

Programs to Locate Missing and Critically Wandering Elders: A Critical Review and a Call for Multiphasic Evaluation

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As America ages, greater numbers of older adults will be living with Alzheimer's disease or a related dementia, leading to increased incidence of wandering. Currently there are several initiatives to assist older adults who go missing. We describe and critically examine three prominent and widespread programs: Safe Return, Project Lifesaver, and Silver Alert. Despite their emergence, there has been little research on their effectiveness. More fundamentally, the nature and scope of the missing elder problem is understudied. We call for further research into this issue, as well as assessments of how well such programs balance individual liberties with safety concerns.

Key Words: Alzheimer's disease, Dementia, MedicAlert + Safe Return, Project Lifesaver, Silver Alert

Given population aging and increased life expectancy, incidents of wandering by elders with cognitive impairments are expected to rise in

the United States. This paper examines three U.S. based programs, the Alzheimer's Association's Medic Alert + Safe Return program, Project Lifesaver International (PLI), and the newest program, Silver Alert (although our analysis is U.S. based, Canada has a version of Medic Alert + Safe Return administered by the Alzheimer's Society of Canada called "SafelyHome." PLI is available in the United States, Canada, and Australia, and Silver Alerts is a program specific to the United States. MedicAlert + Safe Return is the program's complete name, but it is also known simply as Safe Return, the name we will use for the remainder of this paper). We chose these programs because they are visible and widespread programs that address the problem of wandering adults who go missing. MedicAlert + Safe Return is nationwide; Project Lifesaver is available in over 30 U.S. states; and as of late 2010, Silver Alert programs exist in 32 states and five others have legislation pending (National Association for States United for Aging and Disabilities, 2010; National Silver Alert Pro-

gram, 2011). We describe the characteristics and intentions of these three programs within the context of research on the problem of wandering and missing adults. Because an exhaustive review is outside this paper's scope, we focus on literature that bears relevance to the operations and outcomes of these programs. We argue that careful evaluation of such programs is critical to assure that increasingly scarce resources are used as effectively as possible and that the programs effectively balance elders' security and elders' civil rights.

Dementia and Wandering

As baby boomers enter old age, demographers predict a growth of people who live with Alzheimer's disease and other dementias. The Alzheimer's Association estimates that 1 in 8 people over age 65 (13%) have the disease, and they project that by 2050, barring any new medical breakthrough, the number of people over age 65 with Alzheimer's Disease may triple from 5.2 million to 11 to 16 million; these estimates do not include projections for the rise in other types of dementia (Alzheimer's Association, 2011). The Alzheimer's Association (2008) also states that 6 out of 10 of people with Alzheimer's disease will eventually wander. As a result, policy makers, program developers, and political leaders are concerned about the challenges that increased wandering may cause. This concern is often couched in a popular discourse that portrays Alzheimer's disease and wandering as simply defined and causally related unidimensional concepts in which the former results in the latter (Petonito, Muschert & Bhatta, 2010). However, Alzheimer's disease and wandering are complex (Dawson & Ried, 1987). A brief summary of findings with an emphasis on definitions and behaviors that illuminate policy concerns follows.

Wandering among individuals with dementia is a multifaceted behavior that has inspired several comprehensive reviews (Algase, Moore, Vanderweerd, & Gavin-Dreschank, 2007; Lai & Arthur, 2003; Silverstein, Flaherty, & Tobin, 2002). In essence, wandering is typified by locomotive behavior that may be purposeful (e.g., exploring a new area) or not (e.g., mindless pacing), and it may be something of which a person is aware (e.g., escaping from a place) or is unaware (e.g., meandering to fill time). Algase and colleagues (2007, p. 696) provide a provisional definition:

A syndrome of dementia-related locomotion behavior having a frequent, repetitive, temporally-disordered and/or spatially-disoriented nature that is manifested in lapping, random and/or pacing patterns some of which are associated with eloping, eloping attempts or getting lost unless accompanied.

