# When They Wander or Run Away





1

# **Elopement and Wandering**



2

# What is Elopement?

Elopement is when a person leaves (bolts from an area) without permission or notification which usually leads to placing that individual in a potentially dangerous situation.



3

### **Elopement and Wandering**

- 26.7% of all children with I/DD elope
- 49% of children with ASD elope
- 1/3 (more than) cannot communicate their name, address or phone



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### Why Do They Elope?

- Lacking the communication skills to express a need
- To get something or somewhere preferred
- To escape somewhere or something
  - An over-stimulating environment



5

### Teach Your Child to Swim

**71%** of deaths related to wandering caused by drowning

- Swim
- Float
- Doggy paddle
- Water safety







7

#### Call 9-1-1 IMMEDIATELY

- Be truthful about the amount of time your child has been missing
- Tell them your child has autism





8

#### **Information Recall**

- Keep current picture on hand
- Fill out First Responder Form BEFORE a crisis
- Make multiple copies



9



10

### **Practice Safety**

- · Practice crossing streets
  - · During calm times
  - · Use visual cues
  - Less conspicuous blue tooth option





11

# Fleeing School Inform ALL teachers Create IEP goal to address elopement Field trips Attend with your child Have person assigned to stay with the child ICD-9-CM Diagnostic Code for Wandering

# Visit Local Police and Fire Precincts

- Introduce your child to the "safe" people they can go to for help
- Make first responders aware your child has autism
- · Help avoid misunderstandings with police





13

# **Identification Tools**

- State ID
- Autism/IDD Disclosure Card
- Labels in/on clothing
- Shoe tags
- Medic Alert bracelets
- Temporary tattoos
- Sharpie





14



15

# Technology

- No product can replace safety preparation measures
- · Personal GPS
  - Road ID
  - Angel Sense
  - My Buddy Tag
  - Care Trak
  - Jiobit
- Project Lifesaver





16

# **Home Modifications**

- Fence
- Door alarms
- Key bolts
- · Bolts at top of door
- Window bars
- · Reverse door handles
- Assess risk, i.e., house fire



17

# **Social Stories**

- Written or visual guide describing various social interactions, situations, behaviors, skills or concepts
- May respond best if the child is main character









19

# Safety Resources

#### www.pathfindersforautism.org/resources/safety

- PFA Tips articles:
  - –When They Wander or Run Away
  - -PFA Tips: Wandering and Elopement at School
  - -How to Interact with Police
  - -What to Prepare for Firefighters and EMS
  - -Make Swimming Fun and Safe
  - -PFA Tips: Calling 911 in a Crisis
  - -PFA Tips: Tracking Devices



20

# **Safety Resources**

#### www.pathfindersforautism.org/resources/safety

- Wandering & elopement
- Water safety
- Big Red Safety Toolkit First Responder Form
- Friends and Neighbor Alert Letter
- County 9-1-1 flagging systems



# Safety Resources

#### www.pathfindersforautism.org/resources/safety

- First responder training
- Identification tools
- Internet safety
- Tracking devices
- Additional safety resources





22

### FOR MORE INFORMATION





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23

# When They Wander or Run Away

t wasn't that long ago so it's still fresh in my mind. The realization that I could no longer take my kids places alone. The nightmare of being at the grocery store check-out and watching my four-year old son run out the automatic door and straight into the parking lot. Forget the fact that I left my open purse and wallet sitting there on the counter. The true horror was that I was forced to run after him, leaving behind my three-year old daughter. And so the rule became that two adults had to accompany my two kids whenever we left the house. He ran away from the house too, but at least strangers weren't in my home surrounding my daughter. So what do we do if we have a child that elopes?

#### Teach your child water safety

71% of deaths related to wandering are caused by drowning. That's right - 71%. Teach your child to swim, doggy paddle, or float.

#### Call 9-1-1 IMMEDIATELY

The longer you wait, the greater the head start your child has. Be TRUTHFUL to the police regarding how long your child has been missing. It's easy to fall into the trap of saying, "It's only been 15 minutes," when it's really been 45. That time frame changes the rescue team's search perimeter. And tell 9-1-1 your child has autism.

# How quickly can you describe your

Keep a current picture of your child easily accessible so if they elope you can help neighbors and law enforcement identify them on the streets. Before outings, take a picture on your phone to have with you. Pay close attention to what they are wearing each day, which is something you may not notice as much once they no longer need your help picking out clothes and getting dressed. And don't wait for that annual check-up to log their height and weight. You want to be able to quickly provide as many descriptive details as you can, and preferably on ID cards or information sheets you can distribute.

#### Awareness of self and dangers

Our kids may not have real awareness of dangers in their environment. How often have we witnessed our kids run out into a street? Some may also be seeking sensory input, so running or running into objects may help feed that. But our kids aren't watching what's going on around

them when they take off. Practice crossing streets during a non-crisis time. Maybe carry a paper stop sign to hold up, giving them a visual reminder. For older children, try prompting instructions into a less conspicuous Bluetooth.

#### Fleeing school

Inform ALL staff at the school of your child's elopement issues so teachers will be on the lookout if they see them heading towards a door, or to keep a sharp eye on them at recess. Accompany your child on field trips, or make certain that a person is assigned directly to your child for the trip. Just because a teacher knows your child has tendencies to run away doesn't mean that the teacher will keep an eye on them. When my son was in preschool, one of the teachers admitted to me that they lost another child three times during that day's field trip.

