



# WANDERING & AUTISM:

What We Know | What We Need

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National Autism Association  
Wendy Fournier  
IACC | July 9, 2013

**AUTISM&SAFETY**

introduction | video

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[Click to view the video.](#)

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**what we know**



**AUTISM**&SAFETY

# wandering | an update

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## **October 2010:**

- NAA presentation on wandering to IACC
- Case studies
- AMBER Alert criteria
- Need for Data
- Need for School Response Protocols
- Comparison of resources for Alzheimer's community
- Need for Awareness, Resources, Policies and Training
- Medical Diagnosis Code
- Effect of wandering on families
- Recommended an IACC sub-committee on safety issues

# wandering | an update

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## **Since October 2010:**

- We have an ICD-9-CM Medical Diagnosis Code - V40.31 (Wandering in Diseases Classified Elsewhere) went into effect in October 2011
- We now have data confirming our concerns (Published in Pediatrics.)
- Feb. 2011 Letter from IACC to Secretary Sebelius with multiple recommendations including the need for an emergency alert system, the Secretary responded that she would “give serious consideration to the recommendations”

wandering | data



**Wandering Data: Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders, 2012**

**PEDIATRICS**<sup>®</sup>

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>



## AUTISM WANDERING/ELOPEMENT: STATISTICS

- **Roughly half, or 49%**, of children with autism attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings
- More than **one third of children** with autism who wander are never or rarely able to communicate their name, address, or phone number
- **Half of families with elopers** report they had never received advice or guidance about elopement from a physician or other professional





## Wandering: Effects On The Family

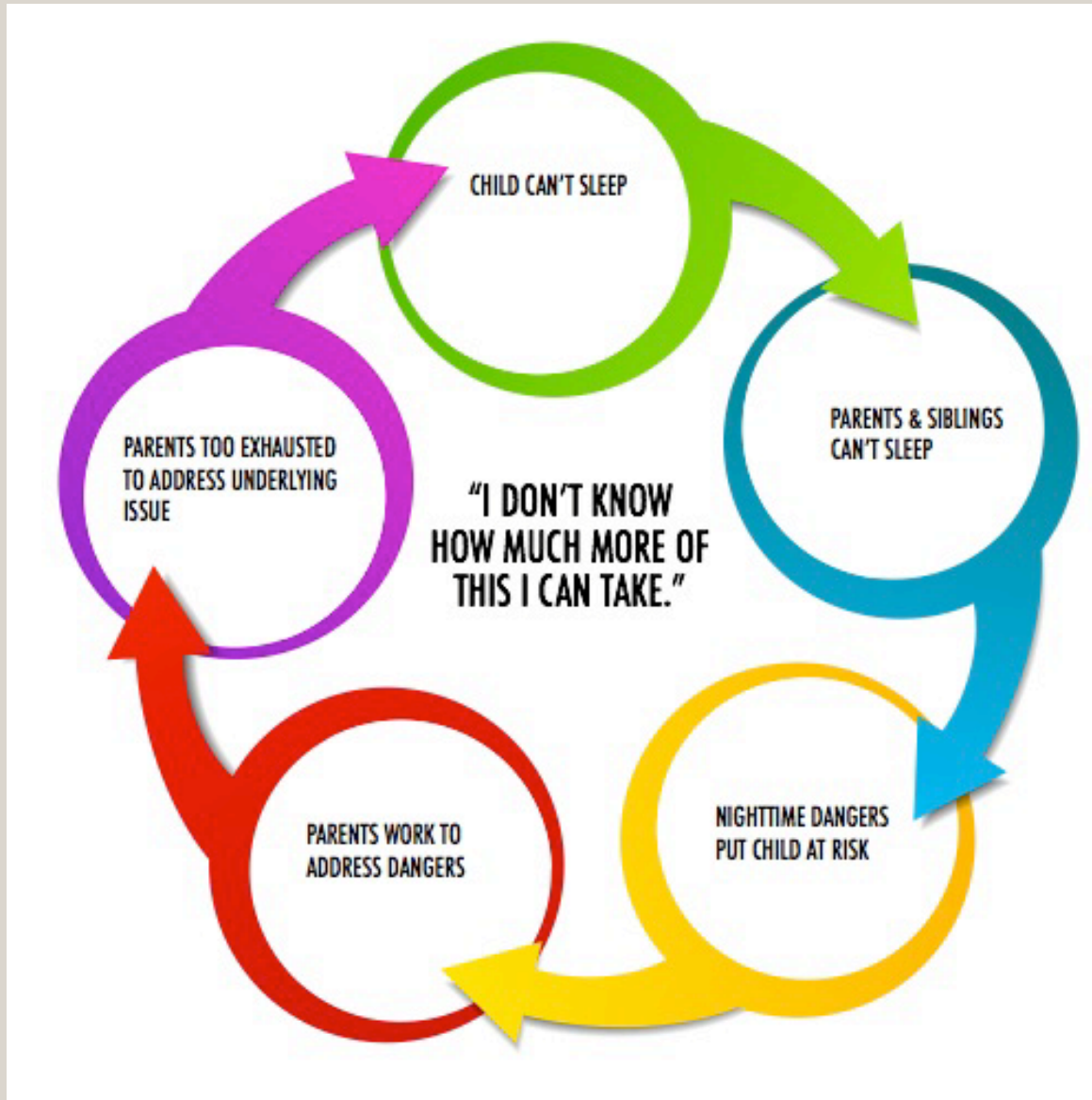
Living under great stress; Lowered quality of life; Unable to leave home; **Sleep deprivation**; Lack of support/understanding/resources; Fear of accusations of neglect - CPS or Police involvement

