A Guide to Law Enforcement on

Voluntary Registry Programs for Vulnerable Populations

IACP's Alzheimer's INITIATIVES

Safeguarding the Maturing Population

BJA
Bureau of Justice Assistance
U.S. Department of Justice

www.theIACP.org/alzheimers

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executive summary

In 2013, approximately 5.1 million Americans were living with Alzheimer's disease and related dementias.[1] In the coming decades, it is projected that the baby boom generation will add about 10 million to the total number of people in the United States with Alzheimer's disease.[2] By 2050, the total estimated prevalence of Alzheimer's disease is expected to be 13.8 million.[3] Of those living with Alzheimer's disease, approximately 60 percent will wander at least once during the progression of their disease (many will wander more frequently).[4]

Law enforcement executives cannot afford to ignore the implications of these statistics. The initial response to a missing person with Alzheimer's disease could be the most crucial component of the investigation. Increasing numbers of seniors and other individuals with Alzheimer's disease and similar diseases, mean more cases of individuals who wander, and who will display behavior that law enforcement agencies must be prepared to respond to. In addition, an average search and rescue costs $13,500 per effort.[5] Having information already submitted through a voluntary registry system could cut that cost substantially by providing information that would reduce the time, manpower, and resources necessary to locate a missing individual with Alzheimer's disease.

Law enforcement agencies around the country are beginning to address the need to respond to these populations in innovative ways, including utilizing voluntary registry systems that provide officers with critical information on individuals with special needs such as those with Alzheimer's disease. These law enforcement agencies have found that such registries can

- promote community safety;
- improve officer safety;
- increase the speed and efficiency in which officers are able to respond, decreasing department liability;
- reduce strain on department resources (human and financial) during emergencies;
- give community members peace of mind; and
- promote community partnerships in responding to special needs community members.

Voluntary registry systems enable law enforcement agencies to obtain critical information (prior to an actual emergency) that assists in response to calls for service involving an individual with Alzheimer's disease. This information proves especially valuable when police are called to locate a

1 National Institutes of Health (NIH), "What Is Alzheimer's Disease?" NIH Senior Health web page, http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/01.html (accessed January 28, 2014).

2 Willliam Thies, Laura Bleiler, and the Alzheimer's Association, "2013 Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* 9, no. 2 (March 2013): 208-245, http://www.ncbi.nlm.nih.gov/pubmed/23507120 (accessed January 28, 2014).

3 Ibid.

4 Ibid.

5 Alzheimer's Foundation of America, *Lost and…FOUND: A Review of Available Methods of Technologies to Aid Law Enforcement in Locating Missing Adults with Dementia* (June 2012), http://www.alzfdn.org/documents/Lost&Found_forweb.pdf (accessed on December 2, 2013).

wandering individual with Alzheimer's disease. Voluntary registry information provided to law enforcement could, for example, include a location that holds special interest to a missing individual with Alzheimer's disease; in which direction they tend to wander; a history of past interests or residences that may shine light on their behavior; whether or not they are verbal (and able to respond to questions); and, often, a picture of the individual. This type of information can expedite the search for a wandering individual by reducing the amount of information collection necessary after a call for service, enhancing immediate efforts, and providing a basis from which additional information can be gathered to further tailor the search. In addition, the information assists officers by preparing them to respectfully and appropriately interact with the individual once they have been located.

In many participating departments, voluntary registry systems are equally helpful in responding to individuals in other special needs populations. Departments utilize the system for community members living with Alzheimer's disease, as well as for those

"...voluntary registry systems are equally helpful in responding to individuals in other special needs populations"

with autism spectrum disorders (ASD), developmental disabilities, attention deficit/hyperactivity disorder (ADHD), epilepsy, brain injury, mental illness, and other disabilities that may affect the way individuals interact and respond to law enforcement officers and other first responders.

This guide provides an overview of existing voluntary registry system programs; lays out key considerations for implementation of a voluntary registry system; and provides samples of documentation from existing programs in place around the United States.

background

MISSING ALZHEIMER'S DISEASE PATIENT INITIATIVE

This guide has been developed as part of the IACP's *Alzheimer's Initiative*. The IACP, in partnership with the Bureau of Justice Assistance, Office of Justice Programs, U.S. Department of Justice, launched its Alzheimer's Initiatives program in 2009. The goal of the initiative is to enhance the capacity of law enforcement to handle calls involving persons with Alzheimer's disease and related dementias, thereby strengthening police-community relations and providing improved services to this growing segment in our communities. IACP's Alzheimer's Initiatives program provides education, resources, and training to help law enforcement better recognize those with Alzheimer's disease or who may be at risk; improve interactions with persons with Alzheimer's disease to facilitate positive outcomes; and develop policies related to search and rescue operations, specific to those with Alzheimer's disease.

IACP's Alzheimer's Initiatives program offers a host of resources, information, and training regarding law enforcement's response to persons with Alzheimer's disease or dementia. The following resources can be accessed or requested by visiting IACP's website at **www.theiacp.org/alzheimers**:

- A Model Policy and Issues and Concepts Paper on Missing Persons with Alzheimer's disease
- A state-by-state guide to Silver Alert programs
- A podcast on IACP's Alzheimer's Initiatives
- Several resources and tools for law enforcement
- No-cost training and educational seminars for law enforcement
- Roll-call training video
- A guide to locative technologies for missing persons with Alzheimer's disease.[6]

THE INTERNATIONAL ASSOCIATION OF CHIEFS OF POLICE (IACP)

The IACP is the world's largest and most innovative nonprofit membership organization of police executives, with 27,000 members in over 130 countries. The IACP was founded in 1893 to promote the highest standards of performance and conduct within the police profession. IACP's leadership consists of the chief executives of federal, state, tribal,

6 *IACP's Alzheimer's Initiatives Program*, overview brochure, http://www.theiacp.org/portals/0/pdfs/AlzheimersOverviewBrochure.pdf (accessed April 11, 2014).

territorial, and local law enforcement agencies of all sizes. In addition to chief executives and law enforcement personnel of other ranks, IACP members include criminal justice researchers, university faculty, and private sector professionals.

The association's goals are to advance the science and art of police services; to develop and disseminate improved administrative, technical, and operational practices and promote their use in police work; to foster police cooperation and the exchange of information and experience among police administrators throughout the world; and to bring about recruitment and training of qualified persons in the police profession.

The IACP is a dynamic organization that serves as the professional voice of law enforcement. Building on its past success, the IACP addresses cutting-edge issues confronting law enforcement through advocacy, programs, and research, as well as training and other professional services. IACP is a comprehensive professional organization that supports the law enforcement leaders of today and develops the leaders of tomorrow.

THE BUREAU OF JUSTICE ASSISTANCE (BJA)

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THE GUIDE'S PURPOSE & METHODOLOGY

This guide has been developed as one of many resources in the IACP's *Alzheimer's Initiative* toolbox. It is designed to provide an introduction to the use of voluntary registry systems to aid law enforcement agencies in responding to cases involving individuals with Alzheimer's disease.

The guide provides the following:

- an overview of voluntary registry systems;
- an analysis of the need for voluntary registry systems;
- sample registration forms, training documentation, and marketing documentation.

Information included in this guide has been gathered through interviews with representatives from law enforcement agencies throughout the United States that have designed and implemented voluntary registry systems for use in their communities. The systems featured in this document are not funded by the U.S. Department of Justice. They are meant as a cross section or compilation of types of systems that are currently being used for this type of work.

The programs included have been selected to represent a broad range of agency size, geographic location, and type. The resulting information has been synthesized into overarching strategies to guide law enforcement agencies interested in similar approaches. The table below gives a snapshot of law enforcement agencies interviewed, and their voluntary registry system programs.

DEPARTMENT NAME	POPULATION SERVED	TOTAL # MEMBERS OF DEPARTMENT	VOLUNTARY REGISTRY SYSTEM NAME	YEAR SYSTEM ESTABLISHED	POPULATIONS SERVED	# REGISTERED (AS OF 11/13)	TECHNOLOGY USED	LEVERAGED EXTERNAL PARTNERSHIPS?
Canton, Connecticut Police Department	10,000	15	Alzheimer's Voluntary Registry	2012	Alzheimer's/ Seniors	4	Paper File	Yes
Colerain, Ohio Police Department	60,000	50	Children and Residents Encounter (CARE)	2009	All Special Needs	85	Database	No
Franklin, Wisconsin Police Department	35,520	75	Special Needs Registry	2013	All Special Needs	7	RMS	No
Highland, Indiana Police Department	23,000	50	Special Needs Registry for First Responders	2012	Autism, Alzheimer's, Developmental Disabilities	15	RMS	No
Irvine, California Police Department	300,000	4,200	Return Home Registry	2008	All Special Needs	500	SQL Database	Yes
Polk County, Florida Sheriff's Office	378,000	1,650	Project Safe & Sound	2007	Any condition that causes individual to wander	359	Bracelet/ Database	Yes
San Diego, California Sheriff's Office	870,780	3,942	Take Me Home Program	2008	All Special Needs	526	Database	Yes
Upper Saddle River, New Jersey Police Department	8,400	21	At Risk Resident Registry	2013	All Special Needs	4	Paper File	Yes

introduction

In 2013, approximately 5.1 million Americans were living with Alzheimer's disease and related dementias.[7] In the coming decades, it is projected that the baby boom generation will add about 10 million to the total number of people in the United States with Alzheimer's disease. By 2050, the total estimated prevalence of Alzheimer's disease is expected to be 13.8 million. This is one new case every 33 seconds, or nearly a million new cases a year.[8]

Of the more than 5 million people living with Alzheimer's disease, approximately 60 percent will wander at least once during the progression of their disease (many will wander more frequently).[9] That means approximately 3 million people will wander due to the effects of Alzheimer's disease in the coming months and years. Projections on the aging population in the United States and the number of individuals with Alzheimer's disease predict that this number will only continue to grow.

