASD Wandering/ Elopement 2011-2016*. <http://nationalautismassociation.org>





Risk of Wandering in ASD +/- ID vs ID-only

	ASD-only	ASD + ID	ID-only
Total, N	492	924	2,085
% Male	32.5	37.2	22.3
% Female	34.2	24.9	23.6
% Aged 6-11 years	41.6	40.6	30.4
% Aged 12-17 years	22.5	27.1	15.6

BOTH ASD-only & ASD+ID were more likely to wander than ID-only.

THEREFORE, RISK OF WANDERING IS SIGNIFICANT FOR ASD WITH ALL COGNITIVE LEVELS

Kiely B, Migdal TR, Vettam S, Adesman A. Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States. PloS one. 2016;11(2):e0148337.

 **Big Red Safety Box**
Caregiver Edition [NEW]


NEARLY HALF OF CHILDREN WITH AUTISM WANDER AWAY FROM SAFE SETTINGS.
The Big Red Safety Box is designed to help prevent a wandering incident.

 
#wandering **safety needs**

 
BIG RED SAFETY BOX
NATIONAL AUTISM ASSOCIATION

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

 **Big Red Safety Box**
Teacher Edition [NEW]


AUTISM AFFECTS 1 OUT OF EVERY 68 CHILDREN.
Almost half of children with autism wander away from safe settings.

 
#wandering **safety resources**

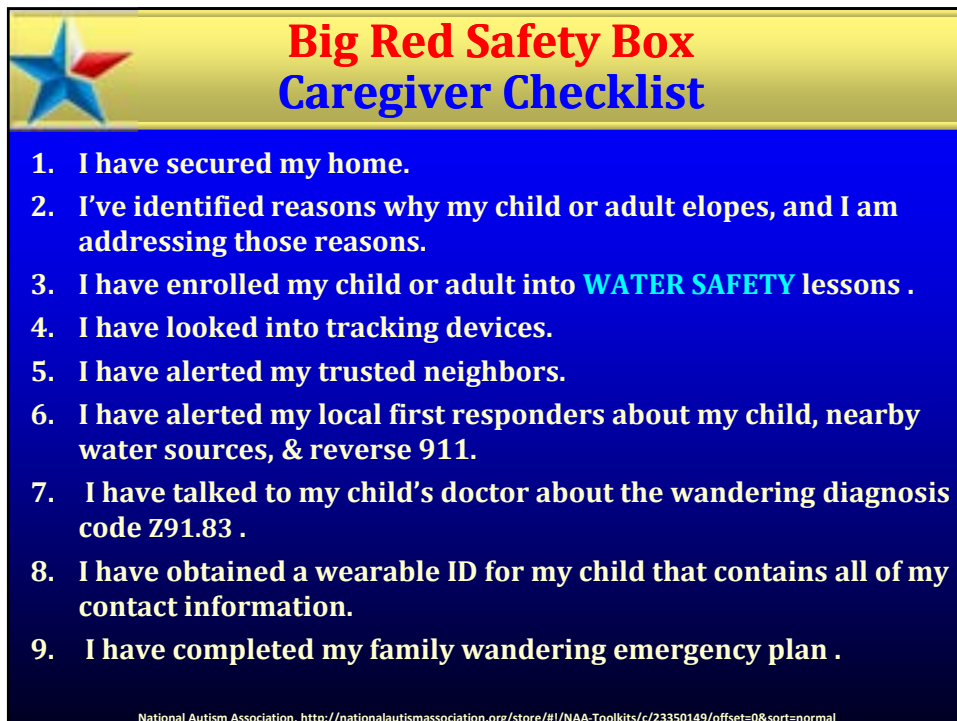
 
BIG RED SAFETY BOX
NATIONAL AUTISM ASSOCIATION



Big Red Safety Box
First Responder Edition [NEW]

First Responder Toolkit:
A Guide to Searching for Missing Persons on the Autism Spectrum


The graphic features a collage of images related to emergency services: a person walking on a path, a fire truck, a police car, a fire hydrant, and a fire truck with "FIRE & RESCUE" written on its side. The National Autism Association logo is also present.



