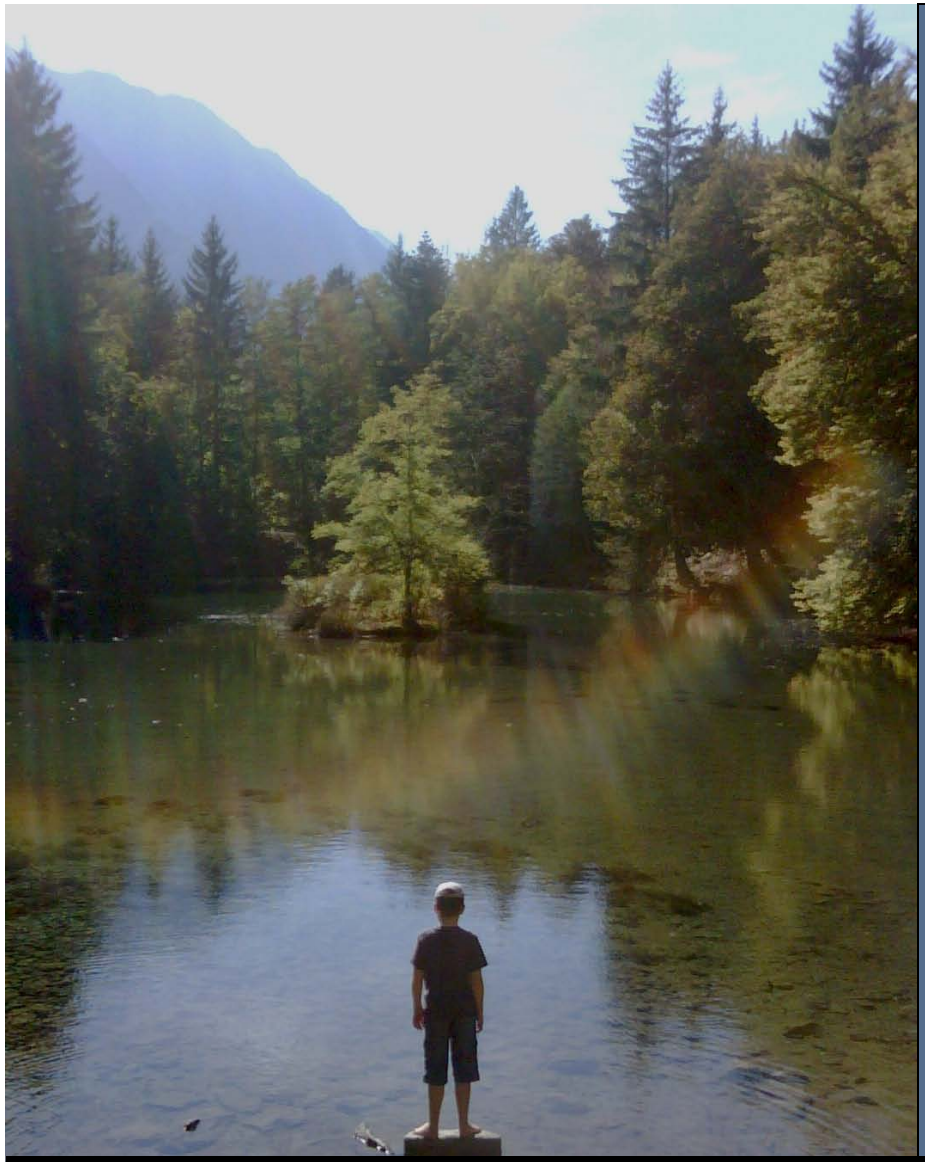


Wandering & Autism:

