Summary Report:

Mortality & Risk In ASD Wandering/Elopement 2011-2016

MARCH 2017





Summary Report: Mortality & Risk In ASD Wandering/Elopement 2011-2016

Published March 2017

Lori McIlwain, National Autism Association Wendy Fournier, National Autism Association

Table of Contents

Introduction	1
Methods/Objective	2
Results	3
Conclusions & Recommendations	5
References	6
Acknowledgments	6



Introduction

Wandering/elopement behaviors in individuals with an Autism Spectrum Disorder (ASD) remains a critical issue among all age groups.

In early 2017, a seven-year-old boy with autism exited his home in Franklin County, North Carolina, just before 9pm while his mother used the restroom. After a brief search, the child was found approximately one mile away after being fatally struck by a vehicle. The driver was charged with a D.U.I. ¹

In Tulsa, a 17-year-old with autism was reported missing at 3am, approximately 40 minutes before being struck and critically injured by an SUV that fled the scene. A motorist who initially swerved to avoid hitting the boy turned around in an attempt to assist him before witnessing him being struck. The teen died several days later.²

In Burbank, a 20-year-old man with autism left his home and was located in a Burbank wash via tracking technology.³

Wandering/elopement behaviors in individuals with Autism Spectrum Disorders (ASD) remain

a critical issue among all age groups, often leading to significant risk of bodily harm and death. Since 2009, 158 individuals⁴ with ASD have died after exiting settings that include home, school, public places, group homes, and foster care.

Elopers also face non-lethal trauma ranging from near drownings, vehicular injuries, sexual assault and restraints, to exposure, dehydration and psychological harm. Second-party risk is an additional key factor. Bystanders, search volunteers and search personnel also face serious physical risk and emotional trauma.

Some programs have been established over the last decade to address ASD elopement behaviors; however, outreach, prevention resources and police training remain low and sporadic throughout the U.S.



A 20-year-old man with autism was found in the wash near the Burbank and Glendale border, after he had been reported missing from his home earlier that day. (Courtesy of the Glendale Police Department)

latimes.com, January 2017

Lethal Outcome, age 7 (2017)

"A neighbor said his mother had gone to the bathroom; when she left the room she



(Courtesy of WRAL.com)

noticed the front door was open. Neighbors began to search for the child, but he made it about a mile up the road. 'It is just a horribly sad situation. It's tragic.' said [a neighbor]. 'As a parent you do everything you possibly can do to protect your children and even doing that, things can happen.'"

· · · · · WRAL.com, January 2017

2017 Risk Outcome, age 19 (2017)

"The unseasonably cold water was up to his neck and indications were that he had been there for some time and could have easily drowned. Fortunately, Air Support was able to lead a Sheriff's Search and Rescue team member and a Sheriff's Volunteer to his location. The Sheriff's Volunteer knew the missing teenager from periodically changing the batteries on his Project Lifesaver bracelet. When the teenager heard his familiar voice, he agreed to reach his hands out and was pulled over the slippery water basin to safety."

..... SBSheriff.org, February 2017

Medical Outcome, age 7 (2017)

"Officer Jonathan Pruziner remembered from his training that people with autism are often attracted to water and started searching in the area of a nearby pond. He found [her] cold and wet near the pond. 'She was really cold. I've suffered from hypothermia in the past and I was pretty sure that's what was going on.""

· · · · · · · · · · · NBC Washington, March 2017

Mortality & Risk In ASD Wandering/Elopement: 2011-2016

The Centers for Disease Control and Prevention (CDC) estimates that an average of 1 in 68 children in the U.S. have an Autism Spectrum Disorder (ASD)⁵ 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 leave the safety of a responsible person's care or a safe area, also known as wandering/elopement.

According to data published in 2012 by Pediatrics, 49% 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, investigation of lethal outcomes is necessary and ongoing.

Methods and Objective

From January 1, 2011 to December 31st, 2016, the National Autism Association collected missing person cases and "found missing" cases in the U.S. involving individuals with an ASD who wandered or eloped from a safe setting, and were serious enough to require media and/or police involvement.

The main objective for this report was to look at total outcomes including mortality, injury, and risk in an effort to gain insights into better prevention and response strategies.