49% of children with ASD elope, often from a safe environment

27% of children with I/DD elope

33% of children with ASD cannot communicate their name, address or phone number

71% of deaths related to wandering caused by drowning

#### Take your child to the local police and fire precincts

There are multiple reasons for doing this. First, introduce the first responders to your child and make them aware they have autism. This way if they see them out in



the community and they seem out of place, they will be aware that maybe they have run away. A second reason to introduce your child to local law enforcement, especially if your child is older, is so that if your child is approached by the police, misunderstandings can be avoided. If your child does run away, we want them to know who is safe to approach. Introduce them to the "safe" people they can go to for help. And practice the steps of what to do if your child ever becomes lost. For more tips read "PFA Tips: How to Interact with Police" at https://pathfindersforautism.org/articles/ safety/parent-tips-how-to-interact-withpolice/.

#### Tattoos and tags

We don't think twice about buying ID tags for our dogs, but how many of us consider personal identification for our kids? Whether it's an ID bracelet for the wrist or ankle, a shoelace tag, or a pretty necklace designed for your daughter, this piece of "jewelry" could tell first responders what your child can't. Another option is to go with ink. Safety Tat offers a variety of child ID temporary tattoos, while If I Need Help designs scannable clothing tags and patches.

continued on back



#### When They Wander ... - continued







#### **Super pet**

I will admit, when we got my dog, the intent was to have him trained to be a service dog that could perform search and rescue operations. That didn't happen, but he's a great family pet. Service and therapy dogs can be a true gift. But be prepared for the commitment and the cost as training can run about \$10,000. To find training centers and service dog programs, go to our Provider Directory and choose Category > Therapy and Companion Dogs.

#### Tell me a story

Social stories can be effective ways to describe a situation and the appropriate social or behavioral responses for that situation. Depending on your child, they may respond best to a story that features them as the main character or star, or they may feel less defensive if the story is about a fictional character. Your speech therapist, psychologist, or special educator might also be able to help create a social story specific to your child.

#### Don't fence me in

If your child elopes, you may need to do just that. Be sure to check with your homeowners association or rental office for rules of what's allowed. Are your neighbors considering a fence? If so, maybe you can share the costs of your common sides. Get multiple vendor quotes and explore funding options.

#### **Technology to the rescue**

There are low and high tech gadgets out there to alert us when our children leave, and help track them. For the home, consider door and window alarms or motion sensors. Bells offer a good, lowcost alternative. On the doors, you can use locks that are placed at the top of the door, keeping in mind that at some point your child will grow, or will be able to stand on a stool to reach the lock. Twoway key locks (a key is required on both sides) are another option. But keep the keys out of reach and out of sight - how many of our kids see us do something only once and can then do it themselves? Technology, such as GPS devices, can be an amazing tool, but tracking should be the last step. Always start with preventive measures and preparation. Before making any purchase, do your homework on the product, and consider if your child would remove a device they need to wear.

#### Why do they run?

In addition to devices designed to prevent our kids from eloping, and gadgets to find them when they do, behavior therapy may serve as a more lasting tool. A behavior therapist can work to determine the function of the elopement, whether it's escaping a difficult situation, running to a preferred activity, or seeking something sensory. Once the function is identified, appropriate interventions can be developed.

# The ICD-10-CM code Z91.83 Diagnostic Code for Wandering

Effective October 1, 2011, wandering was added to the diagnostic coding system clinicians use, which is known as the International Classification of Diseases. The wandering code is not linked to a specific diagnosis, nor is it part of the diagnostic codes used for autism or intellectual disabilities. The ICD-10-CM classifies behaviors and risk factors in addition to diseases and syndromes; as such, the wandering code is used in conjunction with other diagnostic and symptom or procedure codes. This code is intended to capture information about individuals, with any condition classified in the ICD, who wander. Wandering should be coded if documented in the medical record by the provider (i.e., physician).

If your child is given this diagnostic code, you may want to share that information with your IEP team. This code is not really a legal aspect of the IEP. However, if you know that your child wanders and the school states they do not see this behavior, having this code will support the perceived risk that they may run away. It also serves a purpose for data collection and should be addressed in your child's Functional Behavior Assessment (FBA) and Behavior Intervention Plan (BIP).

#### **Additional Resources**

"When They Wander or Run Away" recorded webinar <a href="https://pathfindersforautism.org/when-they-wander-webinar/">https://pathfindersforautism.org/when-they-wander-webinar/</a>

PFA Tips: Wandering and Elopement at School <a href="https://pathfindersforautism.org/articles/safety/elope-at-school/">https://pathfindersforautism.org/articles/safety/elope-at-school/</a>

**Identification Tools** 

https://pathfindersforautism.org/resources/safety/identification-tools/

**Tracking Devices** 

https://pathfindersforautism.org/resources/safety/tracking-devices/

PFA Safety Resources <a href="https://pathfindersforautism.org/resources/safety/">https://pathfindersforautism.org/resources/safety/</a>

Pathfinders for Autism Provider Directory <a href="http://pathfindersforautism.org/providers-services/">http://pathfindersforautism.org/providers-services/</a>

Written by Shelly McLaughlin, Director of Safety Programs, Pathfinders for Autism

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# Wandering and Elopement at School

Cafety is the first concern with wandering and elopement behaviors. Safety of the student who is trying to flee an area as well as the safety of the school staff. Often these behaviors aren't addressed early and they become a pattern for a student. Even worse, the natural response to run after the student might be an unintentional reinforcement for this unsafe behavior. The following information should be considered to develop a thoughtful and meaningful plan to curb elopement behaviors. (This is an excerpt - to read the full article visit pathfindersforautism.org/articles/safety/elope-at-school/)

As with all behaviors, especially when they reach a crisis level, and deal with the safety of a student, we often want and need quick answers and responses. Unfortunately, it is hard to put a behavior plan in place when there isn't any data. However, before we discuss the data collection process, there are some natural environmental supports that could be tried while you are collecting data.

#### **Preventative Measures to** Help with Wandering and **Elopement**

#### Establish a safe area with clear **boundaries**

In a classroom this might be the back of the room (if large enough) or a designated area in the hallway (marked with tape or cones to visually show the boundaries). In a larger environment, it might be a space in the auditorium (again clearly marked) or an area near the student's location in the building. Establishing the assigned "safe wandering area" with the student should be done at the beginning of the class or before lunch/recess.

