



*Elopement
and Wandering:*
Your Guide
to Safety
Resources



Autism™
NEW JERSEY

Elopement and Wandering: Your Guide to Safety Resources

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Elopement is one of the most concerning challenging behaviors for individuals with autism spectrum disorders. Due to the growing prevalence of autism and the potential dangers associated with elopement, awareness about available resources is vital. This publication describes the scope of the problem and its effect on the individual and the family; provides information on identification products and tracking devices; and offers suggestions to improve elopement assessment and intervention. This publication will be helpful for parents and caregivers, schools, law enforcement, and agencies that serve individuals with autism.

What is Elopement?

Elopement is defined as running away from, wandering, bolting or leaving a designated area such as a classroom or the home.

Why is it a problem?

Individuals with autism may have challenges with communication and intellectual delays. This makes elopement a highly dangerous behavior. In 2011, the Autism Research Institute, the Autism Science Foundation, Autism Speaks, and the Global Autism Collaboration partnered with the Interactive Autism Network (IAN) to create a national survey on elopement in ASD.¹ More than 800 families of children with ASD from across the U.S. completed the Elopement and Wandering Questionnaire. The survey yielded the following statistics:



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- Nearly half (49%) of children with ASD between the ages of 4 and 10 have engaged in elopement behavior.
 - This rate is nearly four times higher than for the children's unaffected siblings.
- 30% of children with ASD between the ages of 7 and 10 are still engaging in elopement behavior.
 - This rate is nearly eight times higher than the children's unaffected siblings.

¹IAN Research Report: Elopement and Wandering. (2011, April 20). Interactive Autism Network. Retrieved July 14, 2014, from http://www.iancommunity.org/cs/ian_research

- 35% of families with children who elope report their children are “never” or “rarely” able to communicate their name, address, or phone number.
- Nearly half of the children who attempted to elope actually succeeded and were missing long enough to cause parents significant concern about their safety.
- The situations were serious enough that 32% of parents in this situation called the police.
- Two out of three parents reported their wandering child had a “close call” with traffic injury.
- Almost a third of parents reported a “close call” with drowning.


This behavior presents unique safety risks. Dangers associated with elopement include:

- Drowning
- Getting struck by a vehicle
- Falling from a high place
- Dehydration
- Hypothermia
- Abduction
- Victimization
- Assault

Drowning, prolonged exposure, and other wandering-related factors remain among the top causes of death for individuals with autism.

Effects of Elopement on Families

While parents experience many joys raising their children with autism, they may also face behaviors that are understandably stressful, such as self-injury, rigidity, aggression and meltdowns. When parents of children who elope compared the stress involved with elopement with other challenging behaviors:



More than half (57%) of parents reported that elopement was the most, or among the most, stressful of ASD-related behaviors.

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- Fear that a child would escape their home during the night disrupted sleep for more than 40% of these families.
- Fear of elopement kept 62% of families from attending or enjoying activities outside the home, increasing social isolation.
- In 2009, 2010, and 2011, accidental drowning accounted for 91% total U.S. deaths reported in children with an ASD ages 14 and younger subsequent to wandering/elopement.

Issues that parents/caregivers face:

- Living under great stress
- Lowered quality of life
- Difficulty leaving home
- Sleep deprivation
- Fear of accusations of neglect
- Lack of support, understanding, and resources



If you or a loved one are facing these challenges, call Autism New Jersey's helpline at 800.4.AUTISM for information and referrals for providers and support groups.

Despite the difficulties families have faced, 51% reported they had never received any advice or guidance about their child's elopement behavior from a professional. Only 14% reported receiving such advice from a pediatrician or other physician and only 19% receiving such advice from a mental health professional.

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Safety Planning & Identification Products



AWAARE Big Red Safety Tool Kit

The National Autism Association has created the AWAARE (Autism and Wandering Awareness Alerts Response Education) Big Red Safety Tool Kit to help caregivers implement elopement prevention strategies at home. This toolkit includes a Caregiver Checklist, a Family Wandering Emergency Plan, an Autism Elopement Alert Form for first responders, a swimming lessons tool, root-cause scenarios and strategies to help determine why the individual is eloping, social stories, a caregiver log to record the individual's elopement history, a sample wandering prevention IEP letter, tracking technology information, a general awareness letter to get a first-responder facilitated tracking program in the community, a

list of five affordable safety tools, and a list of resources.