IMPLICATIONS FOR LAW ENFORCEMENT

The growth in the number of individuals living with Alzheimer's disease has serious implications for all social institutions, but none more critical than for law enforcement. The nature of Alzheimer's disease creates unique scenarios that police departments must be prepared to address during calls for service. Individuals with Alzheimer's disease who wander face a multitude of dangers including hypothermia, starvation, drowning, and automobile accidents, to name a few. The behavior of those with Alzheimer's disease can be erratic and unpredictable, making search and rescue efforts difficult, ending with tragic results.

"Wandering is the result of the brain being unable to recall familiar surroundings or routes, problems with way-finding and spatial orientation, and the brain's inability to problem solve."[10] Those with Alzheimer's disease may not respond to officers in a way consistent with that of individuals who want or require assistance. Their wandering path may not be a logical one, and they may not respond to the calling of their name. When they are found, they may be frightened and/or combative, may not be able to verbalize, and some have even

from fox news
december 7, 2013

"The last walk that Ronald Westbrook took started around 1 a.m. He slipped unnoticed from his North Georgia home with his two dogs.

It ended three hours later when the 72-year-old Westbrook, who suffered from Alzheimer's disease, knocked on a stranger's door.

Police say a man inside that home, 34-year-old Joe Hendrix, got a .40-caliber handgun, went outside to investigate and shot Westbrook in a horrible mistake.

It was an unlikely collision between two strangers, one of them deeply confused and another who perceived a threat in the dark. It shows the difficulties that caregivers face in keeping loved ones with Alzheimer's safe and the consequences of miscalculation in a state that celebrates its gun culture."[11]

7 National Institutes of Health (NIH), "What Is Alzheimer's Disease?"

8 Thies, Bleiler, and the Alzheimer's Association, "2013 Alzheimer's Disease Facts and Figures."

9 Ibid.

10 The International Association of Chiefs of Police, *IACP Training Key #648: Missing Persons with Alzheimer's Disease* (2013).

11 Associated Press, "Suffering from Alzheimer's Georgia Man Wanders Toward Stranger's Home, Fatally Shot," FoxNews.com, December 7, 2013, http://www.foxnews.com/us/2013/12/07/suffering-from-alzheimers-georgia-man-wanders-toward-stranger-home-fatally-shot (accessed April 11, 2014).

wielded weapons due to diminished cognitive abilities. In the coming years, it is expected that there will be a substantial increase in the number of calls for service and search and rescue calls, for those affected by Alzheimer's disease and other related dementias.

As a result, it is imperative that law enforcement agencies evaluate the way they prepare for and respond to calls for service involving those living with Alzheimer's disease, as well as similar special needs populations. Children with autism spectrum disorders (ASD), for example, can display similar behavior. Children with ASD are prone to wandering; can lack the ability to verbalize; and are often frightened by lights and sirens.

Some law enforcement leaders have begun to address the need. They are requiring training for their officers on how to work with special needs populations, such as those with Alzheimer's disease and ASD. In addition, they are implementing innovative systems and programs to arm their officers with the best information available so that they are better equipped to respond to calls involving special needs individuals. Voluntary registry systems are providing this needed link for law enforcement and other first responders.

"Emergency responders should receive special training on how to search for autistic children who are nonverbal and often scared by lights and sirens. Emergency personnel also need to know to check streams or ponds, since many children with autism are drawn to bodies of water, as well as highways."[12]

12 Roni Caryn Rabin, "Study Shows Children with Autism Tend to Stray," *The New York Times*, October 8, 2012.

voluntary registry systems: an overview

WHAT ARE VOLUNTARY REGISTRY SYSTEMS?

Voluntary registry systems enable law enforcement agencies to obtain critical information (prior to an actual emergency) that assists in response to calls for service involving an individual with Alzheimer's disease. This information proves especially valuable when police are called to locate a wandering individual with Alzheimer's disease. Voluntary registry information provided to law enforcement could, for example, include a location that holds special interest to a missing Alzheimer's disease individual; in which direction they tend to wander; a history of past interests or residences that may shine light on their behavior; whether or not they are verbal (and able to respond to questions); and often includes a picture of the individual. This type of information can expedite the search for a wandering individual by reducing the amount of information collection necessary after a call for service, enhancing immediate efforts, and providing a basis from which additional information can be gathered to further tailor the search. In addition, the information assists officers by preparing them to respectfully and appropriately interact with the individual once they have been located.

In many participating departments, voluntary registry systems are equally helpful in responding to individuals in other special needs populations. Departments utilize the system for Alzheimer's disease community members, as well as for those with ASD, developmental disabilities, attention deficit/hyperactivity disorder (ADHD), epilepsy, brain injury, mental illness, and other disabilities that may affect the way individuals interact and respond to law enforcement officers and other first responders.

> **"...initial response to a missing person with Alzheimer's disease could be the most crucial component of the investigation"**

WHAT ARE SOME BENEFITS OF VOLUNTARY REGISTRY SYSTEMS?

Agencies with established voluntary registry systems point to community safety; officer safety; mitigation of department liability; and reduction of strain on department resources as primary reasons for implementing voluntary registry systems. In addition, they cite providing peace of mind for caregivers of Alzheimer's disease patients and promoting community partnerships as benefits of implementing voluntary registry systems.

First, voluntary registry systems enhance community safety by providing timely information critical to locating wandering individuals quickly, efficiently, and safely. Law enforcement's initial

response to a missing person with Alzheimer's disease could be the most crucial component of the investigation. Studies show that of those individuals requiring law enforcement assistance and found alive, about 60 percent were found within the first 6 hours, and about 30 percent within 6-12 hours (and within 1–5 miles from home).[13] The Virginia Department of Emergency Services found that 61 percent of wanderers not located within the first 24 hours are found deceased.[14] To add to the challenge, first responders often begin the search with a time deficit because caregivers have already spent time searching for the wandering individual, sometimes for hours, prior to even contacting police. Therefore, law enforcement's access to the information that will aid their quick and efficient response is key to the safety of Alzheimer's disease community members.

Information provided through voluntary registry systems helps promote officer safety and can reduce department and officer liability. Departments that have implemented voluntary registry systems that report information regarding client communication methods, fears, and "triggers" often helps to de-escalate calls for service involving individuals with Alzheimer's disease, as well as individuals with other disabilities such as autism spectrum disorders. Officers having information about the nuanced behavior of an individual with Alzheimer's disease, or a child with ASD, prior to responding to their home, is better prepared to bring the call to a peaceful resolution without necessitating the use of force. In the case of children with autism, for example, lights and sirens can be a particularly stimulating trigger for aggressive behavior. Officers can approach the call in a more sensitive manner and may be able to better resolve the situation.

In Irvine, California, an elderly female wandered away from her home and her caretaker. Due to the effects of Alzheimer's disease, she attempted to walk to a home she had lived in many years ago. She walked to the back of the home through a path that was no longer accessible. As she attempted to get to the home, she tripped and fell. IPD did all they could to search for her, using bloodhounds, helicopters, and all other search and rescue support available. She passed away there before being found a few days later. Timely information about her condition, her history, and where she may have been going could have provided the details necessary to locate her earlier, and save her life.[15]

Voluntary registry systems can reduce strain on department resources, particularly in times of crisis. According to the Alzheimer's Foundation of America, a typical search and rescue operation can cost taxpayers $1,500 per hour, with low-tech operations averaging nine hours. That is an average of $13,500 per search and rescue effort.[16] Having information already submitted through a voluntary registry system could cut that cost substantially by providing information that would reduce the time, manpower, and resources necessary to locate a missing person with Alzheimer's disease. For example, knowing that a wandering individual with Alzheimer's disease is attracted to bodies of water or traffic can point officers in the right direction when beginning a search.

Voluntary registry systems also provide peace of mind for caregivers and those with Alzheimer's disease in the community. Caregivers can rest assured that the police department is prepared to respond to calls for service involving their loved one living with Alzheimer's disease. They are armed with the information necessary to immediately expedite a search when someone wanders; and, they are better prepared to treat the individual with

13 The International Association of Chiefs of Police, *IACP Training Key #648: Missing Persons with Alzheimer's Disease*.

14 Alzheimer's Foundation of America, *Lost and…FOUND*.

15 Troy Gielish, telephone interview, November 18, 2013.

16 Alzheimer's Foundation of America, *Lost and…FOUND*.

In 2009, Officer Nick McCarthy of the Colerain, Ohio, Police Department was dispatched to a call involving "an out of control 11/12-year old boy was destroying the house." Upon arriving on scene, McCarthy (whose own son has autism) realized, based on the child's behavior, that the boy had autism. The boy's mother was fearful of having a police officer in her home, so McCarthy was faced with calming her in addition to getting the boy under control. Twice during the call, the boy attacked McCarthy, once with a chair and once with a vase, while he spoke to the boy's mother. The call took three hours to resolve (average call lasts between 5 and 12 minutes). Because of his experience with his own son, McCarthy was eventually able to calm the boy and resolve the situation without further escalation. However, he realized that it could have gone very differently had he not had prior experience with autism spectrum disorders. The incident resonated with McCarthy and made him realize that any officer without the knowledge that he had would have been justified in responding with force. He wanted to identify a way to arm officers responding to similar situations with information that would help them best serve the special needs community and protect themselves.

appropriate dignity and respect when they do find him or her. This proactive approach provides a positive bond between the police department and community. Some departments have even found that stronger relationships with the special needs community can reduce calls for service from those community members, ultimately reducing costs.

Finally, police department representatives report that having a voluntary registry system in their community promotes partnerships. Although some departments have "gone it alone," implementing systems without external involvement, many others develop and leverage strong partnerships with community groups, government agencies, and other stakeholder groups to develop, implement, and maintain the voluntary registry program. In doing so, the benefits of these partnerships extend well beyond the confines of rescuing individuals with Alzheimer's disease who wander. They allow for a more open dialogue with Alzheimer's disease (and other special needs) organizations. In addition, working with community organizations helps to create a more knowledgeable police force that is better able to connect special needs community members with helpful resources.