#### Place everyone strategically

If you know a student is prone to elopement, strategically place them away from an accessible door. It is recommended that a teacher, assistant or other adult be positioned near the student as well as the door to redirect the student if he attempts to leave.

#### Include staff throughout the building in the plan

Multiple staff – including those who may

not directly teach the student - need to serve as reinforcements throughout the building. Include them in the wandering and elopement plan and equip them with walkie talkies so they can assist quickly if needed. Staff also need to understand why a student might be "wandering in the hallway" and be aware of the "safe zone areas" designated for the student.

#### The Elopement Plan

#### How a sample plan might read

An elopement plan might include: I. If the student elopes from the classroom, an aid or adult will follow him. 2. The aid/teacher will immediately alert the support team through a call or walkie

- 3. The principal will immediately go to the front doors of the building. Assistant principal will cover the side exit, counselor will cover the recess doors, etc.
- 4. The person following the student will communicate with the support team what is happening (where the student is located, if they are walking, running, crying, etc.).
- 5. The team will communicate when the student is secure and debrief if the plan was effective.
- 6. An additional plan will need to be developed for returning the student to the learning environment after an elopement has occurred.
- 7. As with all behaviors that deal with the safety of a student, the incident should be documented, and parents should be informed immediately.

#### Developing a behavior plan

To develop a meaningful behavior plan,



specific data collection is critical. School teams often collect data through the process of a Functional Behavioral Assessment (FBA) to gain more information about a specific behavior. However, you do not need to wait for an FBA to be conducted to start collecting data, especially for elopement.

#### Collecting the data to establish a baseline

- I. First identify the behavior you are targeting. Example: Elopement.
- 2. Clearly specify what elopement looks like to someone observing the actual behavior. Example: Elopement is defined as: The student leaving his chair and running for the nearest exit to escape the classroom and or the school building. The student runs full speed and is very quick and agile. The student will stop sometimes to look behind him to see if anyone is following but will continue to run until he is far away from an adult.
- 3. Start a data collection sheet to track the student's elopement (as defined above). The most common form of data collection is ABC data chart (antecedent, behavior, consequence). Example of an ABC data collect chart:



#### Eloping at School – continued







Date	Time	Location	Antecedent	Behavior	Consequence	Response
2/26/20 Monday	11:30am	ELA/Mrs. Thompson-24 students	Mrs.Thompson asked Jack to take out his pencil to start the writing assignment.	Jack immediately yelled "no way" and darted toward the door. He got out the door and ran down the hallway toward the office screaming, "I am not writing!"	Aid immediately followed. Support team was called. Principal was waiting for him at the end of the hallway and was able to catch him.	Principal to the student," I see you are upset about something. Let's walk together and catch our breath." Principal and student walk holding hands until student seems calm to talk. Jack brought his work to the office and completed it there.
2/27/20 Tuesday	9:00am	Homeroom/ Mr. Seward-23 students	Mr. Seward greeted Jack good morning and explained the morning activity. Jack saw the coloring paper activity on his desk and was directed to get his crayons.	Jack immediately bolted for the door. He knocked two students along the way. The classroom aid was near the door and was able to stop him. He screamed and cried he didn't want to write.	The aid helped Jack take deep breaths and told him once he did this they could go for a walk. Jack gave 3 breaths. The aid told him they had to hold hands and walk. Jack agreed. They went for a walk and talked about Jack's weekend.	The aid established what Jack wanted to do for his break, Jack said playdough. The aid told him he could use the playdough after he completed his morning paper. She offered to take turns coloring with him. She reminded him of the safety rules.
3/4/2020 Wednesday	2:20pm	Music Class-23 students	Mrs. Garner asked the students to draw a picture of what they see in their head when they heard Row Your Boat.	Jack immediately ran out of the classroom and out the front door of the building. He sat outside on the front stoop and cried.	The support team quickly got to Jack to make sure he was ok. Jack had to sit in the office for the rest of the day.	Jack sat in a chair and sang to himself until it was time to go home.
3/11/2020 Monday	9:00am	Homeroom/ Mr. Seward-23 students	Mr. Seward greeted Jack good morning.	Jack said hello and went to unpack. He heard something in the hallway on his way to his chair and ran into the hallway to find the noise.	The aid brought Jack back to class. She reminded him of the safety rules while they walked back to class.	

- 4. Summarize the data collection period. Example: Data collection for elopement was collected over a 2-week period (2/26/20-3/11/20), 10 school days. Of the 10 school days, Jack eloped (as defined above) 8 times.
- 5. **Discuss the data trends** using a Functional Behavior Assessment tool. **Example**

**Time of Day:** Jack only eloped during times when he was in a general education classroom with more than 20 kids.

**Dates:** Three of the elopements were on Monday mornings.

**Antecedents:** Request to write or draw (5/8 times).

**Behavior:** Elopement from the class 7/8 times. Elopement from the building 1/8 times.

**Consequence:** Sitting in principal office, taking walks, giving him choices, reminder about first/then chart.

**Determine Function of Behavior by asking the main question:** What does Jack gain by eloping from the room or building????

6. Once you have a function for this behavior (in Jack's case to escape written work) the team can start working on preventative strategies to decrease the student's behavior. This is called a BIP (Behavior Intervention Plan).

# Behavior Intervention Plan for Elopement (Example)

#### **Preventative Strategies:**

- Allow Jack to come into homeroom each morning with nothing on his desk.
- Read Jack's social stories on School Safety Rules and Staying in the Classroom Keeps Me Safe.
- Present Jack a choice of tools to practice his letters the iPad or magnetic letter board.
- · Establish what Jack will earn once he

practices his letters for 8 minutes.