The need for data and resources

Lori McIlwain | Wendy Fournier

NATIONAL AUTISM ASSOCIATION | INTERAGENCY AUTISM COORDINATING COMMITTEE MEETING | 10.22.10

what we know

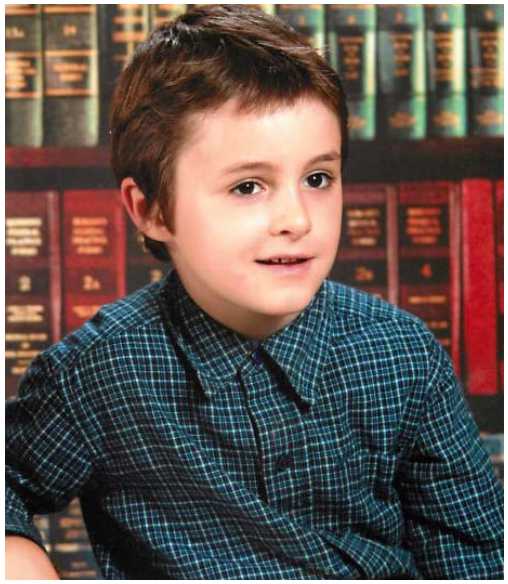
April 30 Sampling of Fatalities - Autism Elopement

- Erik Lippmann, 30, drowning
- Aiden Johnson, 3, drowning
- Christian Dejons, 6, drowning
- James Delorey, 7, prolonged exposure
- Bernard Latimore, 9, drowning
- Devine Farrier, 11, struck by vehicle

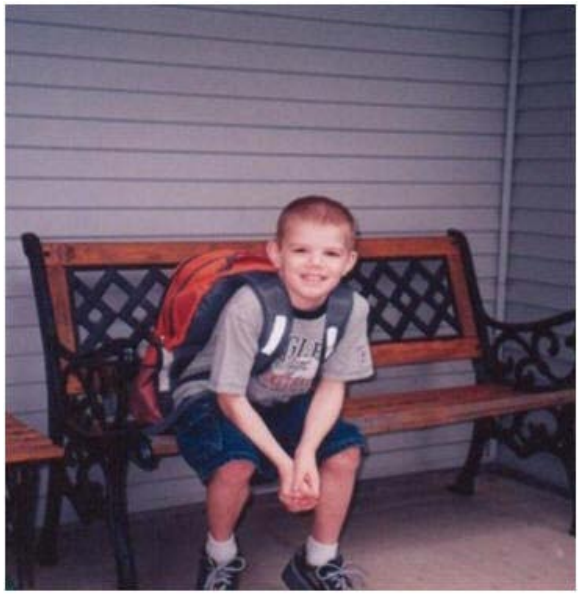
More Recent Sampling, Incidents & Fatalities

Mason Medlam, 5, *drowning* **|** **Susan Petras**, 59, found after four days **|** **Nathan Chapman,** 14, wandered twice in two-week period **|** Name Not released, 5, *struck by vehicle* **|** **Nathan Kinderdine**, 7, wandered from school, *drowning* **|** **Bradley Clayton**, 9, found after two days **|** **Ingvar Slettnes,** 7, found by hikers **|** **Benjamin Lehr**, 3, found in woods **|** **James Malloy**, 20, missing since July 20th **|** **Erick Svoboda,** 30, found after four days **|** **Adlai Kugblenu**, 8, *drowning* **|** **Armhan Parish**, 12 found after nine-hour search **|** **Zachary Clark**, 5, *drowning*

Cases of Note, Winter, Prolonged Exposure



James Delorey, Age 7
-December 2009
-South Bar, NS
-Found unconscious after two days
-Died in hospital



Logan Mitcheltree, Age 9
-December 2004
-South Williamsport, PA
-Found dead after three-day search

Project Lifesaver "Recent Rescues" Log

Ref #	Date	City or County, State	Diagnosis	Recovery Time
2,203	9/10/2010	Portsmouth, VA	Schizophrenic	2 minutes
2,202	8/27/2010	Rosenhayn, NJ	Alzheimer's	2 minutes
2,201	9/11/10	Chillicothe, OH	Epilepsy	21 minutes
2,200	9/9/2010	Nicholasville, KY	Alzheimer's	2 minutes
2,199	8/31/2010	Nova Scotia, CAN	Autism	9 minutes
2,198	9/8/2010	Quincy, MA	Severe Autism	11 minutes
2,197	9/8/2010	Norfolk, VA	Dementia	1 hour 11 minutes
2,196	9/9/2010	Marion, IN	Dementia	8 minutes
2,195	8/30/2010	Pell City, AL	Alzheimer's	6 minutes
2,194	9/7/2010	Norfolk, VA	Mental Retardation	40 minutes