HOW DO VOLUNTARY REGISTRY SYSTEMS WORK?

Although there are myriad variations of voluntary registry systems (which will be discussed in more detail in the next section of this document), all provide a means for caregivers of community members with Alzheimer's disease (or other disabilities) to voluntarily submit information to law enforcement agencies. The information is

"Voluntary registry systems provide peace of mind for caregivers and those with Alzheimer's disease in the community"

At the Colerain, Ohio, Police Department, officers use registry information to identify homes that may benefit from "pop-ins." Officers stop by these homes on a regular basis to forge relationships with the special needs individuals residing there and their caregivers. By doing this, officers believe that calls for service to those homes (which cost approximately $18.25 per call) can be reduced.

then used to bolster officer efforts in the event of an emergency.

Some departments allow for information to be provided via electronic forms on the Internet. Others have caregivers fill them out by hand and mail or drop them off at the department. Still others require that department members conduct individual interviews with caregivers to gather the information. Registration forms request a broad range of information from caregivers of special needs individuals.[17] Basic information requested includes full name; nickname; full contact information for caregivers and others (such as neighbors or other family); physical descriptors; and diagnosis. In addition, many departments ask for more specified information regarding the individual's special need that will help officers respond to calls for service including: whether or not they are verbal; behaviors; sensitivities; fears; and triggers. Most forms also request a picture of the individual be included.

"For most departments there is little or no additional cost to develop, implement and maintain their voluntary registry programs"

Once submitted, the information from the form is reviewed, organized, and stored in the appropriate location within the police department. In many departments, the Crime Prevention Unit, Community Policing Unit, or similar unit or division within the department is responsible for the voluntary registry system. In others, the Communications Division has oversight. In others still, the task falls to whoever has the interest and skill set needed to manage the program. In some departments registration forms are kept in a paper file, while others keep registry data in a searchable electronic database. Some departments utilize existing records management systems (RMS) to store registry data.

Once registry data is entered and stored, internal processes are put in place for officers to access the information during calls for service. Again, the variation is broad. In some cases, the job of searching the registry falls to dispatchers during calls for service. In other cases, both premise and individual data is tagged in the RMS, and responding officers can access the data using their mobile data terminal (MDT).

Most departments report that there is little to no additional cost to develop, implement, and maintain their voluntary registry program, although some do report a slight cost to purchase new technology to organize, store, and access registry information.

17 Examples of voluntary registry forms in use in law enforcement agencies around the United States are included in Appendices A of this document.

key considerations for voluntary registry system implementation

IDENTIFYING THE NEED

Voluntary registry programs have been implemented in response to an identified need in a community. Some departments report that they have already begun to see an increased number of seniors in their community and are responding to wandering individuals with Alzheimer's disease more frequently. In many instances, high-profile cases of missing Alzheimer's disease (or other special needs individuals) shine the spotlight on the department's response and challenge police department leadership to identify a better way to respond to vulnerable populations.

In some cases, the idea for the voluntary registry system comes from inside the department. Savvy officers or progressive leaders; officers who have personal connections to Alzheimer's disease (or other vulnerable populations); or department staff who have received specialized Alzheimer's disease training may bring the need to light. Other departments receive external input from community members or stakeholder groups encouraging them to begin a registry system.

Regardless of the genesis of the voluntary registry program, it is important that law enforcement executives recognize the significance of the issue and support efforts to get it under way. Resources such as manpower, and in some case, funding may be necessary to move the program forward. In addition, support from the chief executive gives the program validity and facilitates getting others, including reluctant community members, on board with the system.

Sergeant Troy Gielish of the Irvine, California, Police Department, whose mother was reaching an age where she was forgetting where she was going and why she was there, feared what could happen if she wandered alone. Although focused on more enforcement activities during his career, Gielish realized the importance of programs that utilized prevention to help his department respond to the Alzheimer's disease population. Gielish used his knowledge of policing, coupled with his concern for community members like his mother to develop Irvine Police Department's "Return Home Registry" Program.

A community member in Franklin, Wisconsin, stopped by the Franklin Police Department (FPD) to drop off a special needs registration form from a neighboring agency. She suggested that FPD start a similar program. The dispatch desk officer who received the form brought it to the Communications Supervisor who received approval and began to develop the program. Six months later, the Franklin Police Department Special Needs Registry was up and running.

CONSIDERATIONS FOR COST AND BUDGETING

The majority of law enforcement agencies interviewed for this guide find their voluntary registry program to be **primarily cost neutral**. They cite nominal program costs, such as:

- manpower (officers/staff time);
- marketing/outreach (e.g., printing of brochures, holding events); and
- costs to upgrade or build databases and other technology (many agencies, however, did not incur technology costs).

For the most part, agencies have been able to create, implement and maintain a voluntary registry program with little to no additional budget. They have used existing resources, stretched budgets and included voluntary registry expenses in overarching crime prevention budgets in an effort to provide more services to their communities.

> **"The majority of law enforcement agencies interviewed for this guide find their voluntary registry program to be primarily cost neutral"**

Those who have required additional funding to implement a voluntary registry system have had success using various strategies. They have:

- made a case for additional city budget funding by citing the cost for search and rescue efforts versus the cost to run the voluntary registry system, which is still nominal in comparison;
- identified public and private grant opportunities;
- re-appropriated existing funds to support the program; and
- leveraged partnerships to reduce costs or gain access to additional resources.

The cost to develop and maintain a voluntary registry program stands in stark contrast to costs for search and rescue efforts necessary to find wandering individuals with Alzheimer's disease. As cited earlier, according to the Alzheimer's Foundation of America, a typical search and rescue operation can cost taxpayers $1,500 per hour, with low-tech operations averaging nine hours. That is an average of $13,500 per search and rescue effort.[18] Given the increased number of individuals who will be diagnosed with Alzheimer's disease in the coming years, and prone to wandering, the cost to law enforcement agencies could be staggering.

18 Alzheimer's Foundation of America, *Lost and…FOUND*.

Having information provided by a caregiver through a voluntary registry system could cut costs substantially by providing officers information that:

- helps focus deployed officers more efficiently;
- reduces the number of man hours necessary to locate a missing individual;
- provides officers with information that can be critical to bringing interactions with an individual with special needs to a successful resolution, reducing the need for use of force;
- improves the public's perception of the law enforcement effort to assist special needs communities;
- potentially reduces the number of officers (as well as other staff and volunteers) necessary to respond, as searchers are prepared with more information; and
- potentially decreases the need to deploy other search and rescue resources (helicopters, dogs, etc.), or the length of time that they are needed.

Each law enforcement agency interviewed for this guide employed different cost structures and budget strategies. What they do agree on, however, is that the benefits of having the voluntary registry in place within their agency far outweigh the costs.

cost scenario

Below are two scenarios involving a missing man with Alzheimer's disease. While the scenarios are fictitious, they are descriptive of the types of benefits provided by voluntary registry systems.

SCENARIO 1 (Police Department A has not yet implemented a Voluntary Registry System):

An 85-year-old man wanders out of his home without his caretaker's knowledge. It is the dead of winter and his coat is still hanging on the coat rack by the door. The caretaker spends an hour searching for the man before calling the police. Dispatch sends the closest officer to the call. The officer spends 30 minutes gathering preliminary information before rushing to search, learning that the man has Alzheimer's disease and has wandered before. The caretaker tells the officer that the man is drawn to a lake a half a mile away, as it is the one at which he had gone fishing with his son when his son was a boy. The caretaker is frightened and frazzled and forgets to tell the officer that there is a specific path to the lake that the man typically takes. The officer searches the home, property, and neighborhood with no sign of the man (who has now been missing for two hours). A search and rescue effort is launched, four officers, four volunteers, a K-9 Unit, and a helicopter are all deployed during the search. The man is found four hours later in a densely wooded area leading to his favorite lake with severe hypothermia.

The cost to the department included:

- **4 officers @ 4 hours of search time**
- **1 civilian staff to coordinate volunteers**
- **1 K-9 Unit @ 2 hours search time**
- **Helicopter deployment costs**
- **Lawyer fees for family's law suit against police department and/or PR firm to handle negative media coverage**

continued on page 16

continued from page 15

SCENARIO 2:

An 85-year-old man wanders out of home without his caretaker's knowledge. It is the dead of winter and his coat is still hanging on the coat rack by the door. The caretaker searches the house and the property, and decides that since she has already established a relationship with the local police department through the department's Alzheimer's Voluntary Registry Program, she will call her favorite officer on his cell phone to help her search. The officer is familiar with the caretaker, and knows that the missing man has Alzheimer's disease and is registered with the department. He quickly pulls up the man's registry information on his MDT, and heads to the man's home to continue the interview with the caretaker. In the meantime, based on information in the registry profile, the officer requests a second unit to respond to a wooded area leading to the lake that the man often wanders to. According to the registry, this is the path he has taken in the past. The officers are also notified (based on his registry profile) that the man is frightened by lights and sirens and are requested to approach without using them. Within 30 minutes, the man is located by the unit responding to the wooded area. They approach him quietly and calmly, and verify (using the picture in the voluntary registry) that it is in fact the missing man, as he does not respond to his name. They take him to a local hospital for observation where he is met by his loved ones.

Cost to the department:
- **Voluntary registry implementation costs**
- **2 officers x 2 hours cost scenario**

STAFFING

Like most policing activities, the most critical resource in developing a voluntary registry system is manpower. Department staff is often responsible for all aspects of the program, making manpower the primary cost associated with it. Voluntary registry system program responsibilities include, program design and implementation; marketing and outreach; input and quality control of data; maintenance of information management systems; department outreach and training; and on-going maintenance of registry data. Some departments utilize different units such as the Crime Prevention Unit or the Community Policing Unit to administer voluntary registry programs. In other departments, the Communications Division has oversight. The tasks may even fall to whoever has the interest and skill set needed to manage the program.