- **58%** report wandering/elopement as the most stressful of ASD behaviors
- **62%** of families with 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**





effects on family



vicious  
risk  
cycle



## Autism Wandering/Elopement Lethal Outcome Cases from 2009 to 2011:



- accidental drowning accounted for 91%
- 68% died in a nearby pond, lake, creek or river
- 23% were in the care of someone other than a parent
- lethal outcomes in ASD  
wandering/elopement in girls were twice as high than in boys



## **Wandering Occurs Across All Settings and Under All Types of Supervision, Including:**

- Homes
- Schools, Daycares, Summer Camps
- Residential and Day Program Facilities
- Public Places, Parks, Camp Sites, Hiking Trails
- Under care of parents, grandparents, siblings, relatives, babysitters, neighbors & friends, camp counselors, teachers/aides, therapists, service professionals





## **Based On NAA's Monitoring Of Missing Person Cases, Autism-related Wandering Incidents Happen Most:**

- During warmer months – seasonal transitions
- During holidays such as Mother's Day, Memorial Day, Father's Day, Fourth of July, Labor Day, and other warm-climate holidays
- During family gatherings, parties, outdoor activities
- Camping & hiking outings
- Visits to non-home settings, such as a friend's home or vacation setting
- After a family moves to a new home
- When adjustments have been made to a home to accommodate warmer weather, especially window screens, window fan units, A/C units and screen doors.
- During classroom transitions from one classroom to another, or during other transitions.
- During times of stress or when escalation triggers arise (typically the child/adult will bolt)

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**prevention resources**



**AUTISM**&SAFETY

# prevention resources



## NAA Initiatives

- Established the Big Red Safety Box Program in 2011 providing 7,500 families with prevention tools and educational materials
- Created free toolkits for caregivers and first responders available at [AWAARE.org](http://AWAARE.org)
- Provided \$100,000 worth of grants to law enforcement agencies for Project Lifesaver Tracking equipment
- Helped fund and write the parent questionnaire for the wandering study published in *Pediatrics*
- Worked with the National Center for Missing & Exploited Children on search-and-rescue guidelines specific to children with special needs
- Published a white paper on lethal outcomes related to wandering
- Reached out to YMCA headquarters for a listing of Y's across the country that provide special-needs swimming lessons
- First-responder, social worker and parent training in the U.S. and Canada
- Give A Voice – providing a way for kids to help keep themselves safe



