

**Lethal Outcomes In Autism Spectrum Disorders (ASD) Wandering/Elopement**

*Lori McIlwain, Wendy Fournier - National Autism Association, January 20, 2012*

## TABLE OF CONTENTS

<b>Executive Summary</b> .....	<b>3</b>
<b>Introduction</b> .....	<b>3</b>
<b>2011 Fatalities</b> .....	<b>4</b>
<b>2010 Fatalities</b> .....	<b>5</b>
<b>2009 Fatalities</b> .....	<b>5</b>
<b>Circumstances of Note</b> .....	<b>5</b>
<b>Seasonal Patterns</b> .....	<b>6</b>
<b>Locations</b> .....	<b>6</b>
<b>Gender</b> .....	<b>6</b>
<b>Supervision</b> .....	<b>7</b>
<b>Response</b> .....	<b>7</b>
<b>Reasoning</b> .....	<b>7</b>
<b>Extraordinary Non-Lethal Outcomes</b> .....	<b>7</b>
<b>Lethal Outcomes Outside the U.S.</b> .....	<b>8</b>
<b>Caregiver Challenges</b> .....	<b>9</b>
<b>New Resources</b> .....	<b>10</b>
<b>Recommendations</b> .....	<b>10</b>
<b>Conclusion</b> .....	<b>12</b>
<b>References</b> .....	<b>12</b>
<b>Acknowledgements</b> .....	<b>12</b>

## **Executive Summary**

Similar to wandering behaviors in the Alzheimer's community, wandering and elopement in the Autism Spectrum Disorder (ASD) population has raised serious concerns in recent years. According to preliminary data released in April 2011 by the Interactive Autism Network (IAN) through the Kennedy Krieger Institute (KKI), roughly half, or 48%, of children with an ASD attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings.

Although current data and analyses focus on non-lethal outcomes in ASD wandering/elopement, further investigation of lethal outcomes is warranted. Since 2009, a reported 22 fatalities – 15 male and 7 female – occurred in the U.S. involving children with an ASD who wandered or eloped from a safe environment. Though new resources emerged in 2011, many federal and health organization channels remain absent or unutilized.

This paper is intended to evaluate a three-year total of reported lethal outcomes following wandering/elopement in children and adults with an ASD, and provide observations and recommendations for enhancements in outreach, understanding, prevention and response.

## **Introduction**

Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 110 individuals in the U.S. have an ASD that can cause significant social, communication and behavioral challenges.<sup>1</sup> These challenges often present unique safety risks, including those associated with a person's tendency to wander or elope from a safe environment. According to preliminary data released in April 2011 by the Interactive Autism Network (IAN) through the Kennedy Krieger Institute (KKI)<sup>2</sup>:

- Roughly half, or 48%, of children with an ASD attempt to elope from a safe environment, a rate nearly four times higher than their unaffected siblings
- More than one third of ASD children 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
- Children with ASD are eight times more likely to elope between the ages of 7 and 10 than their typically-developing siblings

Historically, medical literature has maintained that ASD does not affect life expectancy; however, in 2008, Danish researchers found that the mortality rate among the ASD population is twice as high as the general population.<sup>3</sup> In 2001, a California research team attributed elevated ASD death rates in large part to drowning.<sup>4</sup> In 2009, 2010, and 2011, accidental drowning accounted for 20 out of 22 (91%) total U.S. deaths reported in children with an ASD ages 14 and younger subsequent to wandering/elopement. This combined three-year total is based on media reporting<sup>5</sup> and may not be an accurate representation of lethal outcomes due to inaccurate or misleading reporting, lack of reporting mechanisms, lack of formal data collection, and absence of formal diagnosis in affected individuals. Given the detailed nature of the reports, it is unlikely that there are any "false reports" included. However, canvassing all potential cases of mortality via media reporting is unlikely to be comprehensive and thus, if anything, under represent the true incidence of mortality related to elopement.

### 2011 Fatalities

In 2011, nine children with an ASD died between the months of February and September. Based on media reporting, each death was ruled as an accidental drowning following wandering/elopement.

GENDER	AGE	CAUSE OF DEATH	CITY	STATE	2011 MONTH
Female	7	drowning	Lawton	OK	February
Male	4	drowning	Ida Township	MI	March
Male	3	drowning	Fort Lupton	CO	April
Male	4	drowning	Cushing	OK	April
Female	10	drowning	Arvada	CO	May
Male	7	drowning	Aurora	IN	June
Female	4	drowning	Bakersfield	CA	July
Female	5	drowning	Hampton	VA	September
Female	10	drowning	Murfreesboro	TN	September

### 2010 Fatalities

In 2010, nine children with an ASD died between the months of April and October. Based on media reporting, each death was ruled as an accidental drowning following wandering/ elopement.