Not all wandering is problematic; it can benefit older adults with dementia by providing exercise, sensory stimulation, and/or a strategy for coping with loneliness or stress (Lai & Arthur, 2003). However, we focus on what Algase and colleagues (2007) refer to as "critical wandering," which occurs when an elder leaves an institution or home and is unaware of his or her situation in terms of place and/or time. Critical wandering exposes the person to potential dangers such as falling, traffic accidents, and/or adverse weather conditions.

Employing the notion "critical wandering" helps make sense of disparate statistics. The Alzheimer's Association estimated that 60% of people with Alzheimer's disease will wander, but they do not specify what type of wandering is included in this statistic nor whether this statistic also applies to those diagnosed with other forms of dementia. Pomerantz (2006), who focused specifically on incidences of critical wandering, estimated that 12% people with dementia who live at home and 39% of people with dementia who live in nursing homes wander. McShane and colleagues (1998) reported that 40% of people with dementia get lost, and 5% get lost repeatedly. Although our interest is in wandering behavior that places individuals at risk (i.e., critical wandering), we believe that more general wandering that results in boundary transgression (i.e., when a person leaves a place where others expect her or him to be; Algase et al., 2007) has the potential to result in critical wandering. As such, we use the terms critical wandering and wandering interchangeably throughout this paper. Elders who critically wander are also characterized as missing people, but as the following review demonstrates, some researchers see wandering and going missing as two separate phenomena.

The Problem of Missing Adults

In contrast to the literature on wandering, there is surprisingly little research on the problem of missing people, and what does exist focuses on missing children (Muschert, Young-Spillers, & Carr, 2006; Sedlak, Finkelhor, Hammer, & Schultz, 2002). Scholarship on missing adults consists of mostly demographic and descriptive data, whether

in the United States (Hirschel & Lab, 1988) or elsewhere (Biehal, Mitchell, & Wade, 2002; James, Anderson, & Putt, 2008). Despite this research, there remains definitional fuzziness over exactly what constitutes a “missing” person. Essentially, a missing person is someone who “appears to have gone missing when they do not fulfill (sic) their normal patterns of life and responsibilities because they are absent from where they are expected to be” (Payne, 1995, p. 335). This broad definition of “missing” does little to help program developers understand the causes and circumstances surrounding missing elders or individuals with dementia.

In 1992, Koester and Stooksbury published a path-breaking study of missing persons with dementia aimed at search and rescuers. Drawing data from actual search requests reported to the Virginia Department of Emergency Services (VDES) from 1987 to 1990, they discovered that 29 out of 245 cases (12%) involved missing persons with dementia. Of these, six were found dead, but 23 were recovered, with 12 requiring further medical assistance. Their findings emphasized the need for speedy recoveries to avoid illness and death. In a later work, Koester (1998) emphasized that searches should be launched within 24 hr of disappearance given that all missing persons with dementia found within that time were recovered alive, whereas only 54% of those found after 24 hr survived their ordeal.

Since that study, much of the knowledge gained about missing individuals with dementia is based on a small number of retrospective studies that utilize newspaper reports (Hunt, Brown & Gilman, 2010; Lai et al., 2003; Muschert, Petonito, Bhatta & Manning, 2009; Rowe & Bennett, 2003; Rowe et al., 2011) and the findings are mixed. Lai and colleagues (2003) examined 21 Hong Kong newspapers over a 28-month period, identifying 10 incidents in which elders with dementia went missing, two of which involved the same person. Among the sample of four males and five females (mean age = 77 years), the missing person was located in nine out of the cases; 6 of the 10 were injured due to traffic accidents or falls. Muschert and colleagues (2009) replicated this study in the United States, examining 140 newspaper reports published between 2006 and 2008. They identified 80 incidents covered in 140 articles. Almost two-thirds (64%) of cases were people between the ages of 65 and 84, and 82% suffered from a cognitive impairment. Rowe and Bennett’s (2003) 4-year