This toolkit also comes with two door/window alarms with batteries, one RoadID Personalized, Engraved Shoe ID Tag, five laminated adhesive stop sign visual prompts for doors and windows, two safety alert window clings for car or home windows, and one Red Safety Alert Wristband.

Cost: \$35.00

<http://nationalautismassociation.org/docs/BigRedSafetyToolkit.pdf>



FBI Child ID App

This is a free mobile application created by the FBI that provides a convenient, immediately accessible place to store photos and vital information about a child. Caregivers can show the pictures and provide physical identifiers such as height and weight to security or police officers on the spot. A special tab on the app enables users to quickly e-mail the information to authorities.

The app also includes tips on keeping children safe as well as specific guidance on what to do in those first few crucial hours in the event that a child goes missing.

Download the iPhone app from the App Store on iTunes or the Android app from the apps section on Google Play.

This website offers products that enable parents to keep their child's personal information on hand and organized in case of an emergency. The products include a ChildPrint ID Kit, ChildPrint ID Cards, and ToothPrints. It also offers safety tips that enable parents to teach their child empowering strategies to stay safe.

The ChildPrint ID Kit stores fingerprints, photo, medical records, dental records, and DNA. The ChildPrint ID Cards enable parents to keep their child's personal information with them at all times. ToothPrints is a wafer used to record dental characteristics and capture saliva, a powerful source of human scent, making it effective for scent-dog tracking. The saliva also provides a DNA sample.



MedicAlert Foundation

The MedicAlert Foundation offers medical IDs and jewelry supported by a live 24/7 support network. Emergency responders and medical professionals are trained to recognize MedicAlert IDs and call the Emergency Response Center, which grants them immediate access to the MedicAlert member's health information. MedicAlert's Emergency Response Center is staffed by medically trained personnel who then: communicate vital medical information to emergency responders/medical personnel, transmit medical records to the responding hospital to ensure proper treatment, provide translation services in over 140 languages, contact caregivers to relay the

individual's whereabouts and make certain the individual is reunited with loved ones.

<http://www.medicalert.org/>

1.888.633.4298

6am-5pm Monday-Friday

8am-5pm Saturdays

All times Pacific



Safely Back Home

Safely Back Home custom imprints the individual's clothing with emergency contact information and can easily be seen so that an individual who wanders and appears lost can quickly reunite with family or caregivers.

Safely Back Home custom imprints either new or used personal clothing. They partner with the response and recovery program Project Lifesaver to print the Project Lifesaver emergency 24-hour phone number, and Project Lifesaver ID# onto the sleeve of the garment. Upon receiving a call, Project Lifesaver coordinates rescue efforts.

www.safelybackhome.org



Service Dogs

A service dog can also help keep individuals safe. Often, the dog is tethered to the individual while the caregiver holds a leash, or the individual will hold an additional leash. Service dogs are trained to stop or block a person's movement, or they may be trained to alert parents and caregivers to elopement and participate in search and rescue.

While service dogs can increase an individual's ability to participate in public

settings, they require ongoing care and expense, as well as a commitment to train the dog to respond to new or changing behavior.

Resources for service dogs include:

<http://autismservicedogsofamerica.com>

<http://4pawsforability.org>

<http://blessingsunleashed.org>

Tracking Devices



Project Lifesaver

Citizens enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle that emits an individualized tracking signal using radio frequency. If an enrolled client goes missing, the caregiver notifies their local Project Lifesaver agency, and a trained emergency team responds to the area. Most who wander are found within a few miles from home, and search times have been reduced from hours and days to minutes. Recovery times for Project Lifesaver International clients average 30 minutes—95% less time than standard operations.

Traditional Enrollment: Cost varies by county.

