

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

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Summary

Similar to wandering behaviors in the Alzheimer's community, wandering and elopement behaviors in the Autism Spectrum Disorder (ASD) population have 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 (2:1) – 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 resources and channels remain absent or unutilized.

This paper is intended to evaluate lethal outcomes of wandering/elopement in 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 ASD¹ that can cause significant social, communication and behavioral challenges. 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 data² 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; 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; and, 32% of parents reported a “close call” with a possible drowning.

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.³ In 2001, a California research team attributed elevated ASD death rates in large part to drowning.⁴ 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 reporting⁵ 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.

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.

Female, 10, drowning, Murfreesboro, TN (September 2011)

Female, 5, drowning, Hampton, VA (September 2011)

Female, 4, drowning, Bakersfield, CA (July 2011)

Male, Jr., 7, drowning, Aurora, IN (June 2011)

Female, 10, drowning, Arvada, CO (May 2011)

Male 4, drowning, Cushing, OK (April 2011)

Male, 3, drowning, Fort Lupton, CO (April 2011)

Male, 4, drowning, Ida Township, MI (March 2011)

Female, 7, drowning, Lawton, OK (February 2011)

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.

Male, 8, drowning, Salmon, Idaho (October 2010)
Female, 3, drowning, Barling, AK (September 2010)
Male, 5, drowning, Tucson, AZ (August 2010)
Male, 7, drowning, Austintown, OH (August 2010)
Male, 5, drowning, Colwich, KS (July 2010)
Male, 8, drowning, Bernards, NJ (June 2010)
Female, 7, drowning, La Crosse, WI (June 2010)
Male, 6, drowning, Douglasville, GA (April 2010)
Male, 3, drowning, Osage, AR (April 2010)

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.

Male, 10, drowning, Ocala, FL (November 2009)
Male, 11, struck by vehicle, Seattle, WA (October 2009)
Male, 14, drowning, Lindenhurst, LI (August 2009)
Male, 5, struck by vehicle, Tulsa, OK (July 2009)

Circumstances of Note

Five of the 22 (23%) ASD deaths occurred during a family outing. Of those, three occurred during a camping trip; one on a family houseboat; one in a busy shopping district.

At least 15 of the 22 (68%) children died in a nearby pond, lake, creek or river. One death occurred in a school setting (indoor pool) during a transition; one in a neighbor's swimming pool; one in a pool of water at a construction site.

One death occurred following a family move to a new home. Two deaths occurred after the child exited the home through a window.

Five of the 22 children (23%) were under the care of someone other than a parent. One child was wearing a tracking device that failed to emit a signal under water. Though one child was wearing a medical identification bracelet, members of the public who saw the boy shortly before he ran into traffic did not stop him.

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.⁶

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.⁷

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.⁸

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.⁹

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.¹⁰

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.¹¹

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.¹²

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.¹³

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.¹⁴

Observations

IAN findings show no significant relevance between seasonal patterns and ASD wandering/elopement, though media reports show more ASD fatalities occurred in warmer months during 2009, 2010, and 2011 in the U.S.

The National Autism Association's (NAA) surveillance of ASD missing-person reports over the last three years indicates that wandering/elopement cases (lethal and non-lethal) in young children routinely spike in early spring and rapidly decline in early fall. Over the winter seasons of 2009 and 2010, NAA saw fewer missing-person reports involving young ASD children, though a slight increase in school-related wandering was observed during these months. No seasonal changes in the frequency of ASD missing teenagers were observed.

Also 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.

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 ASD missing-person cases and fatalities, children wandered/eloped from multiple caregiver groups, including parents, relatives, babysitters, adult siblings, teachers, and residential staff.

IAN's findings showed that wandering/elopement was ranked among the most stressful ASD behaviors by 58% of parents of elopers. Sixty-two percent of families with children who elope were prevented from attending/enjoying activities outside the home due to fear of wandering, and 40% of parents had suffered sleep disruption due to fear of elopement.

Also according to IAN, half of families with elopers reported they had never received advice or guidance about elopement from a professional.

Parents of elopers who contacted NAA between 2009 and 2011 cited concerns of: lack of local guidance; lack of local resources; unaffordable or unavailable safeguards; lack of support and understanding from first responders and child protective agencies; lack of support and understanding from family members; lack of public knowledge and understanding of the issue; lack of support, strategies and notification from school staff. Multiple caregivers 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.

