

PROMISING PRACTICES TO ADDRESS WANDERING OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES OR DEMENTIA





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EXECUTIVE SUMMARY

ndividuals with intellectual or developmental disabilities (IDD), such as autism spectrum disorder (autism), or dementia, such as Alzheimer's disease, are at risk of walking or wandering away from known environments without considering safety or security. In 2018, the United States Congress enacted the Kevin and Avonte Law¹, which supports programs around the United States to prevent and reduce the injury and death of individuals who wander. The International Association of Chiefs of Police (IACP) and its partners, <u>The Arc's National Center for Criminal Justice and</u> <u>Disability</u> (NCCJD), <u>the National Center for Missing and Exploited Children</u> (NCMEC), and the <u>Autism Society of America</u> (ASA), provide training and technical assistance to meet the needs of individuals who wander and the communities that support them. This report, funded under the Kevin and Avonte Law, is a compilation of promising practices derived from subject matter experts (SMEs) in the field, grantee sites funded through the Kevin and Avonte Law, and project partners.

KEY TAKEAWAYS

The key takeaways from this report include:

- Each individual prone to wandering is unique. Strategies and responses need to be customized to fit the individual's needs.
- The role of communication cannot be overstated. Considerations include communication between law enforcement agencies, other first responders, families, and the public before, during, and after a wandering incident.
- The role of technology related to wandering is an important consideration, but it should not be considered or depended upon as the sole solution. A well-rounded approach, including both technological and non-technological methods, is essential.
- Education for law enforcement, families, caregivers, and the public is imperative.
 Educational efforts should focus on identifying behavioral characteristics, warning signs, response methods, and wandering awareness.

¹ Kevin and Avonte's Law Reauthorization Act of 2022, S.4885 (2022)

All techniques and methods discussed in this report should be considered promising – but not yet evidence-based – practices. The field needs more formal research and data to solidify these approaches into best practices.

FEATURES OF THIS REPORT

This report has four sections that provide a comprehensive overview of the prevention of wandering, response to wandering, and the recovery of individuals who have wandered due to IDD or dementia.

- 1. **Introduction:** This section explores the issue of wandering, the Kevin and Avonte Law, and Project Home Safe. A description of the grantee sites and how meetings and calls with the grantee sites have informed this report.
- 2. **Wandering Prevention:** This section explores the methods of preventing and preparing for a wandering incident. The themes examined in this section include training and education, individual skill building, caregiver tools, and relationship building between individuals, caregivers, law enforcement, and service providers.
- 3. **Wandering Response:** This section explores the methods and considerations applicable when responding to a wandering incident. The themes examined in this section include communication, the use of technology, and search techniques.
- 4. **Wandering Recovery:** This section explores the necessary methods and considerations when recovering an individual who has wandered. The themes examined include challenges in recovery, individual engagement, and connection to community services.





INTRODUCTION

A n average of 600,000 people go missing in the United States every year.² People go missing for many reasons, but populations particularly at risk are individuals with intellectual or developmental disabilities (IDD) or dementia. The conditions most associated with wandering are autism and Alzheimer's disease.

These individuals sometimes leave their environment without notice and may end up in situations that threaten their safety. There is no universally accepted term to describe the behavior, and it is referred to in different ways, including wandering, eloping, absconding, running, fleeing, or going missing. While the terms all have slightly different connotations, they describe similar behavior: an individual leaving their primary environment without explanation or notice, resulting in the individual being missing or absent from daily activities. This report will refer to this behavior as "wandering."

The prevalence of wandering is high. Evidence has shown that:

- Nearly 50% of individuals with autism will wander at some point in their lives, usually starting after four years old.³
- 17% of wandering incidents were fatal; 71% of fatal incidents were due to drowning, and 18% were from traffic injury.⁴

Likewise, evidence has shown that:

- As many as 60% of individuals with dementia will wander at some point during their illness.⁵
- Due to causes such as hypothermia, falls, orthopedic or soft tissue injuries, or malnutrition, 30% of wandering cases documented in news reports involving an individual with dementia were fatal.⁶
- 2 "NamUs: National Missing and Unidentified Persons System," NamUs, U.S. Department of Justice Office of Justice Programs, accessed December 6, 2022, <u>https://namus.nij.ojp.gov/</u>.
- 3 Connie Anderson et al. "Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders," *Pediatrics* 130, no. 5 (2012): 870-877, doi: 10.1542/peds.2012-0762.
- 4 Lori McIlwain and Wendy Fournier, *Morality & Risk in ASD Wandering/Elopement 2011-2016* (Portsmouth: National Autism Association, 2017), <u>https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf</u>.
- 5 "Wandering and Getting Lost: Who's at Risk and How to be Prepared," Alzheimer's Association, January 2023, <u>https://www.alz.org/media/documents/alzheimers-dementia-wandering-behavior-ts.pdf</u>.
- 6 Meredeth A Rowe et al. "Persons with Dementia Missing in the Community: Is it Wandering or Something Unique?," *BMC Geriatrics* 11, no. 28 (2011): doi: 10.1186/1471-2318-11-28.

CONGRESSIONAL ACTION

The Kevin and Avonte Law was signed by the United States Congress in 2018 and was reauthorized in 2022.⁷ The law was named for nine-year-old Kevin Curtis Wills, who, in 2008, wandered away from home and drowned in Iowa's Raccoon River, and for fourteen-year-old Avonte Oguendo, who, in 2014, wandered away from his school and drowned in New York City's East River.8 The law authorized grant funding for healthcare agencies, public safety agencies, law enforcement, and nonprofits to establish and operate programs to support the prevention of wandering incidents and help locate individuals when they wander by providing training and public outreach, or focusing on locative tracking technology dissemination and use. Since 2019, the first year of implementation, 38 communities have been funded through federal grants across the United States.⁹ A list of all sites and their primary deliverables can be found in the Appendix.

The Kevin and Avonte Law also authorized funding for a training and technical assistance (TTA) provider. The International Association of Chiefs of Police (IACP) is proud to serve in that role. The IACP and its partners, <u>the National Center for Missing and Exploited Children</u> (NCMEC) and <u>The Arc's National</u> <u>Center for Criminal Justice and Disability</u> (NCCJD), established Project Home Safe to meet the needs of the grantees, produce resources, and hold webinars and meetings to facilitate sharing of information.

- 7 Autism Society Public Policy Staff, National Statement: Statement on Passage of Kevin and Avonte's Law, Autism Society, December 23, 2022, <u>https://autismsociety.org/</u> <u>national-statement-autism-society-applauds-the-passage-of-kevin-avontes/</u>.
- 8 Ibid
- 9 Ibid





PROJECT HOME SAFE

The grantee sites listed in the <u>Appendix</u> have been working to meet the needs of individuals who have wandered or have the potential to wander. IACP project staff has met with these sites in different settings to discuss their work and its impact, and to compile the information for this report to document promising practices.

Quarterly Check-in Calls IACP project staff held quarterly check-in calls with each of the grantee sites. These calls focused on the sites' progress, their successes, and any barriers they encountered.

Site Needs Assessments IACP project staff met with each site individually for a structured needs assessment. This conversation focused on areas where each site needed support and on gaining insight into what has worked best for them. Sites provided information about the progress of their deliverables, community partnerships, outreach efforts, training programs, and the use of locative technology. **Locative Technology Virtual Roundtable** In July 2021, the project held its first large-scale meeting virtually. The Locative Technology Roundtable was designed to draw on the attendees' experience and expertise to inform the future development of national standards and promising practices on the use of locative technology. The attendees at the roundtable consisted of a multidisciplinary group, including representatives from the FY19 and FY20 grantee sites and other SMEs.

The Best Practices Roundtable IACP project staff organized an in-person roundtable in October 2022 in Dallas, TX. This roundtable explored best practices for preventing wandering events, responding to wandering events, and recovering those who have wandered. The attendees were representatives of grantee sites and project partners.

External SME Calls IACP project staff have had periodic calls with SMEs outside the grantee sites to supplement project-related knowledge and assist in developing resources and webinars. These calls included experts in law enforcement response to wandering, dispatcher training and response, and dementia.

PROMISING PRACTICES IN THE PREPARATION FOR AND PREVENTION OF WANDERING EVENTS



PROMISING PRACTICES IN THE PREPARATION FOR AND PREVENTION OF WANDERING EVENTS

There are effective techniques to prepare for and prevent wandering. Themes include training and education, individual skill building, caregiver tools, and relationship building.

TRAINING AND EDUCATION

The need for training and education falls into three categories: law enforcement training, family training, and public education.