Regardless of the unit or division, virtually all interviewed individuals responsible for voluntary registry programs oversee the program in addition to their regular duties—they are crime prevention specialists, communications supervisors, dispatchers, police officers and even chiefs of police.

Departments that utilize volunteers can leverage those with the appropriate skills for tasks such as technology development, data input, and program maintenance activities.[19] In addition, volunteers can provide a strong community connection to be leveraged during marketing and outreach of the program. Police officers making field contacts with special needs individuals may also be employed to inform the caretakers about the program and to provide them with a registration form once the call is resolved.

Some innovative departments delegate programmatic tasks to reduce dependency

19 For more information on Volunteers in Police Service, visit http:// www.policevolunteers.org/.

on department resources. Partnerships with nonprofit or other government organizations can provide staffing support for administrative or outreach and marketing tasks. Partnerships with private businesses may provide specialized skilled labor, such as development of promotional videos or graphic layout and printing of brochures, at little to no cost.

Despite where the voluntary registry system is housed within the agency or partner organization, the most successful programs seem to be staffed by those who have a passion for the program—and for serving the special needs community.

DEVELOPING THE REGISTRATION PROCESS

For those working to develop voluntary registry programs, ensuring ease of registration for caregivers of special needs individuals is a key consideration. Departments use a number of options to invite potential registrants.

- Web-based (document version) registration form—the form is accessible on the department's, cities, or partner's website. It can be downloaded and filled out on the computer, or by hand, and then emailed, mailed, faxed, or hand delivered back to the department. Once the completed form is submitted, department staff often manually enters the information into an information management system, or it is stored in a paper file.
- Web-based (database version) registration form—the form is accessible on the department's, cities, or partner's website. It can be customized by the law enforcement agency to include check boxes and pull-down menus for ease of completion. It often automatically populates the registry database, eliminating the need for manual data entry by the department.
- Interview—Some voluntary registry systems require that police department personnel conduct face-to-face or telephone interviews with caregivers of special needs individuals to register. Often, the interested caretaker approaches the law enforcement agency via telephone, email, visiting the station, or contacting an officer. An interview is then scheduled, and the information gathered is then input into the registry's information management system.
- Paper registration form—Many departments also produce and provide paper registration forms. They make them available at the police department, city hall, community events, in targeted venues (such as nursing homes or other assisted care facilities), and through partner organizations. Caregivers fill out the form by hand and then return it to the police department.

"Ensuring ease of registration for caregivers of special needs individuals is a key consideration."

Determining what registry information to collect is also paramount. Information gathered should provide officers the tools necessary to find someone who has wandered, identify them, communicate with them, and to provide the appropriate assistance. Some departments work with local branches of organizations such as the Alzheimer's Association or Autism Society to develop the list of questions, while others work directly with parents and caregivers of special needs individuals. Many report that the form itself, and the questions continue to change and grow as the department learns more about the value of information gathered. A sampling of types of questions to include on voluntary registry questionnaires includes:[20]

Personal Information:

- Full Name
- Nickname
- Address
- DOB
- Physical Characteristics (height, weight, race, sex, hair/eye color, scars/marks/tattoos)
- Medical conditions

Caregiver Information:

- Name
- Relationship
- Address

Specific Special Needs Information:

Communication:

- Is the individual verbal or nonverbal?
- What languages does the individual speak?
- Is he or she hearing impaired?
- Preferred method of Communication (If nonverbal)?

Officer Safety:

- Has the individual had any sort of specialized training?
- Is he or she former military?
- Is he or she former law enforcement?
- Is he or she a former boxer or martial arts specialist?

Behavior

- Favorite attractions or locations to where the individual may wander or be drawn?
- Favorite toys, topics, or interests?
- Location of bedroom or other location in the home where the individual may hide?
- Has the individual previously wandered?
- What fears/triggers/sensitivities does the individual have?
- Does the individual fear or will he or she run from police/fire/EMS?
- Best method of approach?
- What calms the individual?
- Is the individual prone to seizures?
- Any other information about the individual that may help police to find, interact, and serve the individual.

Other:

- Names and contact info of other family, friends, neighbors who interact with individual.
- Quality photo of the individual.

20 Full sample registration forms are available in the appendices of this document.

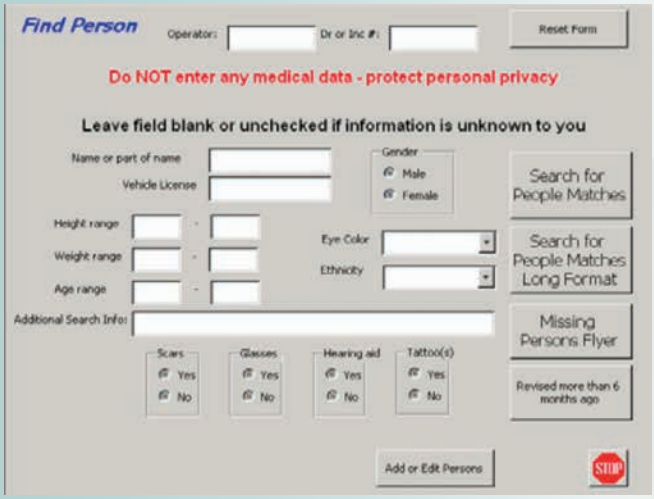
INFORMATION MANAGEMENT & OTHER TECHNOLOGY

The key consideration for management of voluntary registry system information is ensuring timely, accessible, accurate information for first responders. Systems should be searchable; accessible by dispatchers, officers, and/or other pertinent department members; and have the capacity to hold the necessary information to assist officers (to include photos). Many departments also utilize systems that allow regional access to registry information so that neighboring law enforcement agencies are aware when responding to special needs individuals.

Each department interviewed uses its own unique technology to manage voluntary registry information. It is important to remember that each department must determine which type and what implementation of technology will work the best based on department size, capacity (internal technological skill set or ability to access technology skills), and need. The following list provides an overview of systems used to manage voluntary registry data:

- Paper files—Some, particularly smaller departments, or those that do not have ready access to technology, use paper files to keep voluntary registry information. Typically these departments have only a handful of registered individuals and utilize internal manpower to organize, store, and search the paper file when needed.
- Databases—Other departments utilize databases to store registry information. Some departments have started with less robust databases, such as Access- or even spreadsheets such as Excel, to store and organize information. Others have moved to a

The San Diego Sheriff's Office "Take Me Home Registry" (TMHR) utilizes a custom-made database based on the department's regional mug shot database. The database features facial recognition technology and feeds TMHR information directly into the department's communication system. This way if a deputy in the field encounters a member of a vulnerable population, especially one who is nonverbal, the system can be queried, or the client image searched within the system using facial recognition, to identify the client and return him or her home safely.



Screenshot of database query page for Irvine, California, Police Department's Return Home Registry.

more high-capacity database, such as an SQL-based database, that can store and search high-resolution photos and more data. Often the registry information in the database feeds directly into the department's communication system so that dispatchers are automatically aware of the individual's special needs when a call is linked to a registered premise or when individual information comes in. Some departments have chosen to have a new database custom built, and others have been able to adapt existing databases to fit the needs of their voluntary registry system. Many departments have used internal police department staff with IT skills to adapt or build the database, while others utilize technology vendors to assist. Some have even been able to leverage volunteers to do the work.

The Highland, Indiana, Police Department is a medium-sized department located in Northwest Indiana, just outside of Chicago, Illinois. HPD uses a commercial off-the-shelf records management system (RMS) in its day-to-day operations. The department implemented its Special Needs Registry for First Responders in 2012, utilizing existing RMS technology. Once a special needs registry form is received, a flag is placed on the individual's name and premise information in the RMS. The actual registration form and accompanying photo is scanned and attached electronically to the individual's name and address. If an officer is called to that location or individual, he or she automatically sees that the individual is registered and is able to access the detailed registry information on the form by opening the attachment directly from his or her squad car's MDT. The process does not require additional technology or expense.

- Records Management Systems (RMS): Some departments utilize existing RMS technology to manage voluntary registry information. In most cases, the name and address of the individual with Alzheimer's disease (or other special needs) is flagged in the RMS, a capability that comes standard with most commercial RMS. The flag lets first responders know that the individual is registered with the special needs program. In addition, the full registration form and photo can be attached to the premise and individual file in the RMS so that all information provided can be accessed by the officer via his or her MDT, or by the dispatcher, when the officer responds to a special needs call.

- Other technology: Some departments utilize other technology to bolster the efforts of their voluntary registry system. Identification bracelets or ID cards linking the registered individual to their registry file at the police department helps concerned citizens who may stumble upon a wandering individual with Alzheimer's disease. Bracelets, for example, may have the department's phone number, and the individual's voluntary registry number on them so that citizens can easily call the department and identify the individual utilizing the personal ID number. Other departments employ locative technologies such as GPS bracelets to assist in locating wandering individuals with Alzheimer's disease.[21] While these technologies are beneficial for some, they typically do incur additional costs. More information on locative

21 For more information on locative technologies, see http://www.theiacp.org/portals/0/pdfs/AlzheimersLocativeTechnologies101Brochure.pdf.

technologies can be found on the IACP Alzheimer's Initiatives website at **http://www.theiacp.org/portals/o/pdfs/AlzheimersLocativeTechnologies101Brochure.pdf**.

CONFIDENTIALITY OF DATA

Although the majority of departments interviewed have not experienced concern over the confidentiality of information provided through the voluntary registration system, a few have. Confidentiality concerns coupled with a general fear of law enforcement, common in some communities, could create a barrier to community participation in voluntary registry programs. Some community members fear exploitation of registry data. Some fear that registry information collected may be used to violate the rights of special needs individuals by inappropriately releasing the information to outside entities. Others question the Health Insurance Portability & Accountability Act (HIPAA) compliance of registry information collection and storage.

