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### Community Mobility and Dementia: A Review of the Literature

Nina M. Silverstein

*University of Massachusetts Boston, [nina.silverstein@umb.edu](mailto:nina.silverstein@umb.edu)*

Megan Vanderbur

*Indiana University*

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# Community Mobility and Dementia

A Review of the Literature

THE ALZHEIMER'S ASSOCIATION PUBLIC POLICY DIVISION AND  
THE NATIONAL HIGHWAY TRAFFIC SAFETY ADMINISTRATION

Prepared for the Alzheimer's Association Public Policy Division and  
The National Highway Traffic Safety Administration, Washington, DC

Megan Vanderbur  
Indiana University

Nina M. Silverstein, Ph.D.  
Gerontology Institute and  
College of Public and Community Service  
University of Massachusetts Boston

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## EXECUTIVE SUMMARY

By the year 2030, 70 million Americans will be 65 or older (AARP, 2004). Approximately 80 percent of this population will likely be driving themselves. And without appropriate and timely interventions, many are likely to be driving with Alzheimer's disease (AD). Current estimates suggest that 2 percent of the population 65 to 74, 19 percent of the population 75 to 84, and 47 percent of the population 85 and older are likely to suffer from Alzheimer's disease or a related disorder. By the year 2050, the number of Americans with Alzheimer's disease could range from 11.3 million to 16 million (Alzheimer's Association, 2005). This significant portion of the aging population will eventually have its community mobility affected by the disease progression.

The focus of concern surrounding transportation for those with dementia has until recently been on driving cessation. However, while it is important to be aware of issues related to driver screening and assessment, equal attention should be devoted to cessation counseling and helping the driver move to the passenger seat. Currently, alternative modes of transportation are not very "elder-friendly," let alone "dementia-friendly." This paper reviews the available literature on community mobility and dementia, beginning with driving and concluding with community-mobility options. The document provides a starting point for addressing the policy, program, and research issues implicit in finding ways to meet the community mobility needs of a population for whom driving is no longer safe.

### *The Safety of Drivers With Dementia*

Dementia is thought to affect many critical abilities needed for driving, including perception and visual processing; the ability to maintain selective attention on particular stimuli for extended periods of time; the ability to attend to multiple stimuli at once; the ability to make correct judgments (such as which drivers have the right of way); and the ability to react appropriately when pressured in a traffic situation (Janke, 1994; Uc et al., 2004). In the early stages of their disease, individuals with dementia may be capable of driving under normal conditions since the mechanisms of vehicle operation are usually well established within their long-term memories. But the driver may have difficulty responding to new or challenging circumstances, and individuals in this stage are known to become lost while driving (Hunt, 2003; Silverstein, Flaherty, and Tobin, 2002). They may stop scanning their surroundings and instead focus on looking straight ahead. As individuals progress into moderate impairment, the ability to drive competently is highly compromised, as is insight into their level of skill impairment (Janke, 1994; Anstey, Wood, Lord, and Walker, 2004). People with severe impairment are usually nonambulatory.

### ***Monitoring Drivers With Degenerating Abilities***

It is expected that physicians routinely evaluate patients diagnosed with a dementia to determine the progression of their disease and thus are in a position to periodically see and talk to the patient. Maslow (2004) notes that serious coexisting medical conditions, such as diabetes, may accompany dementia. In fact, older people often suffer from one or more chronic conditions, for which they may be taking several medications (Holte and Albrecht, 2004; Lococo and Staplin, 2005b).

Monitoring of driving ability, often by default, falls to the physician, and by itself the presence of a chronic health condition should prompt a discussion about potential impairment in driving skills, and polypharmacy issues should raise concerns as well; yet driving abilities are not typically discussed during the physician visits. In addition, physicians do not often refer patients for a driving competency assessment, nor are they present during actual driving evaluations.

Many State departments of motor vehicles (DMVs) recognize the need to periodically monitor those with dementia, although few have systems in place for doing so. An opportunity exists in that DMVs see drivers periodically at the time of license renewal (unless renewal is by mail or through the Internet). In a report on Medical Advisory Board activity for the National Highway Traffic Safety Administration (Lococo and Staplin, 2005a), 20 DMV jurisdictions reported that they train their licensing personnel how to observe for impairing conditions, with four of the jurisdictions having specialized training related to recognizing impairments in older adults.

States whose licensing laws specifically mention Alzheimer's disease include California and Pennsylvania. Oregon's laws refer to individuals with cognitive impairments while Florida, Georgia, Iowa, Kansas, Kentucky, Nebraska, Nevada, North Dakota, Rhode Island, South Carolina, Utah, Virginia, and the District of Columbia all reference the need to monitor people with mental disease or impairment. All these descriptions could be applied to the individual with dementia. A report submitted by a health care professional or concerned citizen to the DMV in these States would most likely require review and, in some instances, could be heard by the State Medical Advisory Board.