Big Red Safety Box
Caregiver Checklist

1. I have secured my home.
2. I've identified reasons why my child or adult elopes, and I am addressing those reasons.
3. I have enrolled my child or adult into **WATER SAFETY** lessons .
4. I have looked into tracking devices.
5. I have alerted my trusted neighbors.
6. I have alerted my local first responders about my child, nearby water sources, & reverse 911.
7. I have talked to my child's doctor about the wandering diagnosis code Z91.83 .
8. I have obtained a wearable ID for my child that contains all of my contact information.
9. I have completed my family wandering emergency plan .


National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>



Big Red Safety Box Caregiver Checklist

10. I will initiate a “tag, you’re it” system during family gatherings, commotion, transitions.
11. I will monitor changes in my home’s security, *e.g.*, when weather or seasonal transitions affect my home’s layout.
12. I will remain on high alert during transitions, after moving to a new home or school, on summer holidays & during visits to others’ homes, public places, parks, other settings.
13. I have addressed wandering at school, summer camp, and other external settings.
14. I continue to reassess as my child grows and/or learns new ways to possibly exit.
15. If my child or adult is ever missing, I will remain calm, call 911, and search nearby water and busy streets **FIRST**.
16. I continue to document actions taken to protect my loved one.

National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>



Big Red Safety Box IEP Sample Letter

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.

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,

National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>



Big Red Safety Box Physician Sample Letter

To Whom It May Concern:

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-10: Z91.83). 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,

National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>



Big Red Safety Box Affordable Safety Tools

- ✓ **Water Safety Classes [preferable] or Swimming Classes through YMCA special needs programs**
- ✓ **Door/Window Alarms**
- ✓ **Shoe ID Tags**
- ✓ **Stop Sign Visual Prompts**
- ✓ **Guardian Lock**
- ✓ **Temporary Tattoos**

National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>

 **Big Red Safety Tool Box**
Affordable Safety Tools

 **2 pack** GE
GE Personal Security Window/Door Alarm, DIY Home Protection, Burglar Alert, Magnetic Sensor, Off/Chime/Alarm, Easy Installation, Ideal for Home, Garage, Apartment, Dorm, RV and Office, (2 pack), 45115
★★★★☆ • 2,344 customer reviews
| 452 answered questions

List Price: \$12.99
Price: **\$9.84** ✓prime
You Save: \$3.15 (24%)

National Autism Association

 **Big Red Safety Tool Box**
Affordable Safety Tools

Who's Shoes ID Kit - Set of 2 IDs (Pink only)
Category: Store • Big Red Safety Shop



NAME, PHONE, MEDICAL CONDITIONS GO HERE

VELCRO® FASTENER STRAP

<http://nationalautismassociation.org/store/#/Whos-Shoes-ID-Kit-Set-of-2-IDs-Pink-only/p/13353530/category=2416355>

 **Big Red Safety Tool Box**
Affordable Safety Tools

Stop Sign Visual Aids
Category: Store - Big Red Safety Stop



National Autism Association

 **Big Red Safety Tool Box**
Affordable Safety Tools

 *The Door Guardian*



<https://thedoorguardian.com/product/the-door-guardian>

 **Big Red Safety Tool Box**
Affordable Safety Tools


The Guardian Refrigerator Lock


<https://thedoorguardian.com/product/the-guardian-refrigerator-lock/>

 **Big Red Safety Box**
Affordable Safety Tools

Tattoos with a Purpose
Category: Store > Big Red Safety Shop



<http://nationalautismassociation.org/store/#/Tattoos-with-a-Purpose/p/11371265/category=2416355>




Big Red Safety Box First Responder Edition

If Person With Autism is Missing

- *Treat each case as critical.*
- *Search Water First!*
- *Ask about other dangers that the person may be attracted to [busy roads/highways/construction sites, etc.] and immediately dispatch personnel to secure those areas.*
- *Implement Reverse 9-1-1 (achildsmissing.org)*
- *Issue an Endangered Missing Alert*

National Autism Association, <http://nationalautismassociation.org/store/#/NAA-Toolkits/c/23350149/offset=0&sort=normal>



Dying before their time: Addressing premature mortality among autistic people.