To mitigate issues, departments use disclaimers, waivers, or releases on voluntary registry systems' registration forms/questionnaires to notify registrants that providing data is voluntary and to let them know that information will be used solely for the purpose of assisting first responders in providing service. Signature of the waiver at the end of the registration form releases the department from liability.

All police departments interviewed for this guide strongly suggest that a release be added to voluntary registration forms to address confidentiality issues. They also strongly suggest that release wording be reviewed and approved by municipal/city/jurisdictional attorneys to ensure coverage prior to program inception.

release examples

San Diego County, California, Sheriff's Office Take Me Home Registry:

"I acknowledge that I have voluntarily provided this information for entry into the Take Me Home Registry with the understanding it will remain confidential at all times and be released only to police, fire, or medical personnel assisting in the identification, safety, and return of this person if found or reported missing, or otherwise determined to be at-risk by emergency response personnel. I further acknowledge that I have the legal authority to enter the registrant named on this form into the Take Me Home Registry." — Printed Name, Signature, Relationship, and Date.

Franklin, Wisconsin, Police Department:

"IMPORTANT: Please review the following before completing, signing or submitting this form: Responding to this form is strictly voluntary. The information on this form will be added to the Franklin Police Department's record management system and may be distributed to emergency responders in order to better care for you or your family members. The city respects your right to confidentiality and will strive to ensure that your personal information remains confidential. However, by definition of this form, once submitted, is a public record, and may be subject to disclosure under Wis. Stat. 19.35, except as otherwise exempt by law. The city does not collect or maintain information about you that is not essential for your safety and well-being. By completing this Special Needs Registry form, I acknowledge that the information provided here in is accurate and was submitted voluntarily for the sole purpose of assisting Police, Fire and Emergency Response Departments in more effectively responding to a potential emergency in or near my residence. I, therefore, authorize the use of this information for those purposes." — Signature of person completing form, Printed Name if not electronically signed, Date.

COMMUNICATING INTERNALLY: POLICY AND TRAINING[22]

Ensuring that department members understand how and why the voluntary registry system works is essential to its success. Once again, how internal communication takes places varies between departments. While few develop formal standard operating procedures (SOPs), many more utilize informal communication and/or structured training methods to communicate information about voluntary registry system protocol and procedures throughout the department—and with partners.

In some departments, voluntary registry systems are mentioned in and influence SOPs regarding calls for service. However, few police departments have implemented SOPs specifically governing the voluntary registry program. Instead, it was found that most departments interviewed utilize structured internal communication and trainings to inform department members about the voluntary registry program. Training bulletins, briefings, field officer trainings, and roll call trainings all communicate the role of department staff in the program. In addition, progressive departments provide broader training focused on special needs communities served by the voluntary registry system. For example, many departments provide training on the department's voluntary registry program as part of, or in conjunction with, officer training on responding to individuals with Alzheimer's disease, Autism spectrum disorders and other disabilities.

Voluntary Registry System Training may cover the following:

- Program overview
- How to gather information and the type of information to be gathered
- Data input procedures
- Data storage and backup procedures
- Data search capability
- Outreach
- Maintenance of registry information

Internal communications and trainings should be targeted to specific groups within the department—officers, detectives, managers, dispatchers—based on their interaction with the voluntary registry system. Communications should also publicize "early wins" when they happen, letting department and community members know when the program succeeds in helping to find an individual with Alzheimer's disease.

PARTNERSHIPS

Many police departments concur that the key to the success of their voluntary registry system is the strong partnerships formed with interested non-governmental organizations, government agencies, and private businesses. Partnerships can act as force multipliers, expert advisors, resource providers, and ambassadors for voluntary registry system programs. Some programs are born out of existing partnerships focused on providing quality service to seniors, or other special needs communities, such as TRIAD (an agreement between law

22 Examples of actual training documents used in police departments are attached in the appendix of this document.

The San Diego County Sheriff's Office "Take Me Home Registry" (TMHR) Program credits much of its success to strong partnerships with numerous local organizations. These organizations specialize in providing services and support to community members, their caregivers, and loved ones facing various needs and challenges, as this program incorporates multiple vulnerable populations within their community. Partners include Arc of San Diego, Alzheimer's Association – San Diego Chapter, Area Board XIII State Council on Developmental Disabilities, Autism Society of San Diego, Epilepsy Foundation of San Diego, Health and Human Services, Marine & Family Services Children, North Coastal Consortium for Special Education, San Diego-Imperial Counties Developmental Services, Inc., St. Madeleine Sophie's Center, Stepping Stone Resources, and United Cerebral Palsy of San Diego. The organizations not only provided expert input during the design of the program, but also continue to provide ongoing support and guidance. In fact, these organizations serve as the "point of entry" for individuals interested in registering for the TMHR program. Partner organizations can directly input registry information from community members into the TMHR. In addition, the Honorary Deputy Sheriff's Association of San Diego, the Deputy Sheriff's Association of San Diego, and the Regional Access Network Board provided funding for development of the program.

enforcement and community members to help keep older adults safe). Others form partnerships for the purpose of implementing voluntary registry systems.

Departments that have implemented voluntary registry systems have found success in these partnerships:

- Non-governmental (NGO)/ nonprofit / community organizations: NGO, non-profit and community organizations focused on special needs communities are strong allies in implementing voluntary registry systems. Local chapters of the Alzheimer's Association and Autism Society are just two examples of possible voluntary registry system partners. They provide program input such as questions to include on the registry questionnaire and how to best increase participation. They also provide assistance with outreach by identifying ways to access target groups and to advertise the availability of the registry program. More importantly, these groups provide program legitimacy that is often necessary when encouraging caretakers to register their loved one who is suffering from Alzheimer's disease, or who has other special needs.

- Government organizations: Government organizations can provide a strong source of support for law enforcement voluntary registry programs. Neighboring police departments and other local first responder agencies, such as fire and EMS, can provide connections to those in need in the community and can also benefit from the information gathered through the registry. Governmental agencies such as senior and social services also have a vested interest in voluntary registry programs and can often provide support.

The Polk County Sheriff's Department Project Safe and Sound provides bracelets to its registrants in an effort to help identify wandering individuals with Alzheimer's disease. The program leverages partnership with a local engraver who engraves Project Safe and Sound bracelets with ID numbers at no cost for the department.

- Private sector: Businesses in the community may also be able to provide assistance with a voluntary registry program. For example, privately run care providers can facilitate outreach by distributing information about the program to loved ones of residents with Alzheimer's disease.[23] In some cases, businesses have donated goods and services to help bolster voluntary registry system programs. Police departments must ensure that when receiving support from individuals and businesses, they follow all departmental protocols regarding receipt of public donations. Police foundations, established TRIAD programs, community fund organizations, and other local law enforcement or community focused non-profit organizations may be able to help manage such donations.

"In order for the program to succeed, the community must know the registry program exists..."

MARKETING AND OUTREACH TO THE COMMUNITY[24]

Marketing and outreach that promote voluntary registry systems are critical. In order for the program to succeed, the community must know the registry program exists; they must understand its purpose; and they must trust that it will help provide quality service to their loved one or ward living with Alzheimer's disease. Marketing and outreach strategies should be tailored to fit the community. For example, outreach strategies primarily utilizing Internet presence may miss a large portion of the elderly market. Combinations of various strategies to reach target groups provide the best coverage. However, budgetary, staffing, and technological constraints may also dictate the level of marketing possible.

The following are marketing strategies employed by departments who have voluntary registry systems in place.

- Print Media–Brochures, One-pagers & Posters: Most departments create brochures, one-page overviews, or other marketing documents that are distributed at community events or posted in locations throughout the community. Brochure and poster placement at community and senior centers, hospitals, rehabilitation centers, and doctors' offices provide a broad viewing by those who visit these locations.
- Print Media–Articles in local newspapers and periodicals: Press releases covering the launch of the voluntary registry program, or other program events, can be picked up by local print media and published in newspapers and other periodicals,

23 State and municipal business licensing departments retain a list of privately run health care facilities that provide services to elderly and developmentally disabled persons.

24 Examples of actual marketing and outreach materials used in police departments are included in Appendix C of this document.

providing wide readership. Local community groups and local chapters of national associations who provide services to special needs communities may also be interested in publishing articles covering voluntary registry systems in their periodicals.

- Video/Audio Media: Some departments develop videos and/or radio spots to be played on local cable television channels and radio stations to promote voluntary registry systems. This requires having access to technology necessary to develop the media piece. Producers and editors are often interested in special interest pieces that the community can relate to. Broad viewership/listenership could mean excellent exposure for the program.

- Websites and Social Media: Today, most government agencies, including police departments, utilize websites and other social media (such as Facebook or Twitter) to push important information out to their community quickly and easily.[25] Providing information about, and a link to, the voluntary registry system on department, municipality, and partner websites and social media sites can efficiently promote the program with little to no cost. In addition, city e-newsletters and local blogs can help cover the program as a community interest story.

- Other municipal paging system: Many police departments and municipalities across the country have access to systems (such as reverse 9-1-1) that enable them to push information to subscribing community members via email, text message, or telephone message. If access to this type of system is already in place, it can be leveraged to send a short introduction of the voluntary registry program to subscribers.

- Events: Some departments prefer a more face-to-face approach to marketing their voluntary registry system. In many cases, crime prevention specialists or police officers provide information about the system at community events targeting special needs populations.

