



# **Considering Locative Technology in the Disability Community:** *Balancing Autonomy and Safety*

Locative technology is used to determine the location of a person or item. Some of the common technologies used are known as tracking devices, wearable technology, Radio Frequency Identification (RFID), or Global Positioning Systems (GPS) technology. Because some children and adults may be prone to wander or go missing, locative technology can be placed on a person, on their clothing, or integrated with their wireless device as one method to help locate them.

Wandering refers to when a person leaves their known location and could potentially end up in a dangerous situation. Wandering is common in individuals with intellectual or developmental disabilities or those experiencing the loss of cognitive skills and abilities (including but not limited to those with autism spectrum disorder (ASD), Alzheimer's, and dementia). The term bolting is sometimes used when a person with disabilities engages in a sudden instinctive flight from or to a location. This behavior can be an involuntary reaction to a trigger related to the disability.

This resource provides considerations for balancing an individual's autonomy with their safety, discusses alternatives that can be used in place of or in addition to locative technology, and outlines some of the advantages and disadvantages of using locative technology. This resource is not intended as an endorsement of any one specific locative technology or alternative.



# **Key Considerations**

Locative technology can create opportunities, when appropriate, to enhance the safety of individuals with intellectual or developmental disabilities, and conditions where a loss of intellectual capacity has occurred. However, technology used to pinpoint an individual's location raises privacy and autonomy issues. One's autonomy, the ability to provide informed consent, and the protection of personal data are considerations that must be kept in mind.

The decision to use locative technology is a matter of personal choice that, as much as possible, must be reached by the individual who would be wearing the device. When possible, the individual should seek guidance from others they trust to help them make a decision while thinking through all the considerations. Whether an individual is an adult or a minor, it is important that they are included in the discussion and decision-making process to the extent that is developmentally appropriate. In the instance of children, the parent or guardian makes this decision, but children and youth can also be brought into the decision-making process where possible to provide input on what may work best for them. For example, a parent or guardian could ask what type of technology may work best for them.

There are alternative methods to locative technology that may be highly effective in preventing a missing incident and helping find a missing child or adult. These methods may be less expensive and easier to implement. Approaches include outreach, education, and training for law enforcement and community stakeholders to better inform them on how to search for children and adults who have gone missing. According to feedback from the disability community, law enforcement, and search and rescue experts at the National Center for Missing & Exploited Children (NCMEC), the use of locative technology should always be considered as only one tool in your toolbox to help mitigate negative outcomes.

#### **ALTERNATIVES**

Recommended alternative options in addition to, or instead of, locative technology include:

- Identifying the reasons that may trigger the individual to bolt, wander, or go missing, and implementing a proactive plan to address the causes.
- Wearing or carrying a form of identification by the individual and educating them on how to safely show it to law enforcement to prevent any misunderstanding that could result in injury or death.
- Identifying risks for the individual and helping trusted neighbors, relatives, teachers, law enforcement, and others understand the individual's behaviors and characteristics so they know what to do if the individual goes missing to ensure their safe return home. One example from NCMEC is a <u>Letter to</u> <u>Neighbors</u>.
- Contacting your local law enforcement agency to ask about safety programs for individuals with intellectual or developmental disabilities or those experiencing the loss of cognitive skills and abilities. The impact of such programs on privacy and autonomy should be carefully considered.
- Using velvet ropes, change in carpet color, or stop signs by entrances to discourage exiting.
- Installing window and door alarms to alert when exits are opened.
- Installing security, motion, or video systems; keeping them in working order; and ensuring caregivers know how to use them.
- Preparing safety kits, such as the Big Red Safety Box from the National Autism Association, or similar resources from other organizations that support populations who go missing.

# **Considerations to be Explored with Individuals and Families**

The following questions will help guide individuals and families who are considering using locative technology:

- What are the quality, reliability, and stability of the product and its vendor?
- What are the costs?
- Does the person want to wear a visible device (does it create embarrassment or is it stigmatizing)?
- Does the person have sensory challenges that make it physically uncomfortable or painful to wear the device?
- Is it easy to set up and use?
- How easy is it to remove?
- Is the product water-resistant and will it transmit a signal if submerged under water? This is particularly important with children with ASD as they are drawn to bodies of water at higher rates than children without ASD.

- How long does it work before needing new batteries or being recharged?
- Does the system involve a response from trained emergency personnel?
- Have the company or individuals offering the device had training on understanding the needs of the disability community, and do they include people with disabilities as expert consultants or advisors?
- Can the use of the device be limited to a particular activity, or can a less restrictive device be used, such as a walkie-talkie or temporary cell phone?

It is critical to seek reviews and speak with both users and experts as part of thorough research before deciding whether to use locative technology and which device may be most appropriate.

## **ADVANTAGES of Locative Technology**



**Increased safety and timely information:** The ability to pinpoint location can increase the likelihood of finding a person quickly before serious injury or death occurs.



Increased awareness and attentiveness: A device seen as medically necessary may enhance education and attentiveness in others who do not fully understand the seriousness of this issue.