(1998–2002) study found 93 instances of a missing person dying “as a result of becoming lost in the community” (p. 344). They report that 61% of these people lived at home and most (68%) died due to exposure. Hunt and colleagues (2010) focused upon newspaper reports of elders with dementia who went missing while driving. Of 207 cases involving 218 individuals, 70 drivers were not found, 32 drivers were found dead, and 116 drivers were found alive, but of these 35 people were found injured. Finally, Rowe and colleagues (2011) studied 325 cases drawn from U.S. newspaper articles published between July 2003 and June 2008. Of the 325 cases, 68% (222) were found alive, with the majority (98%) reported missing from their residence.

One consistent finding from four of the five studies is that men are more apt to go missing (Hunt et al., 2010; Muschert et al., 2009; Rowe & Bennett, 2003; Rowe et al., 2011); percentages were 73%, 56.2%, 51.3%, and 63%, respectively. These findings are notable since men comprise a smaller proportion of the elder population (Rowe & Glover, 2001). Although this literature provides descriptive information on critical wanderers, newspaper reports have limitations. Newspaper data contain cases where caregivers’ initial searches failed, and the missing elder is reported to local authorities. Conceivably, many more elders go missing than are reported as such by newspapers. A couple of researchers have conducted prospective studies that overcome the limitations of the retrospective studies (Bowen, McKenzie, Steis & Rowe, 2011; Koester, 1998). Koester (1998) worked as a part time employee of the VDES and was notified of all possible searches that involved a person with dementia during June 1996–December 1997. His examination of these records revealed that 87 of the 565 recorded incidents were most likely persons with dementia. Of these, 42 people were found uninjured, and 23 required medical attention. Bowen and colleagues (2011) conducted in-depth interviews with 39 caregivers to home dwelling veterans with dementia. They found that 24 individuals went missing at some point during the year.

The earlier literature intimates but does not explicitly state that wandering resulted in missing incidents, leading one to assume that wandering and going missing are two distinct but related phenomena. As Rowe and Bennett (2003) note: not all people with dementia who wander become lost and not all people with dementia who become lost were wandering. For example, in their study of

99 caregivers of persons with dementia, McShane and colleagues (1998) found that 44% of individuals with dementia went out on their own and 33% lived alone. Rowe and colleagues (2011) discovered that caregivers sometimes permitted persons with dementia to leave their homes or care facilities and they subsequently go missing. Of the 266 cases reviewed, 48% went missing during a planned independent activity in the community; 28% were driving and 20% were walking. Bowen and colleagues (2011) interviewed caregivers of veterans with dementia and reported similar results. Almost half of missing veterans (44%) were engaged in normal independent activity, such as walking around the yard or retrieving the mail. Caregivers discovered they were missing when they took too long to return, and in 46% of the cases caregivers had seen their missing veteran less than 10 min prior.

There is also evidence that cognitively impaired people may “be absent from where they are expected to be” before anyone is aware of it. Bass, Rowe, and Moreno (2007) documented this phenomenon in their examination of the Alzheimer’s Association’s Safe Return program. They state that twice as many Safe Return enrollees are found than are reported missing, since Good Samaritans alert Safe Return by calling the number on an elder’s bracelet or necklace prior to them ever being missed (Bass, Rowe, Moreno, & McKenzie, 2008). Similarly, McShane and colleagues (1998) reported that passers-by by chance found 8 of the 99 cases of persons with dementia who went missing and reported them to the authorities.

Finally, the rate at which missing people are found safe is also unclear. Utilizing data from Safe Return, Rowe and Glover (2001) found that 87% of individuals who wandered were safely returned to their homes. Muschert and colleagues (2009) found that 38.7% (out of 140) of persons reported missing were found dead, Lai and colleagues reported 40% (out of 10) of persons reported missing were found dead, Koester (1998) found that 16% (out of 87) of persons reported missing were found dead, and Rowe and colleagues (2011) noted that 32% of persons reported missing were found dead.