- Give Jack alerts when a writing tasks are scheduled.
- Offer Jack choices for ways to complete the writing tasks.

#### **Teaching Strategies:**

- Read social stories each morning and discuss school rules.
- Model appropriate responses of replacement behaviors for elopement.
- Practice using those replacement behaviors every day.
- Reward Jack immediately when a writing task is introduced, and he reacts appropriately.

#### **Consequences:**

- · Remind Jack of the safety school rules.
- Delay of earned break until he returns to class and finishes the work.
- Remind him Mom and Dad will be notified that he eloped.

# Track the data to determine if the interventions are working

Once you have your data and a plan in place it will be important to continue collecting data using your ABC chart or other system. It will also be important to identify the Behavior Plan in your child's IEP or 504 plan.

#### IEP objectives and goals

Establish goals and objectives around each behavior to ensure progress monitoring is happening at school. School teams can easily write a behavior goal in an IEP once they have the baseline data. See the full article at <a href="https://pathfindersforautism.org/articles/safety/elope-at-school/">https://pathfindersforautism.org/articles/safety/elope-at-school/</a> for sample IEP goals. The full article also includes a link to sample social stories.

Written by Lisa Frank, M.Ed. Educational and Behavioral Consultant, The Special Kids Company

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#### **Additional Resources**

Wandering and Elopement at School - full article (includes sample IEP goals) <a href="https://pathfindersforautism.org/articles/safety/elope-at-school/">https://pathfindersforautism.org/articles/safety/elope-at-school/</a>

PFA Safety Resources (includes wandering and elopement tools) <a href="https://pathfindersforautism.org/resources/safety/">https://pathfindersforautism.org/resources/safety/</a>

# PATIPS Make Sw and Safe

# Make Swimming Fun and Safe

Phelps. Others automatically see a hot summer afternoon with happy kids splashing the day away. And for some, pools evoke fear. What if my child falls in? What if my child can't swim and panics? What if my child doesn't understand the dangers associated with water? How do I even get my child interested in getting near a pool? If you have more than one child, you might experience all three of these scenarios. At age six, I'm delighted my daughter is doing flips off the side. For my seven year old, my goal is simply that he doesn't drown. So how do we ensure that our kids will feel comfortable and be safe around the water?

#### Autism and the drowning risk

Let's begin by pointing out that teaching water safety is critical because 71% of the deaths that occur due to wandering and elopement are due to drowning. Make sure your child can swim, doggy paddle, float... anything to sustain life if they fall into water.

#### **Starting out**

We don't want that first experience to be overwhelming, because we know when that happens, "first" can also mean "last". Consider having the first trip to the pool be during a quieter time of day, to allow for "easing" into the experience. For the first few visits, consider explaining the pool and the layout of the pool facility:

- · Take a walking tour
- Discuss where it is deep and where it is shallow
- Point out the lifeguards
- Explain that they should know where the lifeguards are at all times
- Explain that if they need assistance, they can ask a lifeguard

#### Tip toe through the poolips

Think about who takes your child to the pool or beach and whether they are comfortable around the water. If that person feels uneasy, so will your child. You want to model calm. I know - you don't think "calm" is in your vocabulary. Picture that peaceful, beautiful ocean - even if you're at the public neighborhood pool surrounded by screaming, splashing kids.

#### **Safety First**

We want swimming to be a fun experience,

but safety must be the #1 priority. Always know where your child is AT ALL TIMES. A child can go under in the blink of any eye. And what most people don't realize is that children sink - they don't splash around and yell for help. They just quietly sink to the bottom. Do not assume the lifeguard is watching your child. In the time it takes for the lifeguard to be distracted by another swimmer, your child may have already made it to the bottom of the pool. Know when your child is getting tired and suggest moving on to new activities. And consider enrolling in a learn-to-swim program. Even if your child never perfects a single stroke, just focus on skills to keep from drowning.

#### "Look mom - I'm a dolphin!"

Give plenty of time for free swim and water exploration. Allow your child to experiment, but be there for support. You want your child to enjoy the water, and not associate pools as just one more place for instructional lessons. Don't tell them this but all that fun splashing around is also good practice.

# Water water everywhere and not a drop to drink

Stay hydrated! The sun gets hot, and although you are IN water, you may not be getting enough water IN YOU!

#### Slip, slop, slap

Slip on a shirt, slop on sunscreen, and slap on a hat. Ok, I stole this from an Australian health campaign. But it's good advice in any country. Wear sunscreen. Preferably a high SPF that is also waterproof.



We would like to thank the Michael Phelps Swim School for their contributions to this article.

#### **Additional Resources**

PFA Tips: Finding the Right Swim Lesson https://pathfindersforautism.org/articles/recreation/parent-tips-finding-the-right-swim-lesson/

Tips for Teaching Swimming to Students with Autism

http://pathfindersforautism.org/articles/recreation/tips-for-teaching-swimming-to-students-with-autism/

Video: "Swim School" by Real Look Autism <a href="https://www.youtube.com/">https://www.youtube.com/</a> watch?v=qqjlYfG55ic&feature=youtu.be

SOSecure Containment Swim Brief http://www.sosecureproducts.com/

Written by Shelly McLaughlin, Program Director, Pathfinders for Autism

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# Calling 911 in a Crisis

Inder extreme stress and anxiety, our ability to cognitively process is diminished. It can be difficult to recall the most basic of information - your child's height/weight, what they are wearing that day, their triggers and coping mechanisms. It's important to practice what to say when it's time to place that 911 call for help and have helpful documentation filled out and easily accessible prior to a crisis.

#### Call 911 IMMEDIATELY

If your loved one is demonstrating behaviors that could be dangerous for themselves or others, do not wait to call 911.