# prevention resources



## prevention resources



### From a Mom:

*“My son’s RoadID tag on his shoe from The Big Red Safety Box just brought him home safely after he wandered. I have never been more grateful.”*





incident response

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*SEARCH WATER FIRST*

*TREAT EACH CASE  
AS CRITICAL*





## Case Study: Extraordinary 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.**



**Searching for individuals with Autism presents unique challenges for S&R personnel – training is vitally important!**

# Marlboro Officer Uses Autism Training To Find Missing Girl

Sgt. Steve Levy used the knowledge he gained from Autism Shield Training to find a missing girl in Marlboro.

Posted by [Kaitlyn Anness](#) (Editor), July 20, 2012 at 06:00 PM

**Click here for a free burglar alarm**  
**800-700-6400**  
[www.goldprotective.com](http://www.goldprotective.com)

6 Comment • Recommend •



On June 6, a young autistic girl went missing from her Marlboro home. found her two streets away in a nearby resident's pool.

training



# U.S. NEWS

CHANGE TEXT SIZE

**AUTHOR**



*Laura Colarusso*

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## Ray Gardner Used Autism Training To Find William LaFever

Jul 14, 2012 12:00 AM EDT

Utah Deputy Sheriff Ray Gardner sat in on a lecture about missing autistic children by chance, never thinking he would put its lessons to use. He tells Laura Colarusso how it helped preserve a man's life.

Share 79
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Two months ago, Ray Gardner, a deputy sheriff in Garfield County, Utah, was sitting in a lecture about missing autistic children at the Utah Search and Rescue Association's annual training convention. He remembers thinking at the time that the material was interesting, but he probably wouldn't have any use for it.

"I couldn't even think of anybody I knew that had autism," Gardner said during a telephone interview. "I certainly didn't think the training would have a bearing on any upcoming search I would be on."

Fast forward to July 12, and Gardner found himself relying on the lessons he learned in the class—specifically the fact that individuals with autism are drawn to water. So when he got the call that he'd be the point man on a search and

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**what we need**



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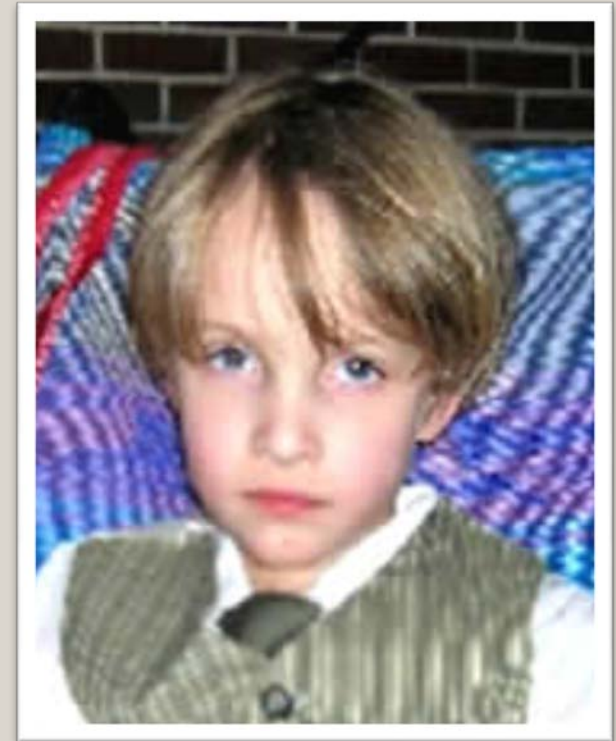
Missing children with autism and other developmental disabilities do not fit the current criteria for AMBER Alert.

Silver Alerts can be issued for missing adults.