David Mandell, *Autism* 2018; 22 (3): <http://journals.sagepub.com/doi/pdf/10.1177/1362361318764742>

“People with autism think about killing themselves and die from suicide at a horrifying rate. Small studies find that:

- *20%–40% of adults with autism have considered killing themselves (Hedley et al., 2017);*
- *15% report making at least one attempt (Balfe and Tantam, 2010).*

“A large Swedish cohort study found that:

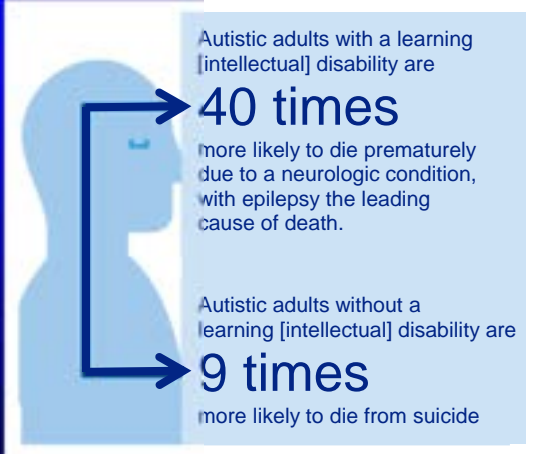
- *adults with autism are nine times more likely to die from suicide than other adults (Hirvikoski et al., 2016).*

“Studies of children with autism find that:

- *11% have suicidal ideation and 4%–7% have made suicide attempts (Mayes et al., 2013);*
- *the risk of making a suicide attempt is six times that of other children (Moses, 2017).“*

“As we think about the urgent task of reducing premature mortality in people with autism, it is worth revisiting some passages from the Autistica report that deserve as much public attention as those describing suicide risk. The risk of early mortality from all causes among people with autism is nearly twice that of the general population.”

Personal tragedies, public crisis.
The urgent need for a national response to early death in autism.



Autistic adults with a learning [intellectual] disability are **40 times** more likely to die prematurely due to a neurologic condition, with epilepsy the leading cause of death.

Autistic adults without a learning [intellectual] disability are **9 times** more likely to die from suicide

Those with autism and no [intellectual] disability die an average of 16 YEARS EARLIER.

Those with autism and [ID] die an average of 30 YEARS EARLIER.

(Hirvikoski et al., 2016).

Cusack, Shaw, Spiers & Sterry, Autistica, UK, 2017

Personal tragedies, public crisis.
The urgent need for a national response to early death in autism.

Conclusions from Autistica 2017:

- 1. "This crisis requires a national response.**
- 2. "Failure to act would be tacit acceptance of the stark inequality in outcomes for autistic people.**
- 3. "We are urgently calling for a combined effort from national and local government, research funders, the NHS, service providers and industry to start saving lives now."**

Cusack, Shaw, Spiers & Sterry, Autistica, UK, 2017



9 years old, Pearland

Thanksgiving Day 2016

"...We were able to review surveillance video from the house, and it gave up a general direction of where he exited'... Police said... that [he] may be drawn to the sound of all-terrain vehicles and may want a ride. They urged searchers on ATVs to drive slowly in case [he] heard them. Texas EquuSearch joined the search for [him]. Police believed [the boy] was on foot in the area and did not suspect foul play. Police said [he] loves the songs, "Wheels on the Bus," "Head, Shoulders, Knees and Toes" and "If You're Happy and You Know It." Police said [the boy's] family were visiting from Connecticut [for Thanksgiving]."

Saturday, Thanksgiving Weekend 2016

"Pearland police and volunteers ended their search Saturday morning after finding the body of a missing boy with autism. [The boy], 9, disappeared around 4 p.m. Thursday... Police notified the public on their Facebook page that they found [the boy's] body Saturday morning... around 7 am in a pond near the family's home [on the family's property]."

Adapted from KHOU and KPRC web stories



11 years old, Houston

An 11-year-old boy who had autism died when he was hit by a sport utility vehicle as he tried to cross the Interstate 10 service road in west Houston.

The boy has special needs and was in the care of his father when he wandered away as the father was doing laundry, said Estella Olguin, spokeswoman for state Child Protective Services.

"He was being watched," Olguin said, "but he just wandered away. It's tragic."

Chron.com