The scope of the wandering problem as it relates to persons who go missing is understudied. Whereas Bowen and colleagues (2011) indicate that elders going missing are a relatively common occurrence, Koester and Stooksbury (1992) suggested that missing elders comprise a small percentage of missing

adults (12%). Hence, more work needs to be done to understand how wandering becomes critical and to distinguish between wandering that is beneficial, critical wandering, and going missing. Moreover, studies need to determine if critical wandering is a more pervasive problem than estimated, or if the claimed prevalence of critical wandering is exaggerated. This is the nexus where several programs to intervene and potentially prevent an elder from going missing are situated.

Management of Elders Who Wander and Go Missing

Traditionally, missing elders have been subjects of search and rescue operations. These operations have sophisticated techniques to track and broadcast missing person cases (Rogers, 1986; Zoglio, 1980). Koester and Stooksbury (1992) recommended that search and rescuers modify their searches for persons with dementia, looking within a mile and a half radius and in heavy brush or creeks, for example. Programs like Safe Return, Project Lifesaver, and Silver Alert emerged as adjuncts to traditional search and rescue operations, tailored specifically to persons with dementia and other adults with cognitive impairment. All of these programs initiate searches when a caregiver reports a person missing, typically well within the critical 24 hr that Koester (1998) reported. A description of each program follows and each is summarized in Table 1.

Safe Return.—Established by the Alzheimer’s Association in 1993, Safe Return uses a community support network that includes local Association chapters and law enforcement agencies to help locate individuals with dementia who wander. To facilitate that goal, Safe Return partnered with MedicAlert, an organization that maintains health databases on individuals for release to authorities in case of medical emergencies. Funding for Safe Return derives from a one-time enrollment (approximately \$50), annual renewal (approximately \$25), and optional caregiver enrollment (approximately \$25) fees. Safe Return is a 24-hr nationwide emergency response service that maintains and utilizes a database of 145,000 registered individuals (Bass et al., 2008). Registrants wear a bracelet or necklace that notes the wearer’s identity, memory problems, and provides a toll-free number to call (Alzheimer’s Association, 2008). If an elder is missing, caregivers call Safe Return’s emergency response line, which

Table 1. Summary of Three Programs Designed to Recover Missing People

	Safe Return	Project Lifesaver International	Silver Alert
Established by	Alzheimer's Association	Project Lifesaver International	Individual states, National program proposed in Congress
Funding	Member enrollment and annual renewal	Member enrollment for maintenance fee for battery; Grant from U.S. Department of Justice allows for free enrollment for up to 1,800 families; donations	Individual states, often using existing AMBER Alert infrastructure
People served	145,000 registered individuals	1,161 agencies	Varies by state. Eligible if meets age and cognitive status criteria. Texas requires individual enrollment
Facilitated returns	11,000 people	2,500 people	Impossible to tell; records kept with states who may or may not make public
Community outreach	Continuing education and follow-up with families following return	Continuing education with enrolled agencies on use of technology and best practices for communicating with people with cognitive impairment; continuing public outreach	None

activates the community support network. Safe Return staff follow-up with families and typically address other safety-related concerns. As of 2007, the Safe Return program claimed that it was responsible for facilitating the return of 11,000 individuals to their caregivers (Bass, Rowe, Moreno, & McKenzie, 2008).