Law enforcement training on IDD and dementia should focus on identifying behaviors and effective responses, rather than on diagnosis. Training should also include information on the nature of wandering behavior and its frequency. An essential topic for wandering training is information about areas of attraction, including bodies of water, highways, or areas of interest specific to the individual who has wandered. Tailoring this training to individual communities is also important, especially when considering areas of attraction or potentially hazardous conditions, such as mountainous or densely wooded areas.

Education for families and caregivers can be done on an individual basis or in a group setting. When working with families and caregivers, education should cover normalizing the call to police when a wandering incident occurs, involving neighbors and other gatekeepers, and methods families and caregivers can use to keep their loved ones safe. Technology-based solutions, such as window and door alarms, and installing security, motion, or video systems, can be discussed. Nontechnological options for discussion include velvet ropes, stop signs, and changing carpet colors. To learn more about prevention methods, refer to <u>Considering Locative Technology in the Disability</u> <u>Community: Balancing Autonomy and Safety</u> and <u>Tips For Caregivers Supporting Children on The</u> <u>Autism Spectrum</u>.

Family and caregiver education should be offered with an understanding that family circumstances vary and should include options appropriate for families with various levels of means and resources. Cultural competence is essential when working with families. Cultural competence can be addressed by providing resources in multiple languages and ensuring that terms align with the supported population's culture. It is important to understand that some terms, such as 'caregiver' may be interpreted differently and, in some instances, be negatively received.



Public education should be tailored to and marketed appropriately for different populations. Some groups to consider for training are medical professionals, teachers, and the general public. Educational sessions for these populations should include lessons on wandering in general, how they can prevent and respond to wandering incidents, whom they can work with to learn more, and whom they should reach out to if they are involved in an incident. There should also be a variety of resources and contact information for community groups working in the area. Besides educational sessions, information about wandering behavior can be disseminated through media campaigns, such as the National Autism Association's #searchwaterfirst campaign, televised Public Service Announcements (PSAs), or billboard campaigns. Public outreach can generate interest, encouraging more people to understand how to recognize and respond to the behavior.

Training for law enforcement, families and caregivers, and the public should be regularly revised to ensure that information is updated with the best available information from research and practice in the field. Whenever possible, individuals with lived experience should be included in developing and delivering such training. Individuals with lived experience are defined as people with personal experience living with an IDD like autism or dementia or with direct experience caring for someone with IDD or dementia. It is advisable to include these individuals as much as possible in training efforts, but with consideration for their comfort level. Their involvement can consist of sharing their personal stories, participating in scenario-based training, or facilitating a classroom course.

INDIVIDUAL SKILL BUILDING

Individual skill building typically looks different when applied to cases of autism or IDD versus dementia. In cases of autism or other IDDs, skill building usually applies to the individual affected. Swimming lessons are the most common example of skill-building for individuals with autism and other IDDs.¹⁰ Since being drawn to water is common among people with autism who wander, this skill is essential. Another example of skill building is working with individuals to identify themselves and where they live through verbal or nonverbal means. Autism identification cards are a great tool to support individuals in identifying themselves. Building compensatory skills can also benefit individuals with autism or other IDDs. These skills are used to help cope with their disabilities and can improve memory, emotional regulation, and other areas.¹¹ One example of compensatory skills is using assistive technology devices to communicate with others.

¹⁰ National Autism Association, "Swimming Lessons," National Autism Association, August 2022, <u>https://nationalautismassociation.</u> <u>org/resources/autism-safety-facts/swimming-instructions/</u>.

¹¹ Norine Jaloway Gill, "Compensatory Strategies: Success at the Workplace," Lecture, University of North Texas, October 12, 2017, https://wise.unt.edu/sites/default/files/Compensatory%20Strategies.pdf.

In cases of dementia, skill-building typically applies to caregivers. Due to the nature of the disease, individuals with dementia, such as Alzheimer's, will lose skills as the disease progresses. Caregivers of these individuals need to build the skills associated with caring for and supporting their unique needs. The <u>Grow Your Caregiving Skills</u> webinar series from Insight Memory Care Center is an excellent source of skill-building for caregivers.