### ***Compliance With Driving Assessments***

In a study by Adler, Rottunda, and Kuskowski (1999), 46 percent of licensed drivers with dementia of the Alzheimer's type reported that they would be reluctant to discontinue driving based solely on a physician's advice. Eighteen percent of drivers and 32 percent of their caregivers believed it was the physician's responsibility to determine when the patient was no longer able to drive safely. The majority of drivers (57%) and a third (35%) of caregivers believed it was the responsibility of the individual with dementia to make that determination. There is also concern that even if impaired



individuals do initially comply with driving assessments, the disease progression might cause them to forget their decision and attempt driving. Officials in State transportation departments have also expressed concern regarding the lack of uniformity in driving regulations from State to State. It is thought that some retirees may relocate to States with less stringent licensing procedures in an effort to maintain mobility longer (Bener, 2005). This would be an especially dangerous practice for drivers with dementia, given the importance of periodic assessment of driving skills.

### ***Impact of Driving Cessation for the Individual With Dementia***

For individuals with Alzheimer's disease, losing the ability to drive has varying effects on their ability to remain active in the community and continue engaging in routine activities of daily living, such as shopping and going to medical appointments. Adler et al. (1999) found that 68 percent of Alzheimer's patients and caregivers believed that driving cessation would inconvenience the individual with Alzheimer's. However, fewer families expected difficulty, with 50 percent of the caregivers believing that cessation would inconvenience the family. These patients were less likely to be depended on to provide transportation for others and were mostly supported by caregivers who provided for their community mobility needs. One recent research report cited transportation as the main type of assistance that caregivers provide to care recipients, with 82 percent of respondents ( $n = 1,247$ ) reporting offering that form of assistance (National Alliance for Caregiving and AARP, 2004).

### ***The Community Mobility Needs of the Person With Dementia: Specialized Needs of a Vulnerable Population***

Once individuals with dementia are no longer able to drive safely, they are often unable to use public transportation systems as well (Rosenbloom, 2003). Those who become lost, easily confused, or cannot reason through complex situations while driving are usually unable to navigate public transportation systems that require the ability to understand maps, routes, and schedules.

Little is known about what can be done for individuals with dementia in order to enable them to use public transportation: Studies evaluating public transportation use by people with dementia have not yet been done (O'Neill and Dobbs, 2004). However, a case study carried out by Adler, Rottunda, Bauer, and Kuskowski (2000) found that transportation for those with dementia must involve as little waiting as possible and it must offer very unrestricted hours and routes. Currently, most public transportation does not have these options. Adapting the concepts of travel training and mobility management, such as is done for disabled populations, might be a useful strategy for people with dementia, particularly in the early stages of the disease process.



## INTRODUCTION

This paper reviews the available literature on community mobility and dementia. The document provides a starting point for addressing the policy, program and research needs implicit in finding solutions for meeting the community mobility needs of a population for whom driving is no longer safe.

The focus of concern surrounding transportation for those with dementia has until recently been on driving cessation. However, while it is important to be aware of issues related to driver screening and assessment, equal attention should be devoted to cessation counseling and helping the driver move to the passenger seat. Currently, alternative modes of transportation are not very “elder friendly,” let alone “dementia friendly.”

Concern is warranted as best illustrated by demographic data. By the year 2030, 70 million Americans will be 65 or older (AARP, 2004). Approximately 80 percent of this population will likely be driving themselves. Current estimates suggest that, 2 percent of the population 65 to 74, 19 percent of the population 75 to 84, and 47 percent of the population 85 and older are likely to suffer from Alzheimer’s disease (AD) or a related disorder (Alzheimer’s Association, 2005). By the year 2050, the number of Americans with AD could range from 11.3 million to 16 million (Alzheimer’s Association, 2005). This significant portion of the projected aging population will eventually have its community mobility affected by the disease progression.

## THE SCOPE OF THE ISSUE

By the year 2030, 70 million Americans will be 65 or older (AARP, 2004), and approximately 80 percent of this population will likely be driving themselves. Currently, the private automobile is the primary mode of transportation for older adults, as it is for other people. For many older people, driving is a necessity because the majority live in suburban or rural areas, where an automobile is often the only mode of transportation (AARP, 2005). This section examines the risk that older drivers pose to themselves and to others, and it also explores the consequences of driving cessation.