**Increased independence**: Locative technology devices may reduce the need for continuous supervision of older teens and adults in some cases, allowing for greater autonomy and decreasing potential conflicts between caregivers and individuals.



Improved ease of use and multiple device options: As technology improves, devices have become smaller and more lightweight, making them easier to carry or attach to clothing and less visible. Devices have also become easier to charge, and the options for different types of technology have increased, offering more choices for people in both rural and densely populated areas.

# **DISADVANTAGES of Locative Technology**



Loss or reduction of autonomy: The importance of self-determination and "dignity of risk" can be compromised by using locative technology. Adults with disabilities have rights to self-determination, which means having the opportunity and support to make choices and decisions about important aspects of their lives. "Dignity of risk" refers to allowing a person with disabilities the dignity to take reasonable risks without putting overprotective safeguards in place that can damage or restrict the person's life.1 Respecting autonomy and self-determination must be balanced with safety concerns when considering locative technology. The least restrictive options should be considered first, with locative technology being a last resort.



Lack of uniform national standards, procedures, and training mandates: The lack of technical and ethical requirements in the development and use of these technologies raises questions about the privacy of information, compliance with privacy laws, and potential for misuse of information. No standard currently exists regarding the effectiveness of the devices in reducing risks associated with wandering. Locative devices should not be exclusively relied upon to increase safety and should always be used alongside other best practices for safety.



Legal concerns: Legal concerns apply to privacy rights, informed consent, and the use or misuse of personal data. The use of supported decision-making and personcentered planning can help, but in the absence of standards or procedures, decision-makers lack guidance in their attempts to determine a person's consent to using a tracking device.



**Cost**: The purchase of the technology or monthly service fees can limit access for some individuals and families. Local law enforcement agencies may be able to assist with the equipment and services, and manufacturers may offer discounts. Be sure to identify and weigh all initial costs for equipment as well as ongoing costs.



False sense of security: When an individual is wearing a locative technology device, it could create a false sense of security for the person or the caregiver about the wearer's physical safety. When an individual is wearing a locative technology device, caregivers may assume that less support and supervision are needed, even in situations where this is not the case. Attentiveness and additional measures remain essential for individuals who frequently go missing,



**Quality and maintenance**: No type of equipment works perfectly all the time. There is always the potential for inaccuracy, weak signals depending on location, geography, or weather, low or short battery life, and the issues with the reliability of the company providing the technology. Devices should be waterproof, tamper-resistant, and be kept charged or have batteries replaced regularly.

To learn more about self-determination, see The Arc's position statement: <a href="https://thearc.org/position-statements/self-determination/">https://thearc.org/position-statements/self-determination/</a>

### Where can you go for more information?

#### **Autism Society**

The Autism Society, including a nationwide network of affiliates, connects people to the resources they need through education, advocacy, support, information and referral, and community programming.

#### **Autistic Self Advocacy Network (ASAN)**

ASAN created the <u>Autism & Safety Toolkit</u>, written by people with autism, that includes information about getting lost or wandering. The toolkit provides safety tips for both people with autism and their family members.

#### **Alzheimer's Association**

The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

#### **National Autism Association**

NAA has extensive resources available to prevent autism-related wandering incidents and deaths. These resources include the <u>Big Red Safety Box</u>, Be REDy Toolkits for <u>Caregivers</u>, <u>First Responders</u>, and <u>Teachers</u> as well as the downloadable <u>Tracking & Locator Technology</u> resource.

#### **Centers for Disease Control and Prevention (CDC)**

CDC provides information and resources on wandering on their website and has served on the Interagency Autism Coordinating Committee (IACC)'s Safety Subcommittee, assisted in data collection on wandering, and worked with partners to raise awareness of wandering as a safety issue.

#### **National Center for Missing & Exploited Children**

The National Center for Missing & Exploited Children (NCMEC) is a private, non-profit 501(c) (3) corporation whose mission is to help find missing children, reduce child sexual exploitation, and prevent child victimization. NCMEC works with families, victims, private industry, law enforcement, and the public to assist with preventing child abductions, recovering missing children, and NCMEC provides many relevant resources on their website.

#### **Pathfinders for Autism Resource Center**

The center works to support and improve the lives of individuals affected by autism through expansive, customized programming, and by providing resources, training, information, and activities free of charge. They also provide information about tracking devices and wandering and elopement.



# The Kevin and Avonte Program: Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities

Through the Kevin and Avonte Program: Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities, the International Association of Chiefs of Police (IACP), in partnership with the National Center for Missing & Exploited Children, The Arc, and the Bureau of Justice Assistance, Office of Justice Programs at the U.S. Department of Justice, supports local jurisdictions' efforts to reduce the number of deaths and injuries of individuals with forms of dementia such as Alzheimer's disease or developmental disabilities such as autism who, due to their condition, wander from safe environments.

#### CONTACT US: homesafe@theiacp.org

**Visit us:** theiacp.org/projects/home-safe

Visit The Arc s webpage: thearc.org/our-initiatives/criminal-justice/ pathway-justice/ **Visit NCMEC's autism webpage:** missingkids.org/theissues/autism