Cases of Note, Summer, Nearby Water

Ashley Brock, Age 6
-May 2008
-Brunswick, ME
-Accidental drowning
-Neighbor's Pool

Nathan Kinderdine, Age 7
-August 2010
-Austintown, OH
-Accidental drowning
-School Indoor Pool

Cases of Note, Struck By Vehicle

Jack Hensley, Age 5
-July 2009
-Tulsa
-Struck, killed by SUV
"Police said Jack was wearing a medical bracelet that indicated his condition and that there were no signs of neglect."

Devine Farrier, Age 11
-October 2009
-Seattle
-Struck, killed by truck

Female, NNR, Age 6
-July 2010
-Deltona, FL
-Ran from house, struck by vehicle
-Hospitalized, no reports indicating fatality
"I am very sorry to hear this but parents need to be more attentive."

Connor, Age 10

In 2007, age 7, was picked up by a man in a car after wandering from a school playground.

School did not call local Authorities.

Police had to search for where he belonged.

Goal-directed incident.

Connor, Age 10

Eight incidents from three different schools.

Two identical incidents since 2008. Unescorted transitions. Therapist encouraging "independence."

Abnormal fight/flight response.

Flees under distress.

Benjy Heil, Age 7

Went missing June, 2007

Authorities could not issue an AMBER Alert because he was not abducted.

Neighbor saw him walking.

Found dead in nearby pond.

AMBER Alert Criteria - All Must Be Met

DOJ's guidance on criteria for issuing AMBER Alerts is:

- Law enforcement must confirm an abduction has taken place
- The child is at risk of serious injury or death
- There is sufficient descriptive information of child, captor, or captor's vehicle to issue an alert
- The child must be 17 years old or younger

Most states' guidelines adhere closely to DOJ's recommended guidelines.

Reference: US Department of Justice

Lack of Data

In a 2007 National Autism Association Survey, 92% of parents reported that their child/children with ASD had wandered from a safe environment one or multiple times.

Parents who are affected by this issue were more likely to respond, so the data reflects a higher percentage.

Causes of Death In Autism

Shavelle RM, Strauss DJ, Pickett J. - Life Expectancy Project, San Francisco, California, USA. ***December 2001***

-Objective was to determine which causes of death are more frequent in persons with autism, and by how much, compared with the general population.

-Subjects were 13,111 ambulatory Californians with autism, followed between 1983 and 1997.

- Observed numbers of cause-specific deaths were compared with numbers expected according to general population mortality rates.

-Standardized mortality rates (SMRs) were computed for each mental retardation level.

-**Elevated death rates were observed for several causes, including seizures and accidents such as suffocation and drowning**

Mortality and causes of death in ASD: an update

Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T.
Department of Child and Adolescent Psychiatry, Bispebjerg University Hospital, Copenhagen, Denmark. ***July 2008***

-Study compared mortality among Danish citizens with autism spectrum disorders (ASDs) with that of the general population.
-A clinical cohort of 341 Danish individuals with variants of ASD, previously followed over the period 1960-93, now on average 43 years of age, were updated with respect to mortality and causes of death.
-Standardized mortality ratios (SMRs) were calculated for various times after diagnosis. In all, 26 persons with ASD had died, whereas the expected number of deaths was 13.5.
-**The mortality risk among those with ASD was nearly twice that of the general population.**

What We Know - Alzheimer's

-According to the Alzheimer's Association, *"More than 60 percent of those with dementia will wander, and if a person is not found within 24 hours, up to half of individuals who wander will suffer serious injury or death."*

-Through the Department of Justice, Alzheimer's receives $5,000,000 each year for first-responder training and grants for Tracking Technology