GENDER	AGE	CAUSE OF DEATH	CITY	STATE	2010 MONTH
Male	3	drowning	Osage	AR	April
Male	6	drowning	Douglasville	GA	April
Female	7	drowning	La Crosse	WI	June
Male	8	drowning	Bernards	NJ	June
Male	5	drowning	Colwich	KS	July
Male	7	drowning	Austintown	OH	August
Male	5	drowning	Tucson	AZ	August
Female	3	drowning	Barling	AK	September
Male	8	drowning	Salmon	Idaho	October

### 2009 Fatalities

In 2009, four children with an ASD died between the months of July and November. Based on media reporting, two deaths were ruled as accidental drowning following wandering/ elopement, and two were the result of injuries sustained after being struck by a vehicle following wandering/elopement.

GENDER	AGE	CAUSE OF DEATH	CITY	STATE	2009 MONTH
Male	5	struck by vehicle	Tulsa	OK	July
Male	14	drowning	Lindenhurst	NY	August
Male	11	struck by vehicle	Seattle	WA	October
Male	10	drowning	Ocala	FL	November

### Circumstances of Note

From 2009 to 2011, the majority of elopement-related fatalities were caused by accidental drowning. Based on media reporting:

- Five of the 22 (23%) ASD deaths occurred during a family outing. Of those, three occurred during a camping trip.

- At least 15 of the 22 (68%) children died in a nearby pond, lake, creek or river.
- Of note, one death occurred in a school setting (indoor pool) during a transition; one in a neighbor's swimming pool; one in a drainage ditch at a construction site.
- Two deaths occurred after the child exited the home through a window.
- One child was wearing a tracking device that failed to emit a signal under water.

### **Seasonal Patterns**

IAN findings show no significant relevance between seasonal patterns and ASD wandering/ elopement, though media reports show more 2009-2011 ASD fatalities occurred in warmer months. National Autism Association's (NAA) surveillance of ASD missing-person reports over the last three years observed:

- Wandering/elopement cases (lethal and non-lethal) in young children routinely spiked in early spring and rapidly declined in early fall
- During winter months, fewer missing-person reports involved young children with ASD, though there was a slight increase in school-related wandering
- Little to no seasonal changes in the frequency of ASD missing adults and teenagers

### **Locations**

Based on NAA's 2009-2011 data, more ASD wandering/elopement deaths happened in locations with heavier seasonal transitions as opposed to climates that are consistently warm year-round.

One reason for this could be that home security patterns change with seasonal patterns, especially during transitions from winter to spring and into summer months. Open doors, screen doors, open windows, cooling units, outdoor activities, and general changes in the home layout or routine, may be one explanation for wandering/elopement fatalities increasing during these times in areas with heavier seasonal transitions.

### **Gender**

Lethal outcomes between 2009 and 2011 were observed to have a 2:1 male-to-female ratio disproportionate to the standard 4:1 ratio seen in ASD. While the numbers are small, this would indicate that lethal outcomes in ASD wandering/elopement in girls are twice as high than in

boys. It should be noted that both the California and Demark studies also found higher overall mortality risk in females with ASD.

### **Supervision**

IAN's findings show that the rate of wandering/elopement is nearly four times higher in ASD children than their unaffected siblings, indicating the problem is not one of bad parenting. Based on NAA's 2009-2011 surveillance of fatalities, five of 22 children (23%) were in the care of someone other than a parent.

### **Response**

A significant number of 2009-2011 non-lethal outcomes observed by NAA involved the assistance of public citizens, though no AMBER Alerts were issued for missing minors with ASD. Current federal AMBER Alert guidelines reserve this emergency response system for abducted minors.<sup>15</sup> According to available information from 2009-2011 media reports, search times for those found deceased ranged from 15 minutes to 20 hours.

### **Reasoning**

Children and Adults with ASD may elope from a safe environment to get to something of interest (water, train tracks, items of obsession), to get away from something (loud noises, commotion, uncomfortable stimuli, meltdown or fight/flight trigger) or because they are disoriented or confused. Based on 2009-2011 lethal outcomes, the majority of children sought out water. Although no clinical reasoning exists to explain water attraction in ASD, many theorize that sensory input may play a role. According to IAN findings, the top five reasons parents believed their children eloped include:

- Enjoys exploring (54%)
- Heads for a favorite place (36%)
- Escapes demands/anxieties (33%)
- Pursues special topic (31%)
- Escapes sensory discomfort (27%)

### **Extraordinary Non-lethal Outcomes**

In 2010 and 2011, four children and one adult with an ASD faced extraordinary risk following wandering/elopement.