#### Remain calm

Easier said than done. This is where practicing during a non-crisis time what you might say on a call will be helpful. 911 call takers need to be able to understand your call in order to dispatch the appropriate personnel. Officers will be more able to listen to and assist you if you are calm and in control.

#### Be an advocate

Provide the call taker and responding officers the diagnosis of your loved one. Be prepared to describe your loved one's triggers, coping strategies, passions, and preferred method of communication.

#### Be clear about your needs

Focus on the critical information you need to provide the 911 call taker and the arriving officers. Explain what type of assistance you need in order to help your loved one. Do you only need time? Space? Support?

#### **Identify** threats

If there is a threat (the individual has a weapon, or is threatening to hurt himself or others), please let officers know. The more information officers have when responding, the better they will be equipped to provide an effective/safe outcome.

#### Assign roles to family members

Make sure all family household members from siblings to grandparents have a "mental mindset" of their roles in a crisis. All members of the household should feel comfortable calling 911 and should know what to say and ask for.

#### Calling 911 about a Critical Missing Person

#### Call 911 IMMEDIATELY

If your child or loved one is missing, the longer you wait to call 911, the greater the headstart your child has.

#### **Prepare BEFORE your loved one** goes missing

It is best to fill out a First Responder Form and keep multiple copies on hand as more than one responder may request a copy. https://bit.ly/39mrj2h, Elopement behavior can begin at any age. Just because your child has never eloped before, does not mean your child will not at some point. For more information on preventive strategies for wandering and elopement, please read "PFA Tips: When They Wander or Run Away" at https://bit. ly/2KZK3eU.

#### Be as accurate as possible

Be truthful to the police regarding how long your child has been missing as this changes the search radius.



#### Offer clues if your child has eloped in the past

- Does your child have a favorite or typical place where they go? (Or has expressed a desire to go?)
- What are your child's triggers, fears and passions? Include specific resources used by search teams -K9s, helicopter, police, police cars, etc.
- Will your child respond to their name?
- Do they have any form of identification on them?
- Do they have sensory issues? What about tolerance for lights, sounds, touch?

Written by Officer Laurie Reyes, Special Operations Division, Autism/IDD, Azheimer's/Dementia Outreach Unit for Montgomery County Police, and Shelly McLaughlin, Program Director, Pathfinders for Autism

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# PFATips

# Wandering & Elopement Tracking Devices

When a loved one wanders or elopes, we want to know: What can be used to help find them? Technology, such as GPS devices, can be an amazing tool, but tracking should be the **LAST** step. Always start with preventive measures and preparation. Before making any purchase, do your homework on the product, review a variety of tracking devices and consider if your child would remove a device he needed to wear.

#### Call 9-1-1 IMMEDIATELY

If your child is out of site and out of the house, call 911. The longer you wait, the greater the head start your child has. Be TRUTHFUL to the police regarding how long your child has been missing. It's easy to fall into the trap of saying, "It's only been 15 minutes," when it's really been 45. That time frame changes the rescue team's search perimeter. And tell 911 your child has autism. Have a "script" ready and with you at all times so that important information is relayed immediately and not forgotten under stress. Review "PFA Tips: Calling 911 in a Crisis" at <a href="https://pathfindersforautism.org/">https://pathfindersforautism.org/</a> articles/safety/calling-911-crisis/.

# Implement safety preparation measures

Remember, tracking devices are only ONE tool. Montgomery County Police actually locate missing vulnerable individuals BEFORE the parents and caregivers realize they are missing in most of their critical missing person cases. They stress that identification tools are more critical than tracking devices. For more information on identification tools, visit <a href="https://pathfindersforautism.org/">https://pathfindersforautism.org/</a> resources/safety/identification-tools/. For ideas on additional preventive strategies such as identification tools, door and window alarms or motion sensors. fencing, behavior plans and more, please read, "PFA Tips: When They Wander or Run Away" at https://pathfindersforautism. org/articles/safety/pfa-tips-when-theywander-or-run-away/.

**Investigate Project Lifesaver** 

Project Lifesaver is administered through local police agencies. Citizens enrolled in Project Lifesaver wear a small personal

transmitter around the wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies their local police, and a trained emergency team responds to the wanderer's area. See if Project Lifesaver is available in your area by visiting <a href="https://projectlifesaver.org/about-us/where-we-are/">https://projectlifesaver.org/about-us/where-we-are/</a>. If your local police agency offers Project Lifesaver, discuss with them the potential limitations, such as what happens if your child goes missing while in another county or state.

#### **Investigate personal GPS devices**

As you investigate personal GPS devices, you may want to consider the following questions, if relevant:

- Does the band have a locking mechanism? Can my loved one remove it easily?
- Can I test the product before purchasing it?
- Is it something my local first responders are familiar with?
- Does the accompanying app work with your phone?
- What is the typical battery life?
- Does the service offer Geo-fence capability?
- Does the product allow for real time mapping?
- What is the cost of not only the device, but the monthly service subscription?

To view a sampling of the products available to help locate and identify your loved one, please visit <a href="https://pathfindersforautism.org/resources/safety/tracking-devices/">https://pathfindersforautism.org/resources/safety/tracking-devices/</a>.



# Funding for Personal GPS Devices

# Low Intensity Support Services (LISS)

The Developmental Disabilities Administration's (DDA) Low Intensity Support Services (LISS) provides up to \$2000 to assist eligible children and adults with developmental disabilities with purchasing eligible services and/or items to address their needs. Tracking devices and their related service subscriptions are covered services under LISS. LISS applications are accepted twice a year and awards are issued through a random selection process. For more information visit <a href="https://dda.health.maryland.gov/Pages/liss.aspx">https://dda.health.maryland.gov/Pages/liss.aspx</a>.