CAREGIVER TOOLS

While there is no single cause for wandering incidents, identifying and addressing why an individual has wandered can be an effective tool to prevent further wandering. Once identified, it is possible to address these causes before someone leaves a safe space. According to experts, there are generally three main categories of wandering.¹²

- Goal-directed wandering happens when an individual attempts to get to a specific place or satisfy a need. Goal-directed wandering is common in individuals with dementia, who often try to return to familiar places or places from their memories. For autism, this behavior tends to focus on favorite places or meeting a need they have been unable to communicate, such as needing water or being warmer. This type of wandering can best be addressed by regular visits to preferred places or through the communication of needs.
- 2. **Bolting or fleeing wandering** happens when someone is trying to get away from or escape a specific trigger. Bolting or fleeing is most common in individuals with autism and other types of IDD when they become overstimulated by the activity around them. This type of wandering can best be addressed by avoiding stressful activities, working with individuals to build compensatory coping skills, or providing a safe place to avoid stimulation.

3. **General wandering** is characterized by simply leaving. It can occur in individuals with autism, IDD, or dementia. This type of wandering can be triggered by a condition known as sundowning. Sundowning refers to a state of confusion or disorientation in the late afternoon and evening, characterized by confusion, anxiety, aggression, and wandering.¹³ It is most common in individuals with dementia, but can also occasionally occur in cases of autism. Due to the lack of a goal or specific cause, sundowning and general wandering are challenging to address preemptively, but awareness helps to mitigate adverse outcomes.

It is impossible to prevent all wandering events, and the best approach for caregivers is to prepare for such incidents. The following tools have shown promising results:

- Registry Programs These programs exist in many law enforcement departments. Usually, they involve a form with a description of the individual likely to wander, a picture, critical behaviors, likes and dislikes, and any other information that may be relevant to assist in a search. These registries help law enforcement initiate a search quickly when the need arises and assist in identifying an individual found wandering. However, it is important to note that the disability community has some concerns about registry programs, such as potentially increased stigma and privacy issues. The Arc's NCCJD released a policy brief to outline these concerns.
- Scent Samples Kits designed to procure and maintain a scent sample are commercially available. Some law enforcement departments have programs to provide these kits free of cost. Kits include instructions and equipment to obtain an uncontaminated scent sample from an individual likely to wander. The scent sample can then be quickly and easily accessible and provided to scent-tracking dogs when an individual goes missing.

12 Stefan Bjes et al., "Exploring Locative Technology: What You Need to Know to Address Wandering" (online webinar, May 9, 2022, https://learn.theiacp.org/products/exploring-locative-technology-what-you-need-to-know-to-address-wandering#tab-product_ tab_overview.

13 Jonathan Graff-Radford, *Sundowning: Late-day Confusion*, Mayo Clinic, May 27, 2022, <u>https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/sundowning/faq-20058511#:-:text=The%20term%20%22sundowning%22%20</u> refers%20to,lead%20to%20pacing%20or%20wandering.

CONTACT US: <u>homesafe@theiacp.org</u>

RELATIONSHIP BUILDING

Cultivating relationships with the community is an excellent method to prepare for and prevent wandering events. Promising practices include:

- Communicating with neighbors: For families and caregivers, this approach can involve getting to know the neighbors or sending neighbors a <u>letter</u> informing them of wandering behaviors. Doing so can encourage neighbors to ask questions and learn more to engage with the individual and family further. Community members can then act as additional gatekeepers, helping to keep the individual safe and preventing wandering.
- **Community Events:** Events targeted to the IDD or dementia communities can allow individuals and caregivers to interact with similarly situated families, engage service providers, and get to know local law enforcement and other first responders. Such events enable first responders to establish relationships with the family and the individual while in a low-stress environment and not during an active search. Community events are an excellent opportunity to create awareness about the various services available and to promote the use of registries. When planning a community event, it is essential to recognize that some individuals can become overwhelmed at community events due to sensory overload. Therefore, ensuring the event is sensory-friendly will help individuals feel less overwhelmed. Constructive steps include providing a designated quiet area or sensory station and ensuring caregivers can attend without additional cost.14



14 Autism Services, Education, Resources, and Training Collaborative, Hosting a Sensory Friendly Event, ASERT, accessed December 15, 2022, <u>https://paautism.org/resource/ hosting-sensory-friendly-event/</u>.



PROMISING PRACTICES IN RESPONSE TO WANDERING EVENTS

Once a wandering event has occurred, the response by law enforcement, families, caregivers, and community members can be critical in ensuring the best possible result. Some important themes in wandering response include communication, the use of technology, and search techniques.