-Wandering-related Dementia carries a medical diagnostic code

-Emergency Broadcast Alert "Silver Alert" was created with seniors in mind, and is often referred to as "The AMBER Alert for Seniors"

Autism In Comparison

-No formal estimates available for autism-specific wandering
-No data available to show how many wander, how often they may wander, from where they may wander, under whose care they've wandered, when they may wander (both time of day/night and time of year), how many die each year, degree of diagnosis, what increases risk of death (amount of time missing, functional language, fight/flight, time of year, age, nearby water, etc.), what safety precautions have/have not been taken, authority involvement/assistance
-No study identifying ASD wandering categories -- goal-directed, random, disorientation, fleeing, etc.
-No data reflecting what types of wandering may happen more frequently and why

Autism In Comparison

-No federal grant dollars to combat autism-specific wandering

-No federal first-responder training programs for ASD wandering

-No federal aide for tracking technology or oversight

-**No medical subclassification coding or general medical coding for ASD wandering (or Down's Syndrome, Brain Injury, etc.)**

-No mandates requiring parental notification of wandering incidents in school – smaller incidents are often dismissed that can lead to more serious incidents if not addressed.

-No Emergency Broadcast Alert Systems for minors with cognitive impairments

-No programs dedicated to special needs swimming lessons

Autism In Comparison

-**Families living under great deal of stress; unable to leave home; low quality of life**
-Little support and understanding from relatives, neighbors, friends, schools, first responders
-**Some parents "hesitate" calling 911 should child go missing: fear of arrest; fear of child being removed from home**
-Tracking technology can be confusing, expensive, inaccessible
-Parents report pressure to allow child more independence, but face harsh judgment following elopement
-Children show no physical abnormalities - seen as mental (or "choice") wanderers instead of medical; parents perceived as neglectful
-**Parents report little physician involvement/guidance/advice**

what we need

Data Collection

-How many individuals are at risk?
-From what settings are individuals with ASD wandering? Home, school, residential facility, community outing?
-What are the circumstances surrounding the wandering incident? Unlocked door/window, unfenced play area, school door, during a family gathering?
-What prompted the wandering incident? Was the child/adult trying to get to something, or away from something?
-How often are wandering incidents reported to authorities?
-Cost analysis – Protection with tracking system vs. search efforts

Awareness, Resources & Policy

-Create toolkits for parents to implement prevention strategies
-Disseminate information to caregivers through AAP Autism Toolkit Family Handouts, CDC's *Learn the Signs. Act Early.*
-Create wandering awareness materials for school personnel, first responders, physicians
-Develop training for first responders on specific challenges faced when searching for an individual with autism
-Establish a central source dedicated to focusing on autism-related wandering that may serve as both a distribution center for information and a registry for at-risk individuals that can provide quick access to information for first responders
-Promote federal laws that mandate parental notification of any wandering or fleeing incidents in schools, and require school emergency response protocols specific to wandering

The AWAARE Collaboration

-A coordinated initiative developed by six national organizations
-Non-branded promotional materials, website, brochures, etc. made available for use by any organization
-Resources for caregivers, school administrators, law enforcement personnel, physicians and therapists