### **A Risk to Public Health: The Prevalence of Unsafe Older Drivers**

#### ***The Safety of All Drivers 65 and Older***

Based on crash rate per population group, older drivers are underrepresented. Older Americans are among the safest drivers on the road. They are involved in the fewest crashes, are more likely to wear seatbelts, and have the lowest rate of crashes due to alcohol impairment (National Center for Statistics and Analysis, 2002). However, when driver safety is assessed in terms of crashes per miles traveled, drivers of the oldest age group (85+) are more likely to be involved in a crash than those in younger age groups (Marottoli, 1998). Thus, although the oldest drivers have less exposure on the road, they have more crashes per mile driven than other age groups (Massachusetts Institute of Technology AgeLab, 2003). Tokoro (2004) notes similarities to the United States in the lower levels of driving exposure among Japanese older drivers and suggests that researchers increase their efforts to understand how older people use cars in their daily lives and what safety strategies can be developed. Hakamies-Blomqvist, Wiklund, and Henriksson (2005) caution that linear projections of older drivers' crash involvement, based on the growth of this age group and in anticipation of their increased presence in traffic, are likely to be overly pessimistic. These authors demonstrated that, compared to the crash involvement of the general population in Sweden, there was a relative decrease in older drivers' crash involvement per licensed driver and per active driver in the period 1983–1999. However, once in a crash, drivers 70 and older are also more likely to suffer severe injuries, and they have the highest probability of being fatally injured (Langford, 2004a, 2004b).

The U.S. Department of Transportation (2003) reports that the rate of driver fatality per 100 million miles driven has begun to increase among the 55 to 59 age group. For the population 80 to 84, the rate has tripled. This is thought to be due in large part to elder frailty. Crash impacts that a younger person could survive may be fatal for older people simply because their bodies are more fragile and they are more likely to suffer from a pre-existing illness that may complicate medical treatment (U.S. Department of Transportation, 2003). The higher fatality rate may also be partially due to the types of crashes that seniors are more likely to experience, such as side-impact crashes at

intersections. Langford (2004b) believes the higher fatality rate may also be due to elderly individuals having problems with gap selection, traffic complexity, high speeds, high traffic volume, and restricted sight distance.

A recent AARP survey (2005) found that most of the Nation's older population lives in rural or suburban settings, and this pattern is expected to continue as baby boomers age. Rural areas and the areas close to home that older drivers frequent are the most common sites for crashes. Older people also rarely use highways and are more likely to travel across town in stop-and-go traffic, which presents a greater likelihood of crash involvement (AARP, 2004). Thus, older drivers are likely to drive in more dangerous settings than other age groups (AARP, 2004).

### ***The Safety of Drivers With Dementia***

Dementia is thought to affect many critical abilities needed for driving, including perception and visual processing; the ability to maintain selective attention on particular stimuli for extended periods of time; the ability to attend to multiple stimuli at once; the ability to make correct judgments (such as which drivers have the right of way); and the ability to react appropriately when pressured in a traffic situation (Janke, 1994; Uc et al., 2004). In the early stages of their disease, individuals with dementia may be capable of driving under normal conditions since the mechanisms of vehicle operation are usually well established within their long-term memories. But the driver may have difficulty responding to new or challenging circumstances, and individuals in this stage are known to become lost while driving (Silverstein, Flaherty, and Tobin, 2002). They may stop scanning their surroundings and instead focus on looking straight ahead. As an individual progresses into moderate impairment, the ability to drive competently is highly compromised, as is insight into the driver's level of skill impairment (Janke, 1994; Anstey, Wood, Lord, and Walker, 2004). People with severe impairment are usually nonambulatory.

Studies relating the yearly crash rates of older Americans with dementia to those of healthy older Americans generally show an inflated crash rate for those with dementia (Hunt, 2003; Janke, 1994; Marottoli, 1998). However, such studies are often done with a small number of participants and therefore have limited generalizability. While caution should be exercised in interpreting these studies, a pattern of concern is nevertheless emerging. Researchers at Washington University in St. Louis estimated that approximately 30 percent of demented drivers would have a crash under normal driving circumstances at some point during the moderate stages of the disease, leading to the conclusion that there is an increased risk to public health (Morris, 2004). The crash risk was shown to be related to the duration of the disease and to gender. Specifically, men in the moderate stages of the disease were shown to be the most unsafe. A study conducted by the California Department of Motor Vehicles, using male drivers only, demonstrated that men with AD are less likely than men without AD to assess their driving skills

accurately and that their caregivers are less likely to recognize the problem (Janke, 1994). Such studies also report that individuals with dementia are less likely than healthy older drivers to realize that their driving is unsafe. The Washington University study found that approximately 50 percent of individuals ceased driving within three years of diagnosis. Whether such cessation was voluntary was not explained; however, given that loss of insight is common, it is unlikely that drivers with Alzheimer's disease or related dementias would stop driving solely because of self-assessment.