COMMUNICATION

For law enforcement, a wandering incident starts at the point of notification, or when the individual is reported missing. However, the wandering incident often begins much earlier for families and caregivers. Many families and caregivers attempt to find the individual themselves before calling law enforcement, which can delay the law enforcement search. Such delays can impact law enforcement's ability to find the individual. Accordingly, families and caregivers should be encouraged to call the police immediately. This behavior should be reinforced by telecommunicators and responding officers, validating the decision to call law enforcement even if a delay has occurred. Doing so may cause less of a delay during future incidents.

Prewritten scripts are recommended for both the caller and 911 call takers. Families and caregivers should participate in the development of scripts specific to the individual at risk of wandering.

The script should contain information about the missing individual, their diagnosis, when they were last seen, information on locative technology, and any other useful information. An example from Montgomery County (MD) Police Department including the information necessary to share with 911 telecommunicators and dispatchers can be found here.¹⁵ For dispatchers, a predetermined set of questions should be used when a caller reports an incident involving dementia or IDD. These questions should elicit essential information, including diagnosis, when they were last seen, locative technology information, information on the direction and means of travel, and any other relevant information. Procedures should be established for telecommunicators to ask about IDD or dementia when a caller is reporting someone missing. Refer to the *Children on the Autism* Spectrum: 911 Telecommunicator & Dispatcher **Checklist** for essential questions telecommunicators should ask callers.

¹⁵ Full web address for 911 script: <u>https://www.montgomerycountymd.gov/pol/Resources/Files/autism/Wandering911Script.pdf</u>



Emergency alert systems can spread the word about a missing individual. It is essential to have protocols that indicate when alerts should be activated and who is responsible for initiating them, in accordance with state requirements. Three general types of alerts are most relevant to these cases, though the use of alerts will be governed by those available in your state and jurisdiction.

1. **Silver Alert:** The Silver Alert is the most popular of these alerts, used in 37 states in the United States. The activation criteria and formal name of the alert vary depending on location. Most commonly, the alert can be activated by law enforcement when an adult, age 65 or older, with a form of dementia or IDD, is missing and believed to be in imminent danger. In some states, the Silver Alert can be used for any missing person with dementia or IDD, regardless of age.

- 2. Enhanced Missing Child Alert: While established in only a few states, such as Florida and Ohio, this alert can be activated by law enforcement in cases when a child under the age of 18 is missing and believed to be at imminent risk. Unlike the AMBER Alert public notification system that outlines a series of protocols to be followed in the event of a child abduction, the Enhanced Missing Child Alert does not require the reasonable belief that an abduction has occurred.
- 3. **Specialty Alerts:** Some states have specialty alerts that go by different names, such as the Purple Alert in Florida. This type of alert can be activated by law enforcement when an individual is believed to be in imminent danger.

The need for these alerts should be driven by communication with telecommunicators or initial officers on the scene and the family and caregivers. Once on scene, communication with the family and caregivers should focus on gathering information to aid in the search, rather than questioning them to determine fault or potential wrongdoing. While it is possible there was wrongdoing on the part of families and caregivers, officers on scene should prioritize the search for the individual.

Communication between law enforcement agencies and other first responders is critical. Efforts should be made to coordinate responses to wandering incidents before they occur. This communication is especially important when the involvement of multiple agencies is likely to occur. While working to locate a missing individual, sharing information with all agencies involved should be a smooth process. Interagency cooperation should expand to all first responders, including specialty rescue teams, jurisdictions where an individual might be headed, or other specialized search and rescue units. Keep in mind that if a missing individual is traveling by car, which is common for men with dementia, this cooperation may need to extend beyond neighboring agencies since the individual will be able to travel much further.¹⁶

¹⁶ International Association of Chiefs of Police, *Missing Persons with Alzheimer's Disease*, (Alexandria: International Association of Chiefs of Police, 2010), <u>https://www.theiacp.org/resources/policy-center-resource/alzheimers</u>.

USE OF TECHNOLOGY

A significant part of the Kevin and Avonte Law and associated funding is the use and distribution of locative technology. Locative technology is used to determine the location of an item or a person through devices. Most commonly, this technology is in the form of a bracelet, similar to a watch.

Several types of locative technology exist, including Radio Frequency Identification (RFID), Global Positioning Systems (GPS), and Bluetooth devices. All of these can be used to help find an individual who has gone missing. It is essential to remember that technology can fail and should be used only in combination with other methods of keeping an individual safe.