The Colerain, Ohio, Police Department holds the Children and Residents Encounter (CARE) program open forum event every September to promote the CARE program, and to register special needs community members. The event targets those with autism spectrum disorders, Alzheimer's/dementia, Down syndrome, and other developmental disorders. It is held at the police department where police, fire, and EMS personnel bring their vehicles for participants to explore; grill hamburgers and hotdogs; and socialize with special needs attendees and their caregivers. At the same time, the attendees are given a registration packet that they can fill out and provide back to CARE personnel to register the special needs individual on the spot. A local photographer volunteers his time to take high-quality photos of the registrants for inclusion in their registry packet. The event not only promotes CARE registration, but also gives special needs community members the opportunity to interact with first responder personnel in a fun, informal, and social environment.

25 Refer to IACP's Center for Social Media to learn more, http://www.iacpsocialmedia.org.

For example, a department may present information, and the opportunity to register, at crime prevention events held at the community's senior center. Some departments even hold events specifically focused on promoting the system and registering community members.

- Officer Contact: Officers carry questionnaires with them while on patrol so that if they are called to, or otherwise encounter an individual who could benefit from the voluntary registry system, they are able to present a questionnaire to caretakers, and encourage them to fill it out.[26]

- Community/Service Organizations: As mentioned in previous sections, partnerships with organizations that provide services to special needs groups provide a myriad of opportunities to promote voluntary registry programs. Local chapters of organizations such as Down syndrome associations and epilepsy associations are often willing to include information about the program in newsletters, blogs, and other regular communications. In addition, their meetings provide opportunities to make face-to-face connections directly with groups the registry is intended to serve. These groups also have internal distribution lists that may be used to get the word out about the voluntary registry program.

PROGRAM MAINTENANCE AND SUSTAINABILITY

As with any department program, it is important to consider the future of the effort. Voluntary registry system programs require leadership to sustain it programmatically, technologically, and even financially.

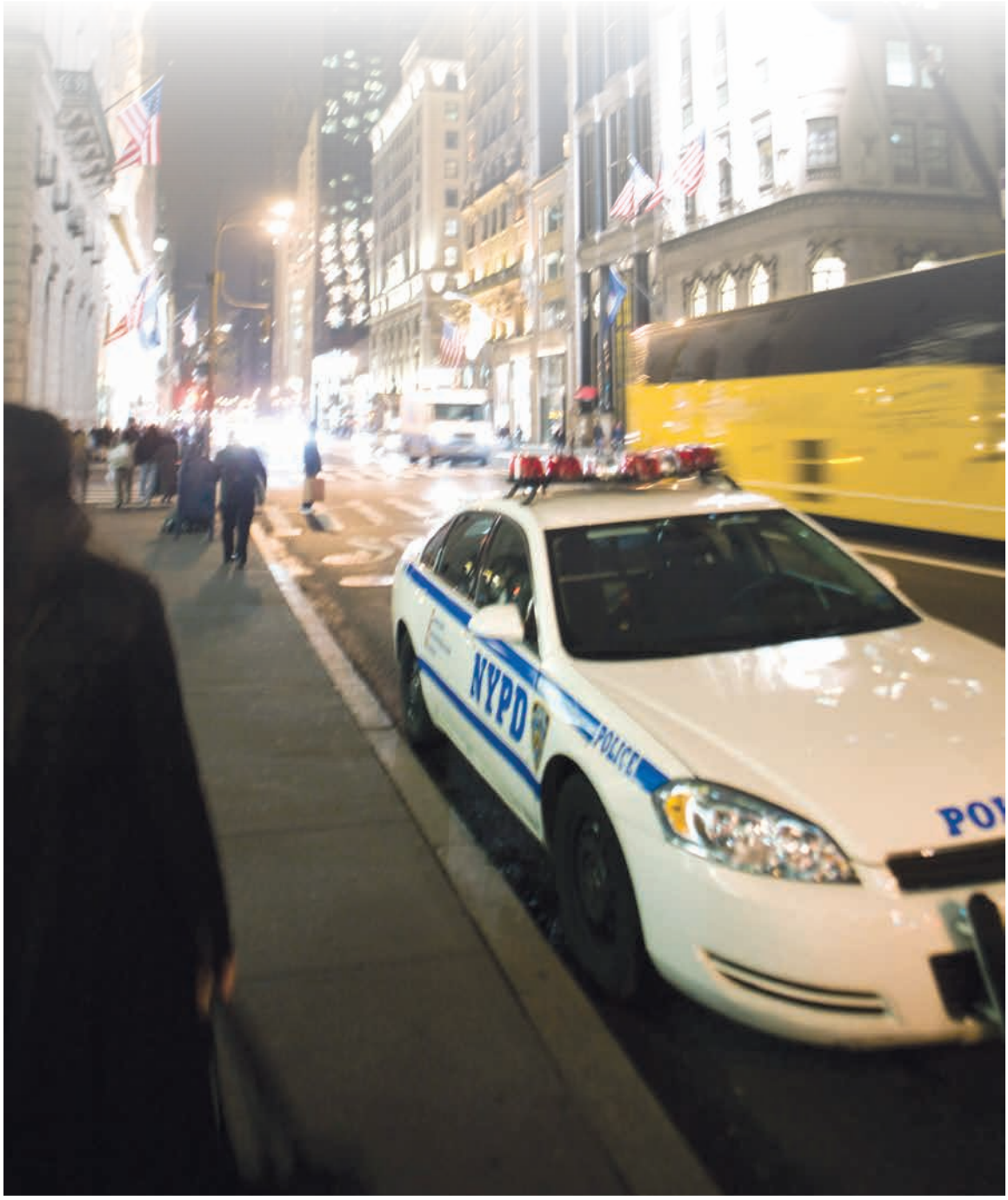
Once the registry is implemented, decisions will need to be made about how to sustain it going forward. Those questions may include the following:

- How do we continue to grow the registry?
- Do we expand to other special needs groups? How?
- Do we need changes to technology to support program growth?
- What partnerships should be included?
- Do we need more staff?
- Do we need to update training?
- How can the program better serve the Alzheimer's disease community?
- What type of registry maintenance is necessary?

Departments that have implemented voluntary registry programs report that developing a process for maintenance of system data should not be overlooked. They suggest that departments ensure there is a written process in place that specifies how data will be kept current and who will be responsible for updating it. Most departments make targeted efforts to update the information semiannually or annually. They make phone calls or send

26 IACP Alzheimer's Initiatives offers a number of resources to assist officers in the field interact with individuals with Alzheimer's. Resources can be found at http://www.theiacp.org/Missing-Alzheimers-Disease-Patient.

emails to those registered (or their caregivers) to request updated information. While this responsibility often falls to program staff, some departments ask volunteers or officers assigned to light duty to take on the task. They note that it is critical to ensure that volunteers, officers, and other staff responsible for maintenance be trained on how to deal with the often-sensitive conversations necessary to update voluntary registry system data. A sample dialogue or script is often helpful to provide to staff and volunteers who are responsible for updating information.



challenges

Most departments employing voluntary registry systems report that benefits of the program far outweigh the challenges of implementation. However, some challenges are worth mentioning so that departments launching programs can prepare to address them.

ENCOURAGING PARTICIPATION

It seems that launching a voluntary registry system can be a lonely endeavor. Many departments report that encouraging participation in the program is the biggest challenge. As mentioned previously, community members who fear law enforcement are often reluctant to participate in the registry. Some may fear that such private and personal information about a loved one's disability is not safe in the hands of law enforcement. They may fear that it could be used inappropriately to deny special needs individuals their rights, or that it may be released to other entities without permission. In addition, caretakers may fear that law enforcement will perceive their quality of care to be insufficient. Some families will even feel that from a cultural standpoint the responsibility of caretaking solely belongs to the family.

In addition to encouraging community participation in the program, some departments have found gaining internal participation a challenge. Incentivizing sworn and civilian department members who are not yet connected to the program to take on additional duties can be tough. Some may not see a need for the program; others may be reluctant to add responsibilities to their heavy workloads. Some departments have also found encouraging neighboring law enforcement agencies' participation challenging. Those departments may have not yet recognized the need within their communities, or competing priorities have stifled their interest in the voluntary registry concept.

Prioritizing ongoing marketing, outreach, and training can ameliorate reluctance to participate. Targeted outreach strategies that focus on special needs groups can help get the word out about the program. Departments can also encourage community connections of their police volunteers to increase participation in the voluntary registry system. Gaining support of groups and individuals respected within the target community can help provide program legitimacy and encourage participation.

Providing department members with training that teaches why the program is important to quality community policing also encourages participation. Ensuring that system successes are well publicized both externally and internally also helps bolster program support.

> "One of the early challenges we met was in marketing the program to the elderly, as they were concerned the program would serve as a "watch dog" and that we were looking to enforce laws against them such as taking away their driver's licenses. Using the VIP's [Volunteers in Police Service] and working directly with organizations such as Alzheimer's Association and the other similar groups helped us overcome this challenge." — Irvine, California, Police Department, Return Home Registry

Finally, chief executives' overt public support for voluntary registry systems provides a powerful weapon in combating complacency and lack of participation.

MAINTENANCE

It is important that those developing voluntary registry systems plan for regular maintenance of the program and, specifically, updating system data. It may seem like a task that can be put off until after the system has been operational for a length of time. However, the status of registered individuals and their caregivers often change. A database full of information that is not maintained will not be useful to officers. It can become a large, difficult-to-manage system providing faulty information. Failing to properly maintain data may deter officers from using the system and may even cause harm if inaccurate information is used during a call.

Planning a regularly scheduled process of updating data helps to mitigate risk and ensures that the voluntary registry system is kept manageable. In addition, having a stated process for maintenance communicates that the department is serious about the program and is willing to do the work to keep it functioning properly. The process for updating system data will depend, in part, on the number of individuals registered and staffing available to take on the task. Many departments make direct contact, through telephone, email, or face-to-face interaction with caretakers on an annual or semiannual basis to check the status of the information in the system. Program staff, officers assigned to light duty, and police volunteers can be responsible for the tasks associated with maintaining data. Those tasked with maintaining data should be properly trained on the appropriate way to make contact with and have sensitive conversations with special needs individuals, their caretakers, and their loved ones.