Cases were collected over a six-year time frame via all available media and agency channels in real time, and existing case information was utilized to collect outcome data retrospectively. Cases were included based on the date of occurrence, ASD diagnosis, U.S. location, reliable and accessible source, and substantial evidence indicating the individual left safe supervision or a safe area.

This combined six-year total is compiled from media and agency reporting and may not be an accurate representation of 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 in this study. However, canvassing all potential cases of mortality and risk via media reporting is unlikely to be comprehensive and thus, if anything, underrepresents the true incidence of mortality and risk related to elopement. Most relevant data were collected from one or more articles applying to each case. Cases were reviewed to identify relevant trends pertaining to the individual's age, gender, race, diagnoses, and any previous elopement behaviors. Annual, seasonal and time-of-day patterns were also reviewed, as well as locations left/found, response data, the physical state in which the individual was found, and other details, such as caregiver arrests and CPS involvement. For cases with no available updates, the National Missing and Unidentified Persons System (NamUs) was used to determine if the individual was still missing.

Sixty-four cases were excluded from the sample, including seven fatalities. Cases were excluded or removed if they fell outside of the U.S., the individual was an adult who demonstrated a substantial level of independence and was not in danger, the individual was found with a trusted family member or trusted adult, the individual was never missing, or the information could no longer be substantiated by an active or accessible source. Two fatalities were removed after the reported diagnosis changed to Angelman syndrome, two were removed after being ruled a homicide, and three were removed because the individuals never left safe supervision.

Of 872 reported ASD missing person cases collected in this sample period, 808 U.S. cases, including 139 deaths, were determined to be the result of ASD wandering/elopement.

Lethal Outcome, age 4

"When his parents last saw him, [the boy] was sound asleep on a couch in his grandparents' home. It was 5 a.m. Sunday. No one expected the 4-year-old boy would somehow let himself out of the house and make his way to a neighboring family's above-ground swimming pool, where he would drown. That tragedy was compounded by another on Monday morning, when the 47-year-old man who owned the pool died himself, crashing his SUV into a house near his home after experiencing 'multiple cardiac conditions' while driving. The [owner's family] was so distraught by the accident that his wife and daughter chose to stay overnight in a hotel rather than be in their house. [He] had wanted to take down the pool before they returned."

Results

Out of 808 reported ASD missing person cases of wandering/elopement in the United States from 2011 to 2016, 17% (n = 139) resulted in death, and an additional 13% (n = 105) required medical attention.

Accidental drowning accounted for 71% (n = 98) of lethal outcomes, followed by 18% (n = 25) caused by traffic injury. Injury or trauma ranged from minor scrapes and bruises to non-fatal traffic injuries, near drownings, and physical/sexual assaults. Close calls with traffic, water and other threats accounted for an additional 38% of cases.

Children 5 to 9 had the highest number of deaths, while children under 5 faced the highest lethal risk with cases ending in death nearly 60% of the time. The lethal risk dropped beyond age 14, but increased in adults 25 to 29.

The average age per year for lethal outcomes increased for most years of the sample period.

Lethal risk in females was higher with 104 cases ending in death 22% of the time compared to 704 male cases ending in death 16% of the time.

Of known ethnicity, 58% (n = 355) were white, 30% (n = 182) were black, 8% (n = 49) were hispanic, 2% (n = 15) were Asian, and 2% (n = 12) were biracial. Less than 1% were Native American (n = 1) and Native Hawaiian (n = 1).

Individuals were under various types of supervision at the time of elopement with non-parent supervision accounting for 45% of cases. Times of transition, commotion and stress increased elopement risk, and those who were noted to be upset or agitated showed a higher risk of abruptly exiting into traffic or other high-threat situations. (cont'd)

Lethal Outcome, age 12

"[The boy], who was autistic, wandered away from his home. As police were seeking the boy, an officer came upon the accident scene. 'It is not a situation involving a pedestrian purposefully running in front of traffic. Investigators have learned at times individuals with autism may wander -- this appears to have been the case here.'"