In selecting the type and brand of device, family and caregivers should carefully consider if the device is developmentally appropriate, the level of required law enforcement involvement, and the ability of law enforcement to work with the device. Not all types of technology will be a good fit for all families, departments, and locations. Considerations include the cost of technology, training requirements, battery life, and geographic location. For example, some technologies, such as GPS, work better in rural areas with clear satellite communication lines, while RFID can be ideal for urban settings.

Personnel training is vital. Some types of technology, such as RFID, can only be tracked using specialized equipment and trained law enforcement personnel. For this approach to be effective, at least one trained individual should be available on all shifts.

As of September 2023, no national standards or guidelines exist for using locative technology in the United States. Therefore, any law enforcement agency that uses locative technology should ensure that its policies are clear and well-researched. This is especially true for policies relating to <u>Unmanned</u> <u>Aircraft Systems (UAS) or drone technology</u>. While UASs can aid search efforts by increasing the range of other locative technology, UAS use may be limited by state or local policies and is not currently supported under the Kevin and Avonte grants.

Locative technology should be used only after careful consideration of the balance of individual safety and individual autonomy. Refer to <u>Considering</u> <u>Locative Technology in the Disability Community:</u> <u>Balancing Autonomy and Safety</u> to learn more about the decision to use locative technology.



SEARCH TECHNIQUES

Law enforcement is generally well-trained in search techniques and knowledgeable of the geographic features of their jurisdiction. Supplementing the typical search response with additional information specific to the situation is essential. In the cases of autism, any bodies of water, including pools, drainage ditches, rivers, or ponds, should be searched as quickly as possible. Other focus areas should include highways, railways, and an individual's favorite locations. Applying what is known regarding the missing person's behavior is important. Potential sources for search guidance, protocols, and strategies include Home Safe's Children on the Autism Spectrum: Search Protocols & Questionnaire for First Responders and the Department of Homeland Security's Lost Persons Behavior Mobile App.



PROMISING PRACTICES IN RECOVERY OF THOSE WHO WANDER

Responses to wandering incidents aim to recover the individual who has wandered. Recovery considerations include challenges in recovery, individual engagement, and connection to community services.

CHALLENGES IN RECOVERY

The recovery of individuals who have wandered can be more complex than in typical search cases. Individuals with autism or other IDD often easily become frightened or overstimulated. As a result, they may evade or hide from search parties. Children with autism are especially prone to seeking out small or enclosed spaces to hide from search teams. Individuals with IDD or dementia may not respond to searchers calling their names.¹⁷

It is common for individuals with dementia to isolate themselves in areas with less traffic or people. They may not seek assistance even if people nearby can help them.¹⁸ Individuals with dementia are more prone to falls.¹⁹ Search efforts should take these behaviors into account and proceed accordingly.

INDIVIDUAL ENGAGEMENT

Each individual with IDD or dementia is unique. Every person is different regarding what behaviors will be most effective when approaching them and how they will respond. Engaging with the family and caregivers is critical to learning the best techniques to engage with an individual. Registries can also help communicate this information. Several general principles should be considered regarding individual engagement.

 Noise and light: The lights and sirens of police vehicles can be overwhelming, especially for individuals with autism. It is generally recommended that efforts be made to reduce the noise and light from emergency vehicles. Also, be aware that some individuals are attracted to the lights. Be sure to determine what is best for the individual in question.

¹⁷ National Center for Missing & Exploited Children, *Missing Children on the Autism Spectrum* (Alexandria: National Center for Missing & Exploited Children, 2020), <u>https://www.missingkids.org/content/dam/missingkids/pdfs/publications/specialneedsaddendum.pdf</u>.

¹⁸ International Association of Chiefs of Police, "Husband Goes Missing in Car Video," IACPlearn, 2012, <u>https://learn.theiacp.org/products/alzheimers-initiatives-program-roll-call-training-videos</u>.

^{19 &}quot;Dementia and Falls," Canadian Institute for Health Information, accessed March 29, 2023, <u>https://www.cihi.ca/en/dementia-in-</u> <u>canada/spotlight-on-dementia-issues/dementia-and-falls</u>.