The Colerain, Ohio, CARE Program relies on a centralized county dispatch to relay registry information to Colerain Police Department officers. Ensuring that information is passed along in a way that is timely and helpful to officers, when they are called to serve a registrant, continues to be a challenge.

SUSTAINABILITY

One of the cited advantages of a voluntary registry system is the cost-benefit ratio. However, because many departments are able to implement the program with little financial impact, the expectation that it will continue to run with little or no support can exist. Similarly, focusing enough manpower on the program to keep it running properly and growing can be difficult. Making the voluntary registry system a priority in light of many other programs can be a hurdle and may challenge the sustainability of the program.

Strong communication about the voluntary registry system program and its successes can combat this challenge. Keeping both quantitative and qualitative data on the program can also help promote it and keep it from being overlooked during budgeting and staffing decisions.

chief executive's guide to implementing successful voluntary registry systems

While understanding key considerations when implementing a voluntary registry system is important, to achieve success, law enforcement executives should also be aware of over-arching strategies.

STRATEGIC IDEAS

This section suggests a few strategies employed by law enforcement executives to promote successful development and implementation of voluntary registry programs.

- *Implement a voluntary registry system as part of a larger effort to prepare your department for interacting with and serving the Alzheimer's disease community, as well as other special needs communities.* Voluntary registry systems implemented as part of a larger strategy to better serve the special needs community are most successful by ensuring that officers understand the challenges faced by individuals with Alzheimer's disease and their caregivers. As part of the implementation strategy, departments should offer and require training for officers on how to identify characteristics of the disease and how to respond effectively to incidents involving individuals with special needs to help improve agency response. IACP offers a number of Alzheimer's disease training options for police departments, including no-cost classroom training, training videos, and training keys.[27]

- *Leverage Partnerships.* Chief executives can provide leadership in forming and sustaining partnerships with organizations that will serve the special needs community. Leveraging existing relationships; identifying ways to continually involve partners; and giving credit where credit is due are all ways chief executives can aid in forming critical partnerships to advance voluntary registry system programs.

- *Lend YOUR leadership, support, encouragement, and weight.* Although in many departments, the details of the voluntary registry system will be delegated to others, it is important that chief executives understand, believe in, and communicate the merit of the program, both internally and externally.

- *Design processes, policy, technology, and budget that suit your department and your community.* It is important to understand that although the benefits of voluntary registry systems to the Alzheimer's disease community are universal, the design and implementation vary from department to department. Law enforcement

27 More information on IACP Alzheimer's Initiatives training can be found at http://www.theiacp.org/Missing-Alzheimers-Disease-Patient.

Officers of the Borough of Upper Saddle River, New Jersey, Police Department attended training on issues facing officers in dealing with individuals with special needs. After the class, they suggested that the department develop a voluntary registry system. The chief approved the idea, and the At Risk Resident Registry was launched.

Chief Christopher Arciero of the Canton, Connecticut, Police Department attributes much of the success of the Alzheimer's Registry program to the partnership with Canton's Senior and Social Services. He credits the forward motion of the program to the energy and drive of the director of Senior and Social Services, and to the partnerships of the community's TRIAD program.

When presented with the challenge, Chief Daniel Meloy of the Colerain, Ohio, Police Department gave Officer Nick McCarthy the authority and latitude to design and implement the Children and Residents Encounter (CARE) voluntary registry program. As the program grows, Chief Meloy continues to support the program, providing words of encouragement; refocusing program staff on the merits of the program when necessary; and presenting the program in national forums.

In San Diego County, California, Officer Brian Herritt of the Palomar College Police Department not only responded to incidents involving special needs individuals, but also is a father of a special needs child and has received police assistance as the family and caregiver of the child. Officer Herritt understood the challenges from all sides. He brought the idea for the Take Me Home Program to the San Diego County Sheriff's Department and lent clarity and expertise to its implementation.

executives must consider the uniqueness of their communities, including community and department size, demographics, needs, and partnerships when deciding on the implementation details of a voluntary registry system.

- *Whenever possible, choose staff who are passionate about serving the Alzheimer's disease community and/or have a personal connection to the issue to be involved in or take leadership roles in the voluntary registry program.* Although not necessary, having individuals involved in the voluntary registry system program who have a passion, and a vision for better serving a special needs community, helps to drive program implementation and growth. Those individuals often have an unwavering drive to help the program succeed.
- *Be resourceful. Think outside the box.* Police departments have become experienced at doing more with less, at making things happen with few resources, while still providing the best possible service to the community. Skillful utilization of existing resources and continually identifying strategies to promote and expand the use of

"Be resourceful. Think outside the box."

In Colerain, Ohio, Officer McCarthy had both personal and professional experience in dealing with individuals with special needs. This drove him to bring the need to develop a better way to serve the special needs community to Chief Meloy and to implement the CARE Program.

At the Polk County, Florida, Sheriff's Department, existing grant monies were re-appropriated to the Office of Communications to build and sustain Project Safe and Sound. In addition, the program leverages partnerships with two local engravers who create Project Safe and Sound bracelets with ID numbers at no cost.

The Highland, Indiana, Police Department utilizes the existing RMS to store and access voluntary registry information, forgoing the need to spend time and money on building a new database for the Special Needs Registry. HPD has historically used the RMS to tag individuals with information that officers need to know when responding. The department simply expanded on the idea to include Special Needs Registry information.

voluntary registry systems are both helpful to bolstering program success. For example, utilize existing manpower, technology, and resources to build a voluntary registry system. If possible, leverage business partnerships that may provide pro bono services to help defray program costs. Identify ways that the voluntary registry program can expand to serve other special needs populations—or to serve those populations in different ways. Many departments who have implemented voluntary registry programs started by focusing on one special needs community, such as Alzheimer's disease or autism spectrum disorders, but have expanded to serve all special needs individuals in the community.

- *Encourage program staff to keep programmatic data.* Although a seemingly ancillary task, keeping detailed program data can help promote success of voluntary registry systems, both internally and externally. Data on how many special needs missing persons cases are undertaken in a year, as well as costs associated with those cases can help to justify the need for a voluntary registry system. After implementation, statistics such as the number of registrants, percentage of the elderly community participating, and cost data can help promote the program in the community. Anecdotal data, such as descriptions of cases where the voluntary registry program could have or did help locate a missing Alzheimer's disease individual can be immensely helpful in encouraging dispatchers and officers to participate and can show the community the importance of the system. Finally, data such as how often the system was queried; how many officers searched the voluntary registry database; and what types of searches they made can tell quite a bit about how the system is being used within the department. All of this information can help when making programmatic decisions.

conclusion

Voluntary registry systems are an integral part of a holistic approach to Alzheimer's disease, and/or special needs programming in law enforcement agencies; and their benefits are undeniable. The need for officers to have access to information that helps better serve vulnerable populations is becoming increasingly important. The flexibility of these systems allows law enforcement agencies to create programs that best fit their communities. Agencies can reap the benefits of having access to critical information in times of emergency, without depleting budgets or overextending resources.

Departments that have developed voluntary registry systems continue to think outside the box regarding ways to grow and improve the reach of the program. Many look to expand to other vulnerable populations not currently included in their systems by increasing training and outreach to those communities. They also continually identify new, innovative ways to ease the fears of caregivers and family members of special needs clients who are reluctant to provide personal information to law enforcement. In addition, they continue to identify ways to nurture and expand the program without incurring debilitating costs.

Of the departments interviewed, many expressed interest in learning what other law enforcement agencies are doing to better serve the senior, special needs, and other vulnerable populations in their communities. They encourage the development of a national database that provides insight into law enforcement programs serving those populations to be shared among the law enforcement community. Building on the successes of other departments can help law enforcement agencies to continue to evolve the services provided to vulnerable communities.

Looking to the future, some law enforcement agencies also show interest in increased regionalization of the voluntary registry concept. They would like to identify a standardized way to share registry information regionally and nationally, so that if an individual living with Alzheimer's disease wanders farther than their jurisdictional line, neighboring law enforcement agencies have access to their registry data. In addition, others want to see advancing technology to support voluntary registry systems, such as an application that would enable registration quickly and easily through smart device technology.

chief's quotes

Chief Christopher Arciero, Canton (Connecticut) Police Department:

- "This program shows the community that the police are about more than traffic accidents; they are willing to go the extra mile to keep the community safe."

Sheriff William D. Gore, San Diego County, California, Sheriff's Office:

- "Over the last three years we have completed, on average per year, 559 Missing Adult reports and 1,199 Missing/Runaway Juvenile reports. Information that is timely, accurate, searchable, and regional is THE critical component when a loved one goes missing. This is especially true if your loved one has unique challenges that make communicating difficult."
- "This is a program simple in design and highly effective."
- "Through creating a smarter response, we hope to have safer people. The San Diego region endeavors to keep our most vulnerable populations safe from harm."

appendix a

SAMPLES OF VOLUNTARY REGISTRATION APPLICATIONS/QUESTIONNAIRES

Additional samples can be found at www.theIACP.org/alzheimers.