The Oakland Press, January 2015

Table 1: a summary of outcomes from 2011 to 2016

2011-2016	Total		Percentage
Total Outcomes			
Lethal	139		17%
Medical Attention	105		13%
Close Calls	309		38%
Still missing	5	;	1%
Minimal Risk/Unclear	250		31%
Total	808		100%
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%

Socio-demographics	Total	Lethal	Lethal Percentage per Subgroup	
Age				
Younger than 5	45	26	58%	
5 to 9	191	62	32%	
10 to 14	229	25	11%	
15 to 19	192	11	6%	
20 to 24	70	6	9%	
25 to 29	41	7	17%	
30 +	40	2	5%	
Gender				
Female	104	23	22%	
Male	704	116	16%	
Race				
White	355	68	19%	
Black	182	30	16%	
Hispanic	49	7	14%	
Other	29	4	13%	
Unknown	193	30	16%	

Average Age by Year	2011	2012	2013	2014	2015	2016
Non-lethal	14	16	16	14	15	15
Lethal	5	8	9	12	10	13
All Cases	12	15	14	13	15	15

Cause of Death

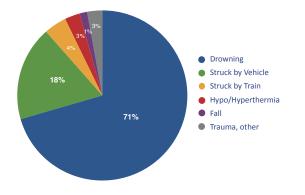


Figure 1: Lethal outcomes by cause of death

Results Cont'd

Water, traffic, woods and a stranger's residence were the top settings where individuals were located, along with low-sensory locations, such as abandoned areas, farms or fields.

The majority of lethal outcomes noted a search time of an hour or less, indicating that fatalities may occur quickly with little time to intervene. Other cases showed successful rescues of individuals missing for upwards of a week without adequate food or water.

Cases were reported in nearly all U.S. states and the District of Columbia with the highest activity reported in California, Florida, New York, Texas and Michigan. Of those with higher activity, Maryland was the only state with no reported deaths.

"We're ecstatic we found this kid with everything stacked against us."

Capt. B.J. Jones, who helped locate a nonverbal 7-year-old boy in a riverbed after an eight-hour search - ModBee, January 2014

In this sample, lethal outcomes occurred at a rate of about once a month on average in 2011 to about two to three times a month on average in 2015 and 2016. It is unclear whether better reporting, warmer average temperatures, or other factors played a role in the increase.

Risk & Injury

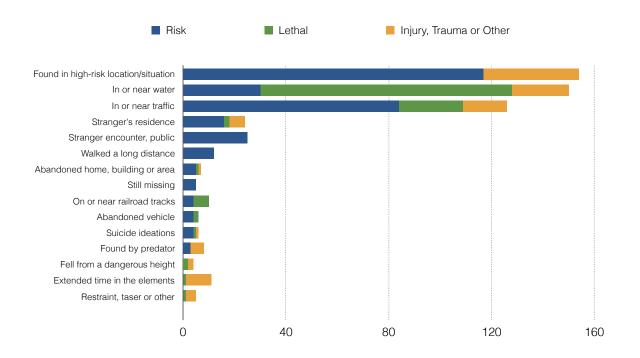


Figure 2: Outcomes by risk and injury

Medical Outcome, age 8

"Because of his autism, [the boy] probably didn't know that he was lost. If he heard people coming through the woods, he might well have taken cover from them, thinking it was a game of hide-and-seek. Or he might not have wanted to be found by a stranger, even one calling out his name. This made efforts to locate him extremely difficult, and it's how [he] managed to elude what would soon become one of the largest search-and-rescue operations in Virginia history."

outsideonline.com, July 2012

Conclusions & Recommendations

In this six-year sample, nearly a third cases were either fatal or required some level of medical attention.

Some cases demonstrated how police training and police familiarity with the specific individual was key in decreasing overall risk, including secondary risks, such as restraint.

To reduce risk, it is recommended that first responders be trained on the signs of ASD, its associated water and traffic (cont'd)

"Sometimes the uniform scares people.

But immediately when I went to the park,
she recognized me and she came to me."