#### **Autism Waiver**

Tracking devices are covered expenses under Environmental Accessibility Adaptations. Unfortunately, at the time of this writing, there are no approved tracking device vendors under the Waiver. We will update this section when vendor options become available.

continued on back

#### Tracking Devices ... - continued







#### **DDA Waivers**

Tracking devices are covered expenses as Assistive Technology Services under the DDA Family Supports Waiver, Community Supports Waiver, and Community Pathways Waiver. For more information about Maryland's DDA Waivers, visit <a href="https://dda.health.maryland.gov/Pages/Medicaid\_Waiver\_Programs.aspx">https://dda.health.maryland.gov/Pages/Medicaid\_Waiver\_Programs.aspx</a>.

# **Explore additional funding sources**

Visit the Pathfinders for Autism provider database and choose Category>Grants and Funding Sources <a href="http://pathfindersforautism.org/providers-services/">http://pathfindersforautism.org/providers-services/</a>.

# Investigate reimbursement through health insurance

Each health insurance plan, and services covered, is different for each person. To see if the expense of the device and the associated subscription plan are a covered benefit, you will need the following information and documentation:

- A diagnosis from a licensed doctor for Wandering
- The CPT codes issued to the tracking device vendor

# The ICD-10-CM code Z91.83 Diagnostic Code for Wandering

Effective October 1, 2011, wandering was added to the diagnostic coding system clinicians use, which is known as the International Classification of Diseases. The wandering code is not linked to a specific diagnosis, nor is it part of the diagnostic codes used for autism or intellectual disabilities. The ICD-10-CM

classifies behaviors and risk factors in addition to diseases and syndromes; as such, the wandering code is used in conjunction with other diagnostic and symptom or procedure codes. This code is intended to capture information about individuals, with any condition classified in the ICD, who wander. Wandering should be coded if documented in the medical record by the provider (i.e., physician). To download a Physician Sample Letter (Word document) from the National Autism Association, visit https:// pathfindersforautism.org/articles/safety/ pfa-tips-when-they-wander-or-run-away/ and scroll down to the section The ICD-10-CM code Z91.83 Diagnostic Code for Wandering.

#### **Vendor CPT Codes**

A Current Procedural Terminology (CPT) code is a unique five digit code that identifies to insurance companies what care was provided to the patient by the vendor. Some device vendors list their CPT codes on their websites with additional insurance information. Some will even offer to work with your case worker. If you do not see the codes on their site, contact them and ask what they can provide for insurance purposes.

Once you have documentation of a Wandering diagnosis and the appropriate CPT code(s), ask your insurance company if the device and associated subscription plan are reimbursable expenses. If they say no, you can request an appeal to their review team. Your insurance company will walk you through that process.

#### **Medicaid**

In Maryland, tracking devices are not a covered benefit under Medicaid.

#### **Additional Resources**

Tracking Devices <a href="http://pathfindersforautism.org/resources/safety/tracking-devices/">http://pathfindersforautism.org/resources/safety/tracking-devices/</a>

Visit the Pathfinders for Autism provider database and choose Category>Safety http://pathfindersforautism.org/providers-services/

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# Identification Tools for Caregivers of Those Who Wander and Elope

When a loved one wanders or elopes, we want to know: What can be used to help find him? If someone finds her, how will they know it's my child/loved one? This is a sampling of the products available to help locate and identify your loved one. But keep in mind, **no product can replace safety preparation measures.** For safety strategies, please visit <a href="https://www.pathfindersforautism.org/resources/safety">www.pathfindersforautism.org/resources/safety</a>. Pathfinders for Autism does not endorse any products or services.

#### **Identification Tools**

#### **Maryland State ID**

https://pathfindersforautism.org/articles/maryland-services/parent-tips-navigating-the-mva-for-state-ids-drivers-licenses-and-other-services/

There is no minimum age for a MD State ID. If your young adult or adult child does not have a Driver's License, there are several reasons why your son or daughter needs a State ID: formal identification communicating who you are in case of an accident or emergency; to open a bank account; to board an airplane; some towns and cities require ID; tightened security, so many individual places are requiring ID; most jobs require ID; hospitals.

#### **Safety Tats**

#### http://www.safetytat.com/

Safety Tat is a temporary safety child ID tattoo that's offered either customized with your mobile phone number or blank so you can write in your cell phone number on them. When applied to the arm of your child or loved one, Safety Tat provides a visible form of child identification that stays in place even when wet.

#### If I Need Help

#### https://www.ifineedhelp.org/

Easy free sign up and membership. Personal wearable QR Codes that immediately alert the public that "Here is a person that needs help" & how to help them. Individuals' profiles can be accessed manually from any web browser or via scanned QR Codes. QR Codes can be read quickly by any smartphone. Available as patches, dog tags and shoe tags.

#### Road ID

#### https://www.roadid.com/

Road ID was developed for runners, but the tracking and identification products can meet the same needs for the autism/I/DD community. Identification tools include wristbands, stainless steel dog tags, ankle bands, and shoe tags.

#### MedicAlert Found® - Support Services for Autism

#### https://www.medicalert.org/autism

The MedicAlert Found® program provides an additional layer of protection for the autism community by offering free enrollment, a free medical ID bracelet or necklace, a free medical ID shoe tag and free 24/7 Wandering Support Service.

#### The Maryland Masonic Child Identification Program

https://mdmasons.org/philanthropy/chips/

When a child participates in the program, all vital statistics are recorded. The child is photographed and digital fingerprints are taken. Additionally, the child is photographed and a video recording of the child speaking is made. All of the above information is then recorded onto a CD. A cheek swab of the child's DNA is collected painlessly. Everything is then sealed in an envelope and given to the parent for safekeeping. The Freemasons retain none of the information. This service is provided free of charge by the Freemasons of Maryland.

#### Free Child ID Kit from the Polly Klaas Foundation

https://www.pollyklaas.org/product/50-child-safety-kit-booklets/

The free Fingerprint & DNA document provides all the forms you need, along with all the instructions.