- Approach When approaching the individual, try not to escalate the situation. Strive to approach in a calm, friendly manner while avoiding sudden movements. It may help to narrate your movements as you approach, so the individual can prepare and understand. The individuals may be touch-avoidant. Respect their space and allow them to move as needed while maintaining their safety.
- 3. **Communication** Communication with the individual can be difficult, especially after a long search or in cases where the individual is nonverbal. Be empathetic and understanding. The individual is likely frightened and tired and may be unable to communicate these feelings. Use simple sentences to increase understanding and allow the individual time to process the information. Watch for signs of frustration and employ empathy and deescalation techniques as needed.
- 4. Support The individual will likely need support when first located. This support can be as simple as offering water or food. This is especially true for individuals with dementia. Having a sensory-friendly kit can be invaluable when helping individuals with autism or other IDD to calm down in stressful situations. These kits include plush stuffed animals, a soft blanket, noise-reducing headphones, and fidget toys. These kits can help the individual stay calm until they are reunited with their families and caregivers.

CONNECTION TO COMMUNITY SERVICES

The outcome of recovery will determine the final steps in the wandering incident. While everyone works for a positive outcome, it is possible that the individual may not be located, or that they may be severely injured or deceased. The family and caregivers should be connected to support resources in these cases. These resources can include law enforcement victim services, community support, or grief counseling.

In cases where the individual remains missing, sometimes called ambiguously lost, providing these services and support is still needed to help families and caregivers.

Even when the individual is located and safe, followup is important. Law enforcement should work with the family and caregivers to identify effective prevention strategies. These approaches can include methods discussed earlier in this report, including law enforcement registries and locative technology, as well as connecting to community services, such as local chapters of The Arc or Alzheimer's Association.

CONCLUSION

Reducing the injury and death of individuals who wander or go missing due to their disability or dementia is still an emerging field. There is much to learn to prevent wandering incidents, improve the response when incidents occur, and strengthen the recovery of individuals who have wandered. Experienced practitioners in the field currently use the practices and methods described in this report, but these should be considered promising practices. There is a need for formal research and data to support their effectiveness in order to transition these strategies from promising to best practices.

It is important to strive to make prevention and response services more universal, and national standards for the use of locative technology should be established. It is equally important to understand that while research can help determine what is best for the general population, each individual with IDD or dementia is unique. What works for most may not work for all, so flexibility will always be essential.

APPENDIX

Principal Activity
Distribute Project Lifesaver ²⁰ devices to any Allegheny County resident who tends to wander from their residence.
Train law enforcement agencies and other community agencies on autism and wandering.
Distribute Project Lifesaver and AngelSense ²¹ devices and train first responders on wandering behavior.
Distribute Project Lifesaver devices and enroll individuals in a voluntary registry.
Provide information for caregivers, medical professionals, and people with dementia about wandering and train first responders on wandering behaviors.
Provide wandering prevention and response training, develop emergency protocols for schools and first responders, and operate a notification system to assist in the recovery of missing individuals.
Distribute Project Lifesaver devices to individuals with dementia or IDD who may wander.
Provide Big Red Safety Boxes and Toolkits to families and schools and educate caregivers, teachers, and first responders about autism-related wandering.
Distribute Project Lifesaver devices to individuals with dementia or IDD who may wander.

20 Project Lifesaver is a locative technology program using radio frequency bracelets to support law enforcement.

21 AngelSense is a locative technology program using GPS-based tracking technology.

Kevin and Avonte (Grantee Sites and Activities
Site	Principal Activity
Fiscal Year 2019 (FY19) Program Sites	
Pathfinders for Autism <i>Hunt Valley, MD</i>	Implement a public education program on the risks and strategies for wandering and train first responders and families on wandering behavior.
Spotsylvania County Sheriff's Office Spotsylvania, VA	Distribute Project Lifesaver devices to individuals with dementia or IDD who may wander.
The Autism Project (TAP) Johnston, RI	Train community members and first responders on strategies to support individuals with autism or another IDD.
Los Angeles County Aging & Disabilities Department/LA Found Unit Los Angeles, CA	Research the use of three different locative technologies in a focused trial with 30 families.
Fiscal Year 2020 (FY20) Program Sites	
Alzheimer's Community Care <i>Port Saint Lucie, FL</i>	Train law enforcement, daycare centers, crisis lines, and family nurse consultants to respond to people with Alzheimer's disease.
Alzheimer's Greater Los Angeles Los Angeles, CA	Educate and support the community and caregivers on how to protect people with Alzheimer's disease who are at risk of wandering.
Hope for Three Autism Advocates Sugar Land, TX	Maintain Fort Bend County's voluntary registry database and educate the community on wandering prevention and response.
Boston Police Department Boston, MA	Distribute SafetyNet ²² devices and train law enforcement about wandering.
Broward County Sheriff's Office Fort Lauderdale, FL	Distribute SafetyNet devices, train law enforcement, and create a public relations campaign about wandering.
Cincinnati Police Department <i>Cincinnati, OH</i>	Educate the community and law enforcement on wandering prevention methods and distribute SmartSole ²³ and iTraq ²⁴ devices to families.