- In October 2011, a male with an ASD, age eight, was found alive by a member of the public nearly six days after he wandered away from his family while walking in a wooded park. Reports note the boy was found in a fetal position in a creek bed, and suffered minor injuries that included a hole in his esophagus. The National Center for Missing & Exploited Children said the six-day search ranks among the most intense on record.<sup>6</sup>
- In September 2011, a male with an ASD, age eight, squeezed through the metal bars of his school playground and ran into a nearby forest. He was found over 24 hours later – dehydration was noted. The child’s favorite music was played to draw him to safety.<sup>7</sup>
- In May 2011, a male with an ASD, age six, was rescued from a neighbor’s pool by a member of the public. The boy reportedly exited his mother’s home through a window. Three weeks before the incident, a vehicle reportedly struck the child after he ran from his aunt’s home into traffic.<sup>8</sup>
- In September 2010, a male with an ASD, age 31, wandered from his adult daycare program into traffic and was subsequently struck by a vehicle. His mother reports her son wandered through two unlocked doors to exit the building. The man suffered a traumatic brain injury, was hospitalized for 29 days, and has since undergone multiple surgeries.<sup>9</sup>
- In April 2010, a female with an ASD, age 11, was found a half mile from her Florida home by a member of the public after spending four days in dense, swampy woods. Dehydration and bug bites were noted.<sup>10</sup>

### **Lethal Outcomes Outside the U.S.**

Although no data are available to show ASD wandering/elopement rates outside of the U.S., several notable cases occurred between 2009 and 2011.



- In April 2011, a male with an ASD, age three, wandered from a home he was visiting with his family in Laval, Quebec. Search efforts took place in frozen waters and ended after three days. His body was found in Laval River roughly five weeks later.<sup>11</sup>
- In March 2011, a train struck and killed a male with an ASD, age six, from Geelong, Australia, who had wandered from home. Australian media reported that witnesses saw the boy 90 minutes before being struck by the train, including one person who saw the boy almost hit by a car an hour beforehand. No calls to the police were made.<sup>12</sup>
- In December 2010, a male with an ASD, age 19, drowned in a pond in Singapore after running from his parent's home on the morning of New Year's Eve.<sup>13</sup>
- In December 2009, a male with an ASD, age seven, went missing from his home in Nova Scotia after following his dog into the woods. He was found huddled in the fetal position in an area of thick brush and snow. Unconscious and suffering from severe hypothermia, he died in the hospital.<sup>14</sup>

### **Caregiver Challenges**

Also according to IAN, half of families with elopers reported 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, and only 14% had received guidance from their pediatrician or another physician. IAN's findings also showed that:

- Wandering/elopement was ranked among the most stressful ASD behaviors by 58% of parents of elopers
- 62% percent 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

Parents of elopers who contacted NAA between 2009 and 2011 noted fire safety as being far less of a concern over wandering/elopement. Some cited hesitation to call local law enforcement for assistance during an elopement incident for fear of arrest. Some cited failure of

school officials to call 911 after a student with ASD was known to be missing, opting instead to dedicate time towards finding the student on their own.

### **New Resources**

At an Interagency Autism Coordinating Committee (IACC) meeting in October 2010,<sup>16</sup> NAA requested assistance in obtaining data and resources to strengthen prevention and response efforts. Three specific requests included data collection on wandering/elopement in ASD, an ICD9 medical diagnostic code assignment for wandering/elopement, and the formation of a safety subcommittee under IACC. IACC, CDC and a number of autism nonprofit organizations were promptly responsive to these requests, and the resources were made available to the ASD community within one year's time. The new medical diagnostic code V40.31 (Wandering in Diseases Classified Elsewhere) went into effect in October 2011.<sup>17</sup>

In 2011, NAA compiled best-practice guidelines for wandering prevention and response, which include a caregiver checklist that focuses on a multi-layered approach to prevent, and respond to, wandering/elopement emergencies. Through a 2011 American Legion grant, NAA provided 2000 free-of-charge safety toolkits to caregivers that included educational materials, visual prompts, child ID materials, and door/window alarms. Also in 2011, autismsafety.org was launched through NAA to provide educational materials to caregivers.