#### Child ID Kit from the National Center for Missing and Exploited Children

https://www.ready.gov/sites/default/files/NCMEC Child ID Kit wc FEMA 508.pdf

Complete this Child ID Kit by attaching a recent photograph of your child and listing all identifying and medical information.

#### **Sharpie**

It may not be stylish, but writing your contact information on your child's arm with a Sharpie may be effective for your needs.



# PLEASE WATCH OUT FOR OUR CHILD WITH AUTISM

We have a child with Autism. Our child's name is
He/she is years old.
We watch our child very carefully, but sometimes he/she unpredictably wanders away.
If you see our child and he/she is alone, please call
We are probably already looking for him/her.
Please also call 911 and tell them that you have found our child.
does not speak very well. Our child does not appreciate danger He/she might approach a dog or walk into the street without looking. He/she might walk in your hous if a door is open.
will become lost very easily and not know he/she is lost. If you ask our child a question he/she will likely not answer.
sometimes has outbursts where he/she may scream or shake. We have included a picture of our child.
Thank you,
Name
Address
Phone

If you would like to know more about autism, please visit <a href="https://www.pathfindersforautism.org">www.pathfindersforautism.org</a>

Thank you Officer Laurie Reyes, Montgomery County Police, for providing this letter.

# AUTISM & WANDERING PREVENTION TIPS

promoting safety in the home & community



Similar to the wandering behaviors in seniors with dementia or Alzheimer's, children and adults with autism spectrum disorder (ASD) are prone to wandering away from a safe environment. Because many children with ASD have challenges in areas of language and cognitive function, it is critical for parents to understand ways to keep their child or adult with autism safe.



#### **Install Home Safeguards**



Install secure locks (exterior doors), door/window chimes; fence yard; secure gates; keep garage opener out of reach; use baby monitors and visual prompts like simple stop signs.

# Secure Personal Safeguards



Have wearable identification on your child; Temporary Tattoos are great for field trips and other outings; Check with local law enforcement to see if they offer Tracking Devices.

#### **Create Community Awareness**



Alert trusted neighbors, and introduce them to your child; fill out an alert form for local police, include a current photo and unique characteristics, likes, fears, and behaviors; alert the school, and hus drivers

#### **Remain Hyper Vigilant**



Stay on extra high alert during warmer months, holidays, vacations, camping trips, transition periods, outdoor gatherings, a recent move to a new home or school, visiting an unfamiliar setting, public outings.

Initiate a "tag, you're it" system during family gatherings and transitions. Tag one responsible adult to closely supervise your child for an agreed-upon period of time.

#### **Identify Triggers/Teach Self-help**



Be aware of any known triggers that could prompt fleeing (loud noises, bright lights, fears, etc.) and work towards teaching your child safe alternative ways to respond.

For an individual who demonstrates bolting behaviors due to fear or stress, etc., use aids, such as noise-cancelling headphones, and teach calming techniques using favorites topics or items.

#### **Teach Safety Skills**



Enroll your child into swimming lessons. Final lessons should be with clothes and shoes on.

Use social stories to teach individuals with autism ways to stay safe, and use favorite objects or tools to demonstrate when it's outside time versus inside time.

#### **Call 911**



Remain calm and always call 911 immediately if an individual with ASD is missing; law enforcement should treat each case as "critical."

Law enforcement agencies are encouraged to contact the National Center for Missing & Exploited Children at 1-800-THE-LOST (1-800-843-5678) for additional assistance.

#### **Search Water First**



Immediately search areas that pose the highest threat first, such as nearby water, busy streets, train tracks, and parked cars.





### **AUTISM ELOPEMENT ALERT FORM**

PERSON-SPECIFIC INFORMATION for FIRST RESPONDERS

Individual's Name		(M.I.) (Last)		
Address:(Street)		(City)	(State) (Zip)	Attach current   photo here  -
Date of Birth	Age_	Preferred Na	me	
Does the Individual live	alone?	_		<u></u>
Individual's Physical De	scription:			
MaleFemale	Height:	Weight:	Eye color:	Hair color:
Scars or other identifyin	g marks:			
Other Relevant Medical	Conditions in additio	on to Autism (checkall tha	t apply):	
No Sense of Danger	BlindDe	eafNon-Verbal	Intellectual D	isability
Attracted to Water _	Prone to Seizures	Cognitive Impa	irmentOther	
If Other, Please explain:				
Prescription Medication	s needed:			
Sensory or dietary issue	s, if any:			
Calming methods, and a	any additional inform	ation First Responder	s may need:	
EMERGENCY CONTACT Name of Emergency Con		lians, Head of Househ	old/Residence, or Ca	re Providers):
Emergency Contact's Ac	ddress:(Street)		(City)	(State) (Zip)
Emergency Contact's Ph			(5.9)	faceral (Elb)
Home:			Cell Phone:	
Name of Alternative Em				
Home:			Cell Phone:	

INFORMATION SPECIFIC TO THE INDIVIDUAL
Nearby water sources & favorite attractions or locations where the individual may be found:
Atypical behaviors or characteristics of the Individual that may attract the attention of Responders:
Individual's favorite toys, objects, music, discussion topics, likes, or dislikes:
Method of Preferred Communication. (If nonverbal: Sign language, picture boards, written words, etc.):
Method of Preferred Communication II. (If verbal: preferred words, sounds, songs, phrases they may respond to):
Identification Information. ( i.e. Does the individual carry or wear jewelry, tags, ID card, medical alert bracelets etc.?):
Tracking Information. (Does the individual have a Project Lifesaver or LoJack SafetyNet Transmitter Number?):

- MANY CHILDREN WITH AUTISM ARE DRAWN TO WATER. SEARCH & SECURE NEARBY WATER SOURCES FIRST.
- REVERSE 911 IS AN EFFECTIVE TOOL FOR FINDING A MISSING CHILD AND FREE TO AGENCIES. VISIT achildismissing.org.