22 Similar to Project Lifesaver, SafetyNet provides radio frequency bracelets for individuals who wander.

23 SmartSole is a GPS tracker company. They create shoe inserts that can be GPS trackers for wanderers.

24 iTraq is a GPS-based company for general tracking products. This technology is also applied to individuals who wander.

Kevin and Avonte Grantee Sites and Activities		
Site	Principal Activity	
Fiscal Year 2020 (FY20) Program Sites		
Franklin County Emergency Management Agency <i>Winchester, TN</i>	Distribute K9 scent tracking kits to families and provide training to first responders on responding to wandering.	
Get Safe Choice Personal Safety Inc <i>Tustin, CA</i>	Train law enforcement, families, and caregivers on wandering prevention for individuals with IDD or dementia.	
Lowell Police Department Lowell, MA	Distribute Project Lifesaver devices and maintain a voluntary registry for individuals who may go missing.	
Madison County Government Denmark, TN	Distribute K9 scent tracking kits to families and help families create individual preparedness plans for wandering incidents.	
Sumter County Sheriff's Office Bushnell, FL	Distribute Theora Care ²⁵ watches devices to individuals with dementia and IDD who may wander.	
United Way of Lee, Hendry, Glades, and Okeechobee Fort Meyers, FL	Train community members, law enforcement, schools, and families on wandering and Distribute K9 scent kits to individuals who may wander.	
Fiscal Year 2021 (FY21) Program Sites		
Alzheimer's San Diego San Diego, CA	Improve community safety for individuals with dementia by training law enforcement, clinical personnel, and community members on wandering and maintaining a voluntary registry.	
Baltimore County Police Department Baltimore, MD	Distribute Project Lifesaver devices to families and train first responders on wandering.	
Brockton Police Department Brockton, MA	Distribute Project Lifesaver devices to individuals who are at risk of wandering.	
Charlotte County Sheriff's Office Punta Gorda, FL	Distribute K9 scent tracking kits to families and enhance public awareness of wandering.	
Folsom Police Department Folsom, CA	Distribute locative technology devices to families of individuals who may wander and offer toolkits to families.	
Framingham Police and Fire Departments' Emergency Management Team Framingham, MA	Distribute SafetyNet devices to help locate individuals who may wander due to dementia or IDD.	
Hudson County Government Hudson County, NJ	Distribute AngelSense devices to families of individuals who are at risk of wandering.	

25 Theora Care is a partner for Project Lifesaver. They specialize in GPS-based watches.

Kevin and Avonte Grantee Sites and Activities		
Site	Principal Activity	
Fiscal Year 2021 (FY21) Program Sites (continued)		
International Association for Indigenous Aging Silver Spring, MD	Develop a wandering search and rescue support strategy with the Pyramid Lake Paiute Tribe reservation and create a replication guide for tribes nationwide.	
Knoxville Police Department <i>Knoxville, TN</i>	Develop a voluntary registry for individuals who may wander and train first responders on best practices for safe interactions with individuals who may have wandered.	
New Jersey Department of Law & Public Safety <i>Trenton, NJ</i>	Develop programming and support materials for first responders on locating individuals with dementia or IDD who may wander.	
North Miami Police Department North Miami, FL	Distribute Project Lifesaver devices to individuals who may wander.	
Pinellas County Sheriff's Office Largo, FL	Distribute SafetyNet devices to families and create a public awareness campaign on wandering prevention.	
Santa Rosa Police Department Santa Rosa, CA	Educate families and train law enforcement on wandering.	

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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 NCMEC, The Arc's National Center for Criminal Justice and Disability, Autism Society of America (ASA), funded by 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 Visit ASA s webpage: autismsociety.org









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