## Case Study: Drowning

- 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 may have saved Benjy's life**

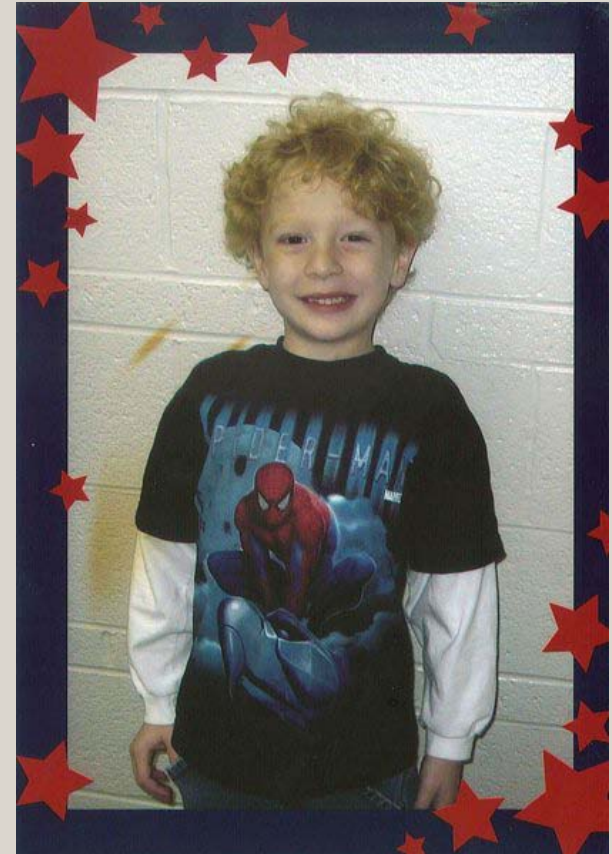


## case study



### Case Study: Struck, Killed by Vehicle

- Jack Hensley – Age 5
- Tulsa, OK
- July 2009
- Busy shopping district
- Was struck and killed by an SUV
- **AMBER Alert may have saved Jack's life**





case study



## Case Study: Drowning

- Owen Black – Age 7
- Perdido Key, FL
- May 2013
- Was seen by a member of the public who wondered why he was alone on the beach
- **AMBER Alert may have saved Owen's life**







## Case Study: Drowning

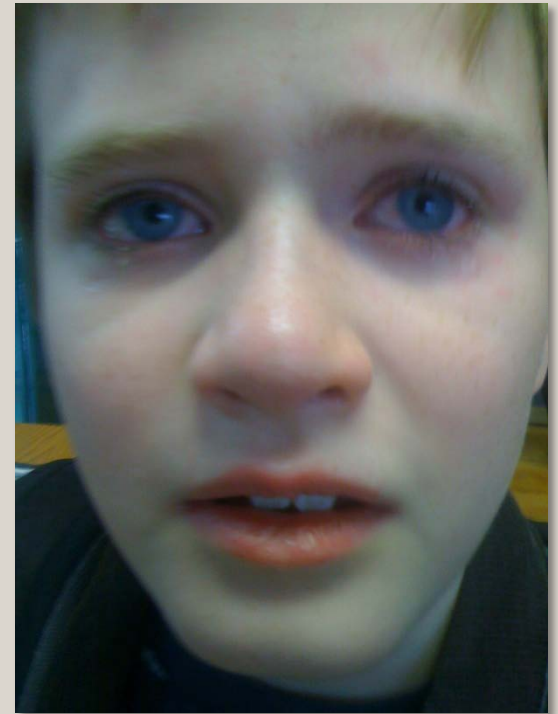
- Mikaela Lynch – Age 9
- Clearlake, CA
- May 2013
- Mikaela disappeared on Mother's Day
- A vehicle drove by Mikaela as she walked down the street
- Her body was found in a nearby creek by divers 3 days later
- **AMBER Alert may have saved Mikaela's life**