#### **CAREGIVER CHECKLIST TOOL:**

#### \_\_I HAVE SECURED MY HOME

- Installed secure locks.
- Installed a home security alarm system or inexpensive battery-operated alarms on doors and windows (available at stores like Walmart and Radio Shack).
- Placed hook and eye locks on all doors, above child's reach.
- Fenced yard.
- Adhered printable STOP SIGNS to doors, windows and other exits, such as gates.

#### \_\_\_I HAVE TAUGHT, OR AM TEACHING, MY CHILD/ADULT ABOUT WANDERING DANGERS

- If the child/adult has functional language, use this as a way to teach them about the dangers of wandering into traffic and water especially, as well as encounters with strangers. Use various methods to teach them how to respond if they find themselves alone or lost outside, in a non-home setting (school, classroom, hotel, etc) or any setting.
- Use the types of language/lingo they like and would respond to. Use favorite characters, topics, props and visual prompts in your explanation if necessary.
- If your child/adult has limited language, use social stories to teach your child/adult about the dangers of wandering into traffic and water especially, as well as encounters with strangers.

#### I HAVE ENROLLED MY CHILD/ADULT IN SWIMMING LESSONS

- Teaching your child how to swim DOES NOT mean your child is safe in water.
- If you own a pool, fence your pool. Use gates that self-close and self-latch higher than your children's reach.

  Remove all toys or items of interest from the pool when not in use.
- Neighbors with pools should be made aware of these safety precautions and your child's tendency to wander.
- To find swimming lessons in your area, visit NationalAutism.org, click Autism & Safety, choose "Swimming Instructions." The final lesson should be with clothes on.

#### I HAVE LOOKED INTO TRACKING DEVICES/PERSONAL LOCATOR TECHNOLOGY:

Visit ProjectLifesaver.org or LoJackSafetyNet.com

#### I HAVE ALERTED MY TRUSTED NEIGHBORS

- Give your neighbor a simple handout with your name, address, and phone number.
- Ask them to call you immediately if they see your child outside the home.
- Does your child have a fear of cars and animals or is he/she drawn to them?
- Does your child gravitate towards pools or nearby ponds or creeks?
- Does he/she respond to their name, have sensory issues, or meltdown triggers?
- Approach neighbors you trust. Beforehand, check your neighborhood for nearby sex offenders by visiting familywatchdog.us

#### I HAVE ALERTED MY LOCAL FIRST RESPONDERS

 Provide name of child or adult, current photograph and physical description including any scars or other identifying marks or behaviors

THIS AUTISM SAFETY INITIATIVE IS BROUGHT TO YOU BY THE NATIONAL AUTISM ASSOCIATION | nationalautism.org

- Identify your child's favorite song, toy or character
- Provide names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Provide sensory, medical, or dietary issues and requirements
- List favorite attractions and locations where the person may be found
- Provide likes, dislikes, fears, triggers, and de- escalation techniques
- Provide your child's preferred method of communication (note if nonverbal, uses sign language, picture boards, or written words)
- List if they wear an ID, jewelry, tags on clothes
- Provide map and address guide to nearby properties with water sources and dangerous locations highlighted –
   instruct to search these areas first

# \_\_\_I HAVE OBTAINED A WEARABLE ID FOR MY CHILD THAT CONTAINS ALL OF MY CONTACT INFORMATION

#### \_ I WILL INITIATE A "TAG, YOU'RE IT" SYSTEM DURING FAMILY GATHERINGS, COMMOTION, TRANSITIONS

- Recognize that many incidents occur during a family gathering, school function or transition
- Initiate a "tag" strategy a well-coordinated system that TAGS the adult who is to closely supervise the individual. Explain the tag system to those who may be responsible for watching your child/adult and make sure they understand the expectations and their responsibilities.
- During walks, hiking, or any other outdoor activities, use the "Bookends" approach one adult on each side of the child.

# \_\_ I WILL MONITOR ANY CHANGES IN MY HOME'S SECURITY, ESPECIALLY WHEN WARMER WEATHER OR SEASONAL TRANSITIONS AFFECT MY HOME'S LAYOUT

- According the National Autism Association, autism missing-person cases tend to increase in the late winter/early spring months especially in mid sections of the country.
- I WILL BE ON HIGH ALERT DURING SUMMER HOLIDAYS, SUCH AS MEMORIAL DAY, LABOR DAY, 4<sup>TH</sup> OF JULY, AND DURING VISITS TO FRIENDS/FAMILY'S HOMES, PUBLIC PLACES, PARKS, AND OTHER NON-HOME SETTINGS

#### I HAVE ADDRESSED WANDERING AT SCHOOL, SUMMER CAMP, AND OTHER EXTERNAL SETTINGS

- If you haven't done so previously, ask "What are the school's policies on wandering prevention?"
- Write a letter requesting that you always be informed, in writing, of any wandering incident on or off the campus.
- If your child/adult is an active wanderer and poses safety risks, consider addressing wandering issues in his/her IEP or personal care plan.
- Take note of all architectural barriers (fences, etc.) around the school, day care or summer camp, or lack thereof. Make the facility aware of any lack of barriers and ask for barriers to be put in place.

_I CONTINUE TO REASSESS AS MY CHILD/ADULT GROWS AND/OR LEARNS NEW WAYS TO POSSIBLY
EXIT

I CONTINUE TO DOCUMENT ACTIONS TAKEN TO PROTECT MY LOVED ONE

CREATE YOUR FAMILY WANDERING EMERGENCY PLAN (FWEP) BY DOWNLOADING A FREE TEMPLATE AVAILABLE AT AWAARE.ORG