Deputy Amanda Vollmer, who helped locate a nonverbal 7-year-old girl who went missing in Nebraska - KETV.com, August 2016

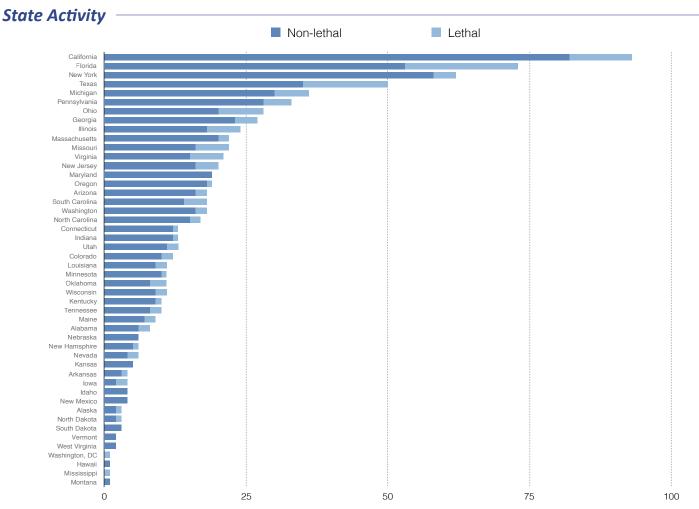


Figure 3: Lethal and non-lethal outcomes by state

Risk Outcome, age 10 (2017)

"Law enforcement poured into [the] neighborhood within minutes to help search for the young girl. [He] says her father found her a short time later. The young girl had wandered off into the woods and was stuck in a ravine 20 minutes away. 'We've noticed a rise in search and rescues with missing [persons with] autism,' said Lieutenant Jim Byers of the El Dorado County Sheriff's Office. He says those incidents spiked in the early 2000's. And in 2005, the Sheriff's Office launched an autism registry to help."

. . . sacramento.cbslocal.com, March 2017

Conclusions & Recommendations Cont'd

risks, and proper interaction techniques.

Because nearly half of lethal outcomes noted a search time of an hour or less, programs that focus on prevention, water safety, and guicker response time are critical.

Radio Frequency (RF) Technology through local law enforcement and other safety agencies has been shown to reduce search time; therefore, it is recommended that agencies be made aware of these options for high-risk elopers, along with other resources, such as registries, endangered missing advisories and reverse 911 technology.

States with Silver Alerts that carry age restrictions should expand age criteria to include children, teens and adults with disabilities. Most ASD elopement cases do not qualify for an AMBER Alert, which is limited to children who have been abducted.

Advocates, clinicians, and service professionals should advise parents, foster parents and caretaker staff on elopement risks and when/where elopement is more likely to occur. Encourage them to enroll individuals with ASD into swimming lessons and to introduce their child or client to members of local law enforcement, and neighbors. Tools, such as door alarms, visual prompts and identification should be recommended, and information about different tracking technology options should be provided.

"I was able to lay down on the deck and he reached out to me and I pulled him up. I just grabbed him, bear hugged him wrapped him in my jacket and took off running."

Patrolman Joshua Leveronne, who rescued a nonverbal 4-year-old boy from a wastewater treatment pool - WDRB.com, March 2015

Elopement cases in this sample reflected a variety of safety topics affecting the ASD population, including suicide ideation and self-harm, bullying, heightened stress response, and lack of proper services and supports. Research, medical protocols and programs addressing these issues may reduce exit-seeking behaviors in individuals with ASD.

Further study is needed to determine whether lethal outcomes and average ages are increasing, and what may be contributing to the rise. The disproportionate risk among black individuals with ASD also needs further study and guidance.

Overall, these findings underscore the need for widespread first responder training and resources, broader outreach, education and prevention tools for families, school staff, foster care providers and residential caretakers.

References -

- 1. 7-year-old hit, killed in Franklin County; driver charged with DWI WRAL.com, January 2017
- Tulsa Police Locate SUV That Injured Autistic Teen In Hit-And-Run - NewsOn6.com, February 2017; Grieving Family Focused On Life Of 17-Year-Old Hit, Killed By SUV -NewsOn6.com, March 2017
- **3.** Glendale police use tracking device to find deaf man with autism reported missing LATimes.com, January 2017
- **4.** Ongoing surveillance of ASD wandering/elopement lethal outcomes, 2009 to date National Autism Association
- 5. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012, April 1, 2016 / 65(3);1–23 - cdc.gov
- 6. 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

Acknowledgments

Special thanks to Krystal Higgins of the National Autism Association and Dr. Paul Lipkin of Interactive Autism Network and Kennedy Krieger Institute. For the full report, or information on prevention/response resources, please write to naa@nationalautism.org.