Project Lifesaver.—Project Lifesaver International provides rapid response whereas claiming to “save lives and reduce potential for serious injury for adults and children who wander due to Alzheimer’s, Autism, Down Syndrome, dementia” and other related disorders (PLI Website, 2012). Individuals enrolled in Project Lifesaver wear a transmitter that emits an individualized radio frequency that can be picked up by receivers. Caregivers notify their local Project Lifesaver agency if a person goes missing and a trained emergency team responds. PLI partners with for-profit agencies that supply the locating equipment. Funding comes from donations, a Department of Justice grant that provides an enrollment stipend for up to 1,800 families, and individual enrollment (about \$25) to maintain their battery. (PLI Website, 2012). PLI does not keep statistics on individual persons served because “the number changes by the minute” (telephone conversation with PLI, September 1, 2010). They maintain information on the 1,161 U.S. agencies they serve, which includes 538 sher-

iffs’ departments, 240 police departments, and 47 fire departments. The number of elders served is a small percentage of elders in a community. For example, in Butler County, Ohio, which is estimated to comprise just over 42,000 elders (U.S. Census Bureau, 2010), the local chapter of PLI serves at most 14 people in any given day (telephone conversation with PLI, September 1, 2010). PLI works closely with law enforcement and other public safety agencies in the use of the tracking equipment and educated on best practices for locating and communicating with persons with cognitive impairment. They claim they recovered over 2,500 people with no injuries or fatalities (PLI Website, 2012).

Silver Alert.—Silver Alert relies on integrated efforts to use the media, traffic signs, and law enforcement to inform the public of missing elders who are cognitively impaired (and in some cases any missing adult). Most Silver Alert programs broadcast information about a missing person primarily through television stations (National Association of State Units on Aging [NASUA], 2009), but they also use radio stations and electronic traffic signs. The first program (called Maddie’s Alert) was enacted in Georgia in 2006 and by the end of 2010, 32 states had Silver Alert programs in place and five had legislation pending (NASUA, 2009; National Silver Alert Program, 2011). Since 2008,

several Congressional members have introduced a National Silver Alert Act, with bills pending in the U.S. House and Senate as of late 2011 (Library of Congress 2011A, 2011B).

Unlike Safe Return and PLI, which aim to enhance identification and tracking, Silver Alert seeks to add “eyes and ears” to search and rescue efforts. Silver Alert programs also differ from Project Lifesaver and Safe Return in that they are administered at the state level and, with one exception (i.e., Texas), do not require individual registration. Silver Alert programs typically require individuals to meet two criteria to activate an alert: age and cognitive status (Carr et al., 2010). Most target those age 60–65 years and older, but some programs include any cognitively impaired person over age 18 (Carr & Muschert, 2009). Some but not all programs require a medical diagnosis of cognitive impairment. Because Silver Alert programs are maintained by individual states, there are no compilations of the number of alerts issued nationwide. Data from states that have a Silver Alert policy are recorded in the aggregate from the news media. For example, Toone (2009) reported that 70 individuals of the 71 alerts issued in Georgia between 2006 and 2009 were found. In lieu of independent evaluation studies, media reports provide the only available data on the efficacy of the Silver Alert program. Finally, we have no evidence that Silver Alert programs engage in any community outreach or education or follow-up as is the case with both Safe Alert and PLI, although this information could change as the programs develop.

Proponents of the three programs maintain that they are vital to manage the problem of wandering elders. However, little scholarship empirically assesses the extent to which wandering is a problem and even less has evaluated programs that purport to solve the problems that result from critical wandering. This lack of research is a concern for two key reasons. First, the extent and nature of the problem of critical wandering is unknown, so it is not possible to determine whether programs are using resources as effectively as possible. Second, it is important to consider the extent to which the technology used by these programs may impinge on elders’ civil rights.