The National Center for Missing and Exploited Children (NCMEC), and CDC both assisted in distributing educational materials about ASD wandering/elopement prevention by placing links on their websites. NCMEC has provided ID toolkits, educational materials and safety information to caregivers in the ASD community.

### **Recommendations**

Further research is needed to help us gain better understanding of wandering/elopement triggers, patterns and water attraction in ASD, why risk may be higher in females, and to enhance prevention and response strategies.

Upon review, most federal and health agency web sites currently do not address ASD safety issues, including wandering/elopement. To reduce adverse outcomes:

- Federal and health agency channels should be utilized to raise awareness about safety issues surrounding those with an ASD, and educate caregivers about how to protect their child/adult with an ASD.
- Caregivers, especially those who own a pool or live near water, should be made aware of the potential dangers of elopement in ASD, and have access to prevention and response materials.
- Healthcare providers and developmental specialists should be educated on wandering/elopement tendencies in ASD as this could enhance caregiver outreach and improve outcomes.
- First responders should be made aware of autism spectrum disorders and the associated attraction to water, which could enhance first-responder search efforts and improve outcomes.
- School administrators, residential staff, and day program staff should be educated about wandering/elopement tendencies in ASD and its unique risks. Prevention and response protocols specific to ASD wandering/elopement are needed in non-home settings, and immediate parental notification is necessary. The Department of Education is encouraged to establish and provide policy guidance.
- Child Protective Services and Family Service agencies should be made aware of autism spectrum disorders and its associated behaviors, triggers, and attraction to water. These agencies are often called following a wandering/elopement incident, and opportunities should be taken to provide prevention materials and other supportive resources to families.

Because drowning was responsible for the majority of wandering/elopement-related fatalities, water safety initiatives designed for the ASD community and other special-needs populations are critical, as well as federal programs designed to train first responders on how to respond to a missing child/adult with an ASD. Funding for law-enforcement tracking programs could help save lives while reducing search-and-rescue costs.

Further, a central, disability-focused Emergency Alert System benefiting all children and adults with known cognitive impairments regardless of chronological age is needed. An Emergency Alert System should carry a title suggestive of a disability rather than age.

## **Conclusion**

Wandering/elopement tendencies in those with an ASD have tragic consequences. While lethal outcomes are preventable, awareness, education and resources remain scarce. Developing initiatives aimed at increasing awareness and resources would likely reduce wandering/elopement deaths in the ASD population.

For more information, visit [AWAARE.org](http://AWAARE.org) and [AutismSafety.org](http://AutismSafety.org).

## **References**

**1.** Centers for Disease Control and Prevention; *Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, United States, 2006* **2.** Interactive Autism Network Research Report ASD Elopement, 2011 [http://www.iancommunity.org/cs/ian\\_research\\_reports/ian\\_research\\_report\\_elopement](http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_elopement) **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 *Mortality and causes of death in ASD: an update* **5.** News Channel 5, Nashville; WTKR News Channel 3, Norfolk; *Bakersfield.com*, Bakersfield, CA; Fox 19, Aurora, IN; *Newson6.com*; *9news.com*; *USA today*; *newsok.com*; *5news.com*; *Arizona Daily Star*; *DC Examiner*; *Stillwater News Press*; *Lacrosse Tribune*; *Times-Georgian*; *KIRO Radio Staff at mynorthwest.com*; *Ocala.com*; *Newsday.com*; *Tulsaworld.com*; *AutismKey*; *WKBN, Ohio*; *KTVB, Idaho*; **6.** NBC Washington; **7.** Los Angeles Times **8.** CBC News **9.** Parent Report **10.** *Wesh.com*, Orlando **11.** CBC News **12.** *News.com.au* **13.** *Straightstimes.com*, Singapore **14.** CBC News **15.** Federal AMBER Alert Guidelines: <http://www.amberalert.gov/guidelines.htm> **16.** IACC, October 2010, [http://iacc.hhs.gov/events/2010/slides\\_fournier\\_mcilwain\\_102210.pdf](http://iacc.hhs.gov/events/2010/slides_fournier_mcilwain_102210.pdf) **17.** CDC, ICD-9 Code for Wandering, <http://www.cdc.gov/ncbddd/autism/code.html>

## **Acknowledgements**

Special thanks to Lyn Redwood, R.N., M.S.N., SAFEMINDS; Paul Law, M.D., M.P.H, Kennedy Krieger Institute; Christy Cook, National Autism Association