Funding:

Most agencies joining Project Lifesaver have appealed to the community, i.e., civic, fraternal and service clubs for funding. Many businesses and hospitals have assisted agencies as well. Occasionally, there are grant opportunities available from Project Lifesaver. Write or call for information about whether a grant is currently available.

Contact Chief Tommy Carter at tcarter@projectlifesaver.org, or call 1.877.580.LIFE (5433).

Who has access?

All 21 counties in New Jersey are covered by Project Lifesaver. It is available for people with autism, Alzheimer's and other disabilities.

Sheriffs, police, fire, search and rescue, assisted living facilities, and nursing homes can join Project Lifesaver and then offer the program to those who need it.


The general public can become involved with Project Lifesaver by signing up through the website. Searches, member agency locations, and announcements are available.

Benefits:

- Available in every county in New Jersey and provides a trained emergency team for search
- Uses radio frequency technology which works in densely wooded areas, buildings or shallow water
- Transmitter does not need to be removed for bathing or swimming

Limitations:

- Price may vary depending on county
- Highest monthly fee is \$25 per month
- Radio technology does not offer Geofencing perimeter notifications
- Requires battery change every 30 to 60 days



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PAL (Protection and Locator)

Project Lifesaver's PAL tracking system is both a tracking device and a water resistant digital sports watch. PAL is worn on the wrist just like a normal wrist watch. Along with the digital watch/transmitter, PAL has a portable receiver which notifies the caregiver of a wandering event through the use of GSM and GPS technologies. If an at-risk individual wearing a PAL watch/transmitter breaches the PAL Perimeter, the PAL portable receiver will sound an audible alert and the LCD display will flash red to indicate that the individual has wandered from the established perimeter, such as home or school. PAL will generate an email alert and send an SMS (text message) with the date and location of the wandering event. For the caregiver's convenience, PAL also has an internet portal available that is accessible worldwide from any PC or smart phone and allows for real time tracking with regular location updates. Additionally, the PAL transmitter/digital watch has a locking feature on the band which can only be removed by using a tool provided with the PAL system.

If the caregiver presses the "find" button on the portable receiver, the PAL watch will determine the location of the individual and the address will be displayed on the portable receiver. If the at risk individual wearing the PAL watch/transmitter is lost and chooses to push the panic button on PAL watch, the address will be shown on the portable receiver. Both of these events will also update the internet portal and alert emails and/or SMS text message will be sent to the caregiver.

For those in a Project Lifesaver area, the device is free with a two-year contract. The cost of a one-year contract is \$99.99.

Funding:

PAL is covered by Medicaid but not Medicare. PAL can be covered by private insurance depending on the plan.

Who has access?

Anyone, whether they live in a Project Lifesaver covered area or not.

Benefits:

- Users set up geofencing and receive alerts as soon as the individual leaves the designated perimeter
- Covered by Medicaid and possibly by private insurance
- Available in areas not covered by Project Lifesaver
- Transmitter has a panic button the individual can press which will alert the caregiver and provide the individual's location
- Uses GPS technology which can provide precise, outdoor positioning information at any time of day

Limitations:

- May be expensive
- Barriers between device and satellite such as thick foliage/artificial obstructions such as buildings or dense communities can hinder satellite signals for GPS technology



SafetyNet by LoJack

Once caregivers enroll their loved ones in the service, they receive a SafetyNet Bracelet, which is typically worn on the wrist or ankle. To assist in search and rescue, information about the individual is entered into a secure database. The LoJack® SafetyNet provides 24/7 emergency caregiver support. For participating public safety agencies receive search and rescue receivers, certified training and ongoing support at no cost.

Funding:

Currently not covered by Medicaid or insurance.

Who has access?

Anyone in an area covered by SafetyNet.

Benefits:

- The waterproof transmitter uses radio frequency technology which works in densely wooded areas, a building or shallow water.

Limitations:

- In New Jersey, currently only available in Essex County



Care Trak

Care Trak System is a tracking device with a transmitter worn by the person at risk that is detected by a handheld directional antenna. When the antenna is plugged into the receiver, the radio tracking signal comes in stronger and louder as it gets closer to the person wearing the transmitter.