The Nature of the Problem

In the absence of research on wandering in general, and the incidence of critical wandering in particular, it is unknown whether programs actually work as intended. For example, Rowe and Glover

(2001) and Bass and colleagues (2007) conducted studies using data collected by Safe Return. Rowe and Glover (2001) reported that 82.3% of wandering persons with dementia were found alive and safely returned within 12 hr and Bass and colleagues (2007) noted that half of Safe Return enrollees were found within the first 4 hr of being reported missing, with 88.4% recovered within 24 hr. Yet, neither study determined whether the Safe Return registration or identification jewelry facilitated any of the returns. In fact, Bowen and colleagues (2011) reported that just over half (53%) of Safe Return enrollees did not wear their identification jewelry. Similarly, Florida’s Silver Alert program reported that, of the 377 alerts issued between 2006 and 2011, 367 people were successfully recovered, but only 51 of the cases could be “attributed directly to the Silver Alert” (Department of Elder Affairs, 2011).

We propose that the first step to determine whether the programs actually solve the critical wandering problem is to document the scope of the missing elder problem. Studies should frame the problem broadly, clearly distinguishing between going missing, wandering, and critical wandering. As Algase and colleagues (2007) note, the “lack of a standardized definition of wandering is a fundamental problem that hinders achievement of clinical practice and research goals” (p. 696). Once researchers study the nature and circumstances that result in an elder going missing, with critical wandering as a possible subset of that phenomenon, then they can enhance existing or develop new programs to specifically address the problem.

Second, we suggest that any evaluation of the earlier programs should determine what components of the program are most effective. For example, Safe Return routinely sends a photo and other identifying information to law enforcement and area hospitals when a person is reported missing, so a person could be found without the identifying jewelry. Hence, a possible research question is whether the information provided to law enforcement facilitated the rescue more so than the Good Samaritan calling a number found on an ID bracelet. Similarly, research could examine the impact of the training of law enforcement involved in PLI or if Silver Alert programs should implement community outreach.

The Potential Costs of Existing Programs

Each of the three programs reviewed employ different strategies to address the problem of going

missing and critical wandering. Collectively, these programs can be conceptualized as surveillance practices that include compiling identifying information into a database (Safe Return), use of a transmitter (Project Lifesaver), or the issuance of a public notice (Silver Alert). We can also see such practices at work with the myriad of gerontechnologies, such as motion detectors and weight sensitive mats by the doors that purport to assist persons with dementia age in place (Kearns, Rosenberg, West & Applegarth, 2007) and Internet-based monitoring technologies that assist caregivers in assuring the safety of their relative with dementia (Kinney, Kart, Murdock, & Conley, 2004). Although the surveillance practices vary, they are perceived to be innocuous in the context of the “greater good” of safeguarding older people, decreasing risk and liability, and helping elders “age in place” (Eltis, 2005). These are positive intentions, but the surveillance practices may have unintended consequences. First, they may impede elder’s civil rights and second, they may provide a false sense of security. We examine these two issues in the following.

Much of the concern regarding the curtailment of elder’s civil rights is based upon the notion that cognitively impaired elders never consented to surveillance. Some, but certainly not all, proponents of surveillance practices maintain that dementia has left only a shell of what the person once was (Clarke, 2006) and these individuals cannot give their consent. As a result, “caring for the caregiver” (Adams, 1996) becomes the focus of policies and programs. Nevertheless, caregivers must balance their desire to help the persons for whom they care live autonomously with the need to protect them from harm. This often results in safety “trumping” freedom (Robinson et al., 2007), despite claims that surveillance technologies such as a bracelet, necklace, or transmitter physically differentiates them from other elders (Eltis, 2005; Robinson, Brittain, Lindsay, Jackson & Oliver, 2009) or may impede person centered care (Plastow, 2006). Many caregivers believe that Safe Return, Project Lifesaver, and Silver Alert ensure their elder’s safety.

However, technologies such as those used by the three programs may create a false sense of security that should not replace vigilance and/or common sense (Reed, 2007). The technologies are fallible (i.e., servers that maintain databases “crash” and transmitters can fail), and potentially unreliable (Kinney et al., 2004; White, Montgomery & McShane, 2010). There are areas that are out of range of transmitters and other locating

devices and even if location is possible, rescue efforts could be foiled due to severe weather conditions. Further, Robinson and colleagues (2007) worry that some personal technologies may make an elder a target for thieves. Silver Alert programs broadcast information such as home addresses, license plate numbers, individual characteristics, and photographs to the public, which may place elders at risk for identity theft or other crimes (Yamashita, Carr & Brown, 2010). Finally, some policy makers and political figures claim that adding extra alerts via a Silver Alert program may result in a numbing effect, causing the public to ignore all alerts (Shilling, 2008).