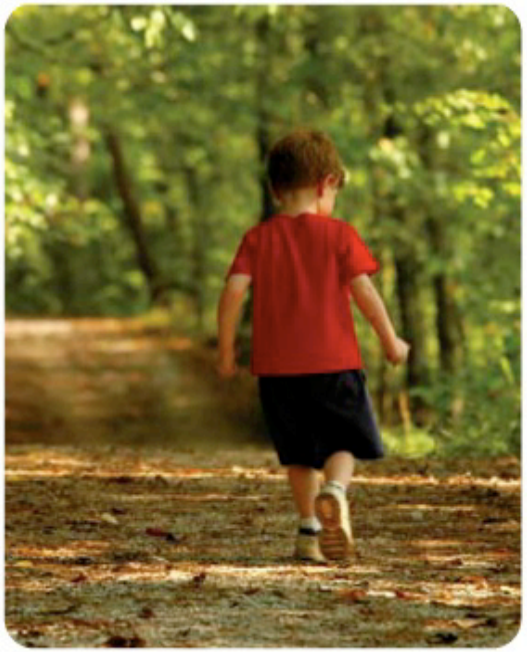
WORKING TO PREVENT WANDERING INCIDENTS AND DEATHS WITHIN THE AUTISM COMMUNITY

AWAARE COLLABORATION

contact us | promote this initiative

SHARE

AUTISM
WANDERING
AWARENESS
ALERTS
RESPONSE
EDUCATION



:: FREQUENTLY ASKED QUESTIONS
:: HELPFUL MATERIALS
:: TRACKING TECHNOLOGY
:: WHERE TO FIND SWIMMING LESSONS
:: PARENT STORIES
:: FOR LAW ENFORCEMENT OFFICIALS
:: FOR PHYSICIANS AND THERAPISTS
:: FOR SCHOOL ADMINISTRATORS

BECOME AWAARE

With little public understanding about autism-related wandering, coupled with a lack of resources to combat occurrences, drowning deaths associated with autism elopement remain a leading cause of fatalities among children and adults on the autism spectrum. Although no formal data exists about the number of wandering incidents per year, cases are becoming increasingly common and awareness alone can play a major role in reducing occurrences. To learn more, click here.

RESEARCH

Autism is a diagnosis that represents many symptoms, some of which can lead to serious health and safety risks, including death. In 2008, Danish researchers found that the mortality rate among the autism population is twice as high as the general population. In 2001, a California research team attributed elevated death rates in large part to drowning. Drowning, prolonged exposure, and other wandering-related factors remain among the top causes of death within the autism population. Currently, no estimates exist and no formal methods are in place to track how many children and adults wander per year, but in a 2007 online poll through the National Autism Association, 92% of parents reported that their child/ren with autism have a tendency to wander.

DOWNLOAD & SHARE

WHAT TO DO IF SOMEONE WANDERS

- Call 911
- Implement your Family Wandering Emergency Plan (FWEP)
- Click here for more information

QUICK LINKS

- Autism Risk Management
- Project Lifesaver
- A Child Is Missing
- AWAARE Brochure
- Social Stories

NEWS, ALERTS, BLOGS

- News Stories
- Join our Facebook Group

Emergency Broadcast Alert System

-Establishment of a new alert system for individuals under the age of 18 with a cognitive impairment
-Or, adding provisions to existing AMBER alert criteria to allow implementation of the system when an individual with a cognitive impairment goes missing

Establishment of Medical Diagnosis Code

-An ICD-10 code has been established for at-risk adults.

F02.81 Dementia with wandering

-A similar medical code for individuals with ASD is needed to:

-Classify tracking devices as medically necessary and reimbursable by insurance

-Combat the misconception that wandering is simply behavioral

-Increase awareness of physicians; open critical dialogue with caregivers

-Strengthen the role of caregivers when dealing with school administrators, IEP development

Tracking Technology

-Tracking technology is becoming a commodity
-Development of reliable, effective, affordable devices
-There is currently no oversight or official recommendations on these types of products
-Caregivers need to be educated on the differences between radio frequency, GPS and cell technology

Federal Funding Needed for:

-Families who are unable to afford, or gain access to proven home safety and security measures
-Tracking technology
-Providing access to special needs swimming instruction
-Development and distribution of awareness materials, toolkits, training programs
-Data Collection
-Medical Research
    -What causes a tendency to wander?
    -OCD, Fight or flight mechanism?

Recommendations to IACC

-Add a new objective to the Strategic Plan focused on ensuring the safety of individuals with ASD

-Establish a sub-committee focusing on safety issues affecting the ASD Community and addressing external causes of death

- -Wandering/Elopement
- -Restraint and Seclusion in Schools
- -Anti-bullying education programs
- -Support for families at the breaking point
- -Education for law enforcement personnel

questions?