## Case Study: Stranger and Police Encounter

- Connor – Age 13
- 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 to classroom
- Picked up by a man in a car
- School did not contact police
- Police had to search for where he belonged and thought he was being uncooperative
- **Connor's case emphasizes the need for AMBER Alert, First Responder Training and for DOE to establish federal guidelines for schools mandating immediate notification to law enforcement and parents**



recent headlines



## Mantua Creek mud snares 9-year-old with autism; police rescue just in time



By Joe Green/South Jersey Times

on March 24, 2013 at 5:59 PM, updated March 24, 2013 at 6:15 PM



By Joe Green/South Jersey Times

on March 24, 2013 at 5:59 PM, updated March 24, 2013 at 6:15 PM

 Print

“Just in time.”



East Greenwich Township Patrolmen (left to right) Brett Pfeiffer, William Crothers and Phillip Owens recalled the rescue of a 9-year-old autistic boy from drowning in the Mantua Creek on Saturday afternoon, Sunday, March 24, 2013. (Staff Photo by Joe Warner/South Jersey Times)

### EAST GREENWICH TWP.

— The minutes ticked by, eternal, it must have seemed, as the flashing lights converged on Billows Drive. A frantic father called again and again for his nine-year-old son, trying to think of where he could have gone on a Saturday afternoon.

The child with autism had wandered off around 3:30 p.m. Police received a report of the missing boy about 15 minutes later.

Little did the father know that the child **was struggling just**

**to keep his head above Mantua Creek's frigid mud**, into which he was sinking.

## recent headlines



### **Boy with autism rescued from Lake Michigan**

April 29, 2013. Northern Michigan authorities located a 6-year-old autistic boy near a cement plant after he became separated from his mother at the Fisherman's Island State Park in Charlevoix County. Silkovski was able to get the boy and remove him from Lake Michigan.

### **Boy With Autism Leaves School, Rides Tricycle on Busy Road**

May 8, 2013. A 12-year-old boy with autism left his school and rode a tricycle through a busy road in Yonkers during rush hour Friday.

### **Passerby pulls floating 5 year-old from North Naples pond**

June 19, 2013. A pool technician sitting in his car heard splashing. He ran and pulled the child out using a pole but she wasn't breathing. 911 dispatcher gave CPR instructions and he was able to save the little girl's life.

### **Missing Autistic Girl From Minnetonka Found Unharmed**

June 30, 2013. Officers say she was found unharmed at a creek near County Road, about a half mile away from where she had gone missing.



missing since saturday



**Terry Smith**

Age 11

Menifee, CA



children lost since last IACC meeting



**Drew Howell**

Age 2

children lost since last IACC meeting



Alyvia Navarro

Age 3

children lost since last IACC meeting



**Christopher Morrison**

Age 5



children lost since last IACC meeting



Owen Black

Age 7

children lost since last IACC meeting



Mikaela Lynch

Age 9

children lost since last IACC meeting



Freddie Williams

Age 14

children lost since last IACC meeting



**Daven Williams**

Age 15

children lost since last IACC meeting



**Donivan Martin**

Age 16

children lost since last IACC meeting



**Michael Kingsbury**

Age 7



# wandering | what we need



## **NAA Recommendations:**

- Resources and advice for families from pediatricians and other professionals
- Access to affordable home safety items and water safety programs
- Insurance coverage and federal funding for tracking technology for at-risk individuals – millions of dollars available for Alzheimer's patients, not Autism
- Access to augmentative communication technology for non-verbal and minimally verbal individuals
- Medical research – obsessive behaviors, fight or flight reactions, sleep disorders
- AMBER Alert
- Education/Toolkits for caregivers to help understand and avoid wandering triggers
- Training for physicians on wandering behaviors and the ICD-9 code
- Resources for schools and specific response protocols
- Training for social workers, school administrators and first responders – Training Summits, Webinar series, etc. – Multiple Agency Involvement - HHS, DOJ, DOE

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NATIONAL AUTISM  
ASSOCIATION

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