## **The Consequences of Driving Cessation: Different Impacts for the Individual with Dementia and the Caregiver**

### ***Impact of Cessation for the Individual With Dementia***

Two major consequences of driving cessation that affect the individual are reported in the literature. There is a loss of the sense of independence and autonomy that is often associated with driving, while reduction in mobility may result in social isolation.

Feelings of autonomy and independence are often associated with driving, so that driving cessation often prompts depressive symptoms and a decrease in activity level (Marottoli, 1998). Having a spouse or relative who drives does not mitigate the emotional impact (Stearns, Sussman, and Skinner, 2004). Therefore, it appears that it is actual loss of the ability to drive that is associated with depressive symptoms, not just the social isolation that can come from a reduction in mobility. Moreover, individuals with dementia may lack the skills to cope with feelings of diminished self-worth and increasing dependency. A recommendation from a doctor to stop driving may be met with resistance or denial, partly because of patients' inability to recognize the danger posed by continuing to drive and also because they may have lost the capacity to manage their emotional responses (Hunt, 2003). Not surprisingly, then, drivers with dementia may continue driving after they have been advised to stop or even after they have had a crash (Talbot et al., 2005). Patients with Alzheimer's disease have reported that driving cessation is one of the most sensitive and difficult issues to discuss (Post, Whitehouse, and Fairhill, 1995). Because strong emotion so often surrounds the issue of driver cessation, the decision to stop driving is often unplanned and sudden (Adler and Kuskowski, 2003).

For individuals with Alzheimer's disease, losing the ability to drive has varying effects on their ability to remain active in the community and to continue engaging in routine activities of daily living, such as shopping and going to medical appointments. In one study (Adler et al., 1999), 68 percent of Alzheimer's patients and caregivers believed that driving cessation would inconvenience the individual with Alzheimer's; however, just half of the caregivers believed it would inconvenience the family. These patients were less likely to be depended on to provide transportation for others and were mostly supported by caregivers who provided for their mobility needs. However, a 2004 AARP survey of

the general aging population (Bailey, 2004) found that on any given day, 50 percent of nondrivers 65 and older stay at home because they lack transportation options. This can result in increased isolation from the community and can seriously impair the individual's ability to age in place (U.S. Department of Transportation, 2003). Driving cessation restricts access to economic, social, and health care activities and services (Stearns, Sussman, and Skinner, 2004). Nondrivers on average make 15 percent fewer trips to the doctor and 65 percent fewer social trips than drivers do (Millar, 2005). There are often additional burdens of mobility loss, such as the increased cost of goods and services that must be delivered and the need either to find substitutes for inaccessible goods or go without them (U.S. Department of Transportation, 2004). Additional research is needed to get a better understanding of the impact of driving cessation on the social lives of people with Alzheimer's.

### ***Impact of Driving Cessation on the Family***

Driving cessation can affect the Alzheimer's caregiver in many ways. They may need to provide transportation for the individual personally or arrange for transportation services, and the nondriving family member may also experience the loss of personal mobility if they were dependent upon the individual with dementia to drive.

With the cessation of driving, responsibility for community mobility of the individual with Alzheimer's typically falls on family members. In one caregiver survey (Alzheimer's Association, 2005), 82 percent reported that they helped provide or arrange transportation for the affected family member. When individuals with dementia do stop driving, the majority of them depend on family members for transportation, with a very small percentage using public transportation such as Medivan or other paratransit services (Adler et al., 2000; Adler and Kuskowski, 2003).

Help with transportation is one of the most common instrumental activities of daily living (IADLs) assumed by Alzheimer's caregivers (Alzheimer's Association, 2005). Twenty-four percent of Alzheimer's caregivers reported using an outside service to provide transportation for the care recipient, and 18 percent used a home-delivery service such as Meals on Wheels to provide meals. The Metlife Foundation found that nearly three-quarters of all caregivers who aided in transportation, shopping, cooking, and management of finances were spending about 22 hours per month to provide this help (National Alliance for Caregiving, 2004). Among caregivers who help arrange such services, 79 percent say that they need help in finding time for themselves, managing their stress, and balancing work and family responsibilities (National Alliance for Caregiving, 2004). It should be noted that transportation for such amenities as visiting others or going to the hairdresser were not included in the trips discussed, even though these have a positive impact on quality of life.

Caregivers are likely to be among the cohort of older women who depend upon spouses for their own transportation (Adler, Rottunda, Rasmussen, and Kuskowski, 2000). Future cohorts of women may be more likely to drive themselves. A study by Adler et al. (2000) found that transportation-dependent caregivers were less likely than nondependent caregivers to have a valid driver's license. Moreover, even among those with licenses, some did not drive, and all reported driving significantly less than the individual with dementia. The most common reasons given for not driving included a lack of a driver's license and medical impairments of their