Care Trak System is telemetry based. Telemetry is radio waves; much like a local broadcast radio station sends a signal to a car or clock radio. Since the radio signal goes through most walls, it is possible to locate an individual in a building. The telemetry signal goes through most objects for pinpoint accuracy. Lost individuals can be located up to a mile, day or night, inside or outside.

The cost of Care Trak is \$3.29 per month or \$39.48 per year for a simple battery and attaching band change 6 times per year. It does not require satellites, subscriptions, software, or additional costs.

<http://www.caretrak.com/>

Funding:

Not covered by Medicaid or Medicare. It may be covered by private insurance depending on the plan.

Who has access?

Available to individuals with diagnosed dementia and special needs.

Benefits:


- Inexpensive, able to track loved one indoors

Limitations:

- Not effective if the individual is farther than a mile away

Assessment and Intervention

Applied Behavior Analysis (ABA)




Autism New Jersey can assist parents during this process and provide a referral list of ABA providers. Call 800.4.AUTISM for more information.

Applied Behavior Analysis (ABA) offers evidence-based assessment and intervention methods to understand why the individual might be eloping and develop family-friendly and effective interventions.

- Parents can explore private or public funding sources for an in-home program to address elopement.
- If elopement is an issue at school, parents can formally request that the school addresses the behavior. Parents can work with the child study team to develop a comprehensive written plan to address the elopement. This plan should include a Functional Behavior Assessment and Behavior Intervention Plan. The Functional Behavior Assessment can help to answer why the elopement occurs and the Behavior Intervention Plan can teach replacement skills instead of eloping.

A list of research studies on the assessment and treatment of elopement is available through the Association of Professional Behavior Analysts at www.apbahome.net.

Autism New Jersey can assist parents during this process and provide a referral list of ABA providers. Call 800.4.AUTISM for more information.



Caregivers of those at risk of wandering should discuss this diagnosis code with their physician.

Medical Diagnosis Code

In October 2011, the Centers for Disease Control and Prevention (CDC) approved a medical diagnosis code for elopement. The code is listed as V40.31 – Wandering in Diseases Classified Elsewhere.

Caregivers of those at risk of wandering should discuss this diagnosis code with their physician. Official diagnosis may assist with insurance coverage for safety equipment and strengthen requests for implementation of safety-related strategies and accommodations in a student's IEP.

- V40.31 will be replaced by an equivalent code (or codes) when the United States transitions from the ICD-9-CM coding system to an updated version, ICD-10-CM on October 1, 2015.

Elopement Emergency Checklist

Elopement can happen in an instant; planning ahead of time will help you respond quickly in case of an emergency.

If an individual is at-risk:

- Have an up-to-date photo and medical information on hand to share with emergency personnel.
- Have the person wear a tracking device or identification.
- Ask neighbors to call you if they see your family member alone. Have a list of friends and family to call to assist with search efforts.
- Many people with autism are drawn to bodies of water. Keep a list of dangerous areas in your neighborhood, such as retention ponds, high-traffic areas, or any areas where the individual may have wandered before.
- Develop a response plan in the event that a child or adult elopes from school grounds or other setting. Ensure that all administrative personnel know that the individual engages in elopement and have a copy of the plan.

If an individual is missing:

- Remain calm, but begin search and rescue immediately.
- Call 911 and report that a child or a vulnerable adult with autism is missing. Contact any agency that the individual is registered with, such as Medic Alert or Project Lifesaver.

- Search around areas where the individual has wandered before, as well as nearby bodies of water.
- Use social networks to post information about the missing individual and the elopement. National Autism Association has an *Autism & Safety: Wandering Prevention* Facebook page and Twitter account. These social networks are used to post ASD missing-persons alerts for wider distribution.



Autism New Jersey is available to assist you with additional questions or concerns about elopement and other issues. Information is available at www.autismnj.org or by contacting Autism New Jersey's helpline at 800.4.AUTISM or information@autismnj.org.



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