Majd Alwan, Director of the Center for Aging Services Technologies stated: “These technologies need to be evaluated” (Neergaard, 2007, p. 1). We agree. Specifically, we assert that it is not only potentially fiscally inefficient to use federal funds to address critical wandering without knowing the nature and scope of the problem but also the costs to those who go missing and to their caregivers are potentially extensive. We also need to assess what level of risk we as a society are willing to accept. The idea that we live in a social context that is sensitive to risk is not new (Beck, 1992, 1999), although a generalized heightened sensitivity to risk may be a new development. Accidents, natural, and industrial disasters, and other tragedies generate social anxiety and fear (Ungar, 2001), and this fear generates greater demands for risk and crisis management. Those who study population aging indicate that society may view aging itself as a risk, even an apocalyptic one for society as a whole (Gee & Gutman, 2000). So, it is important to carefully evaluate the technologies that are employed to manage the problem of wandering, with an emphasis on striking a balance between managing risk by offering security for elders with cognitive impairments and safeguarding their individual civil liberties.

Conclusion and Fruitful Research Directions

Our review of the problem of wandering and the programs designed to address the problem of critical wandering highlights two issues. First, the nature and scope of the missing elder problem is understudied. We recommend that researchers distinguish going missing, wandering, and critical wandering and determine the numbers of such incidents and the surrounding circumstances. An initial step would be a systematic and comprehensive review that links both the wandering and missing adult literature. Once these issues are defined,

categorized, and measured, we can enhance existing or develop new programs that effectively address the problem. Second, neither Safe Return, Project Lifesaver, nor Silver Alert have been evaluated to determine if they address the problem for which they were designed; that is, to return critically wandering elders to safety. Additionally, we maintain that failing to examine existing programs results in unintended consequences of emphasizing safety over ensuring civil rights, thereby resulting in a false sense of security for elders who wander and their caregivers when circumstances arise that make technologies unable to work as designed or when the program to recover a missing elder places her/him at risk for other safety issues.

We recommend that policy makers, program developers, and other stakeholders pause to examine whether policies that purport to foster “aging in place” become “ageism in place,” whereby otherwise socially responsible elders are subjected to increased monitoring and restrictions on their mobility (Kenner, 2008). Policy makers and program developers should attend to the ethical and civil rights implications of such initiatives (Eltis, 2005) and heed the concern of Kitwood and Bredin (1992) with preserving the personhood of people with dementia. In fact, Wiles, Leibing, Guberman, Reeve, and Allen (2011) suggest that elders want choices in how they age in place, maintaining and sense of continuity with, and ties to loved ones and community. Moreover, some research suggests that as a person’s dementia advances, caregivers become increasingly incongruent in recognizing their loved one’s values and preferences (Reamy, Kim, Zarit, & Whitlatch, 2011), suggesting that decisions on how to balance safety and autonomy should be made early in a person’s disease process. Several researchers (e.g., Hanson et al., 2007; Topo et al., 2007) have begun to seek input from elders in early stages of dementia to develop assistive technologies. In a noteworthy example, Robinson and colleagues (2009) used elders’ input in the design and evaluation of assistive technology in their Keeping in Touch Every Day study. The results were fruitful—this program introduced a way for elders who have dementia to engage in “safe walking” outside their home. As the authors note, “people with mild to moderate dementia are eminently capable of providing valuable feedback in the design of such technologies” (p. 501). With elders at the forefront of planning such policies, policy makers can work to alleviate civil rights concerns.

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