Colerain Police Department
C.A.R.E.
SPECIAL NEEDS QUESTIONAIRE

1. Name of your loved one: _____
2. What is the address where your loved one spends the majority of their time? ___

   _____
3. Does your loved one go by a nick name? If so, what? _____
4. Date of birth and age of the registered person: _____
5. Diagnosis of the registered person: _____

   _____
6. List all pertinent names and phone numbers officers may need when dealing with your loved one. _____

   _____
   _____
   _____
7. Physical description of the registered person:

   Height: _____
   Weight: _____
   Hair Color: _____
   Eye Color: _____
   Race: _____
   Gender: _____
   Glasses: ☐ YES ☐ NO
8. Is there a special interest (outside of their residence) that your loved one is drawn to? (For example: trains, water, woods, parks, malls, traffic, etc.). _____

   _____
   _____
9. Has your loved one ever ran away or been reported as missing? If so, where was he/she found? _____

   _____
   _____
10. Is the registered person verbal or non-verbal? Explain in detail. _____

   _____
   _____

appendix a (continued)

11. Does the registered person fear Police or Fire-EMS personnel or emergency vehicles? Explain in detail. _____
_____
_____

12. Name of care givers, parents, grandparents or other family members involved in your loved one's life:_____
_____
_____
_____
_____

13. If your loved one becomes confrontational, how could Officers or Rescue Personnel calm them without your presence?_____
_____
_____
_____
_____

14. Are you willing to allow the Colerain Police Department to place your address and the information of your loved one's needs into the system to insure that officers are better prepared to handle the situation? _____
_____
_____
_____

15. Please explain in detail any other important information that we may need to know that might assist us in not triggering a violent response from your loved one:_____
_____
_____
_____
_____

16. Does your loved one have any triggers ie: lights, sirens, loud radio noise?_____
_____
_____

17. Address you would like your C.A.R.E. card mailed to? _____
_____
_____

Colerain Police Department

C.A.R.E.

Release Waiver

I, _____ give permission to the Colerain Police Department to release any and all pertinent information related to the care or well-being of _____ to the Hamilton County Communications Center. I realize this information may be released to other agencies via the communications center such as Fire Department and Emergency Medical Services.

Signature _____ Date _____

appendix b

POLICY, SOPS, INTERNAL COMMUNICATION & TRAINING SAMPLES

Additional samples can be found at www.theIACP.org/alzheimers.

RETURN HOME REGISTRY
Training Bulletin

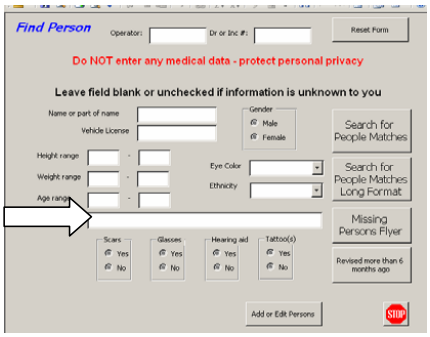
In (*Insert Date Here*), our department began the implementation of the Return Home Registry (RHR). The Registry is a searchable database that can be used by personnel to assist in reuniting lost or found persons with their family members and/or caregivers in the event they wander from their home. Persons who are prone to wander can include persons of all ages who suffer from any developmental disorder or dementia related illness that may impact their ability to safely return home. These conditions include, but are not limited to Alzheimer's, Autism, Cerebral Palsy, Down Syndrome, and children with debilitating illnesses or special needs. The program will be open to any person fitting the criteria that wants to register, or to any family member or caregiver who wants to register another individual. Registration will be limited to persons who have a direct nexus to the City of (XXXXX) either through residence or by caregiver location.

In order to be in compliance with the Health Insurance Portability and Accountability Act (HIPPA), the registry will only contain biographical information, two current photographs (portrait & full body), contact information and locations the person frequents. No medical information will be collected.

PROGRAM APPLICATION:

There are several ways the program can by used by field personnel. In the event a person is contacted and unable to provide biographical information that would assist in identifying their place of residence or caregiver, the officer would run the subjects physical descriptive data through dispatch to obtain a possible match in the RHR software database. This descriptive data includes height, weight, approximate age, hair color, eye color, scars, or other descriptive information.

Another feature of the RHR software is that it is equipped with a "Key Word" search function that can be used to further assist in identifying the registrant. Because each of the aforementioned illnesses has unique characteristics that may affect the persons memory or their ability to communicate effectively this feature was designed.



For example illnesses concerning the elderly such as dementia, the persons are likely to remember events that earlier occurred in their life. For this reason, Officers will attempt to obtain the place the person was born and their previous career that they held. A Key Word search could be done on these areas.

In illnesses affecting younger persons who may suffer from developmental disorders and have difficulties communicating, they are likely to have a unique characteristic the parent or caregiver may share during the registration process. These characteristics can include a clothing item or accessory worn or a specific mannerism from the registrant. When registering persons for the program personnel should ask the parents about these characteristics to obtain information for a Key Word search being mindful not to collect any medical information.

Additional information in the RHR data is locations the person frequents or is likely to wander. This information can be entered in to the Key Word search field as well. Examples would be; “Turtle Rock” or “Library” that could be queried by dispatch.

If a match is found a photograph and contact information will be available to assist in returning the person to their caregiver. The dispatcher will send a photograph via e-mail to the officer’s MDC where a comparison can be performed to identify the subject.

Another application for the program will be when handling a missing person call for service who is a program registrant; the officer could access the database and obtain a current photograph and a template for a Missing Person flyer. The registrants file will also give personnel locations to be included in their search based on data previously collected

REGISTRATION:

(*YOUR CITY NAME*) residents and persons working in the care providing industry will be able to begin the registration process via a link on the City of (XXXXX) website. There will also be several locations throughout the city including the Front Desk of the Police Department, the (Insert other Locations Here), and special advertised events where registration can take place with the assistance of Crime Prevention Personnel and trained volunteers.

Field personnel handling calls for service with persons who fit the criteria will explain the RHR program to the family member or caregiver and attempt to register the individual. Field personnel will complete the RHR Registration Form and have CSI respond to take photographs. If CSI is not available to take photographs a digital camera can be used. The pictures should include (1) portrait style and a (1) full body photograph. The photographs should be downloaded to the following file:

R:\GenFiles\Patrol\Return Home Registry\Photographs

The photographs file name should include the last name and (*your department name*) case number. If the persons are not interested in joining and just want additional information, they can be given a Return Home Registry pamphlet or be referred to RHR website below:

http://www.ci.irvine.ca.us/ipd/in the community/return home registry.asp

Field Personnel handling lost or found persons will reference in their report any use of the RHR database or if there were any referrals to the program. Example:

I advised Jones (family member or caregiver) about the RHR program and completed the RHR registration form and Waiver. CSI/Officer Brown took two digital photographs of Smith (person being registered) which were later downloaded into the RHR folder.

I contacted Smith (person who was lost or wandering) and had dispatch run his identifying information through the RHR Database. It revealed a match and his name and caregiver were identified.

The RHR forms can be located in the Report Writing room adjacent to the Missing Person forms. They will also be available under "Forms" on the Intranet.

The completed forms will be turned in for approval and be forwarded to Crime Prevention. They will not be turned into Records.

Remember that there are many undiagnosed illnesses in young children and one in five people over 65 have early stages of dementia even though they have not been diagnosed with the illness. Please don't hesitate to recommend the program if there is any question the person may be prone to wander. Many family members are also unaware of the initial signs of dementia.

appendix c

MARKETING & OUTREACH SAMPLES

Additional samples can be found at www.theIACP.org/alzheimers.

Expert organizations specialize in providing services and support to the various needs and challenges faced by many of our community members. These expert organizations – both government and community based – exist throughout our region.

The offer of collaboration by stakeholder experts, The Deputy Sheriff's Association (DSA), Rapid Automatic Naming (RAN) Board and HDSA coordinated support for this secure, Sheriff-hosted application.

Funding and support of this program has been provided by HDSA, Rapid Automatic Naming (RAN) Board and DSA.

Stakeholder Organizations

Sheriff's Department

Police Departments

****

****

WORKING TOGETHER TO IMPROVE PUBLIC SAFETY IN THE SAN DIEGO REGION

****

****

For more information about the ***Take Me Home*** program please contact the applicable agency or contact San Diego County Sheriff's Department Henry Tirado at 760.966.3588, Henry.tirado@sdsheriff.org or visit www.sdsheriff.net .

If your local law enforcement agency is not currently participating in the ***Take Me Home*** program, you are encouraged to contact the Public Relations office within your community's agency.

Collaborating for Safety

TAKE ME HOME

...a regional registry for community members with special needs

San Diego Sheriff's Department
William D. Gore, Sheriff

Take Me Home
is intended to serve people with developmental disabilities and/or medical conditions that increase their risk of wandering off and becoming lost. Additionally, members of this group may not be able to identify themselves or provide accurate information to first responders about their immediate needs.

Why do we need
TAKE ME HOME?
Members of our community who have developmental issues or medical conditions are sometimes reported to law enforcement as missing and/or "at risk." Due to their circumstances, they are often unable to identify themselves, their needs, or their caregiver's information.

Via the **confidential** ***Take Me Home*** database, first responders across the region can access critical information about the immediate needs of an individual with special factors.

The system quickly and seamlessly provides crucial information about behavioral considerations, medical conditions, special care instructions, detailed description of the person and a photo. This information minimizes law enforcement response time, and maximizes search efforts.

REGISTRATION IS FREE!

How do I register someone I care for?
Register with ***Take Me Home*** by contacting the appropriate stakeholder organization based on the enrollee's circumstances. Enrollment in the ***Take Me Home*** registry is free and easy. It requires submitting an enrollment form and a digital photo to the appropriate stakeholder organization. Participating organizations are listed below.

ARC of San Diego	619.685.1175
Alzheimer's Assn. San Diego/Imperial Chapter	858.492.4400
Area Board XIII State Council on Developmental Disabilities	619.688.3323
Autism Society of San Diego	619.517.4156
Epilepsy Foundation of San Diego	619.296.0161
Health & Human Services	858.505.6474
Marine & Family Services Children	760.725.6212
North Coastal Consortium for Special Education	760.761.5120
San Diego/Imperial Counties Development Services, Inc.	858.576.2966
St. Madeleine Sophie's Center	619.442.5129
Stepping Stone Resources	760.728.6951
United Cerebral Palsy of San Diego	858.571.7803

INTERNATIONAL ASSOCIATION OF CHIEFS OF POLICE
44 Canal Center Plaza, Suite 200 Alexandria, VA 22314
(800) THE-IACP alzheimers@theiacp.org
www.theIACP.org/alzheimers