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.¹⁵

Lethal outcomes in ASD wandering/elopement 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. Both the California and Demark studies noted higher overall mortality risk in females with ASD.

New Resources

At an Interagency Autism Coordinating Committee (IACC) meeting in October 2010,¹⁶ 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 2011.¹⁷

This year, 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

Drowning was responsible for an estimated 91% of ASD wandering/elopement fatalities from 2009 to 2011. Water safety initiatives designed for the ASD community may reduce adverse outcomes. Caregivers, especially those who own a pool or live near water, should be made aware of the potential dangers, and have access to prevention and response materials. Upon review, most health agency web sites, and autism information offered through health agencies, currently do not address ASD safety issues, including wandering/elopement.

Caregivers are encouraged to use a multilayered approach to safety in home and non-home settings. Water safety/swimming lessons are critical. Life-vest protection during family outings near or on water is encouraged. A “bookends” approach – one adult in front of the child, one behind, or one on either side – is encouraged during mobile activities, such as hiking, camping trips, and family outings. A “tag” approach -- tagging a responsible adult to keep eyes on the child – is encouraged during times of commotion, such as family gatherings and public outings.

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. Understanding and eliminating potential elopement triggers, while implementing coping, de-escalation, self-regulation, and item-of-interest supplementation strategies in safe settings, may help reduce incidents. Caregivers should be especially mindful of changes in home layout and security during seasonal transitions into warmer months, and always call 911 if their child/adult with ASD is missing.

First responders may not be aware of autism spectrum disorders, the associated attraction to water and the unique challenges in searching for an individual with ASD. Better understanding could enhance first-responder search efforts and improve outcomes.

Healthcare providers and developmental specialists may not be aware of wandering/elopement tendencies in ASD. Better understanding could enhance caregiver outreach and improve outcomes.

School administrators, residential staff, and day program staff may not be aware of wandering/elopement tendencies in ASD or its unique risks. Caregivers may not be notified of failed wandering attempts in non-home settings, which may increase the chance of subsequent incidents. Prevention and response protocols specific to ASD wandering/elopement are needed in non-home settings, and immediate parental notification is necessary. Staff should always call 911 if an individual with ASD is missing.

To reduce adverse outcomes, the Department of Education is encouraged to establish and provide policy guidance. Dangerous restraint and seclusion practices as a means to control elopement behaviors should be eliminated. Understanding and eliminating potential elopement triggers, while implementing coping, de-escalation and self-regulation strategies, may help reduce overall risk.

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.

Because caregivers face challenges in obtaining safeguards that would prevent bodily harm or death in their children and adults with ASD, federal safety initiatives for ASD are recommended.

Tracking technology and personal locating devices that operate through trained law enforcement agencies have saved lives according to vendor, media, and local-agency reports, but availability can be limited. Emerging GPS technology through private retailers is more readily available, but relies heavily on caregiver maintenance. Currently there is no federal oversight of various tracking technologies, leaving caregivers to base decisions on seller information. Independent review and field testing is recommended.

The AMBER alert system can only be activated if a confirmed abduction of a child has taken

place. Silver Alert, a similar alert system, is in place in many states to broadcast information to help locate seniors with dementia who have wandered. Most missing children and adults with ASD are not covered by either of these two alert mechanisms, but availability of such a system to families and communities could play a critical role in preventing adverse outcomes. A central, disability-focused Emergency Alert System benefiting all children and adults with known cognitive impairments regardless of chronological age is needed, as well as law enforcement training specific to the unique needs of the ASD population. An Emergency Alert System should carry a title suggestive of a disability rather than age.

Child Protective Services and Family Service agencies may not be aware of autism spectrum disorders and its associated behaviors, triggers, and attraction to water. Because these agencies are often called following a wandering/elopement incident, the opportunity could be used to provide prevention materials and other supportive resources to families.

To reduce lethal outcomes, it is recommended that the appropriate federal agencies and health organizations assign members to address these specific ASD safety issues while utilizing available channels to broaden awareness, strengthen understanding, increase outreach, and enhance prevention and response efforts.

Caregivers are encouraged to visit AWAARE.org and AutismSafety.org for tips on ASD wandering/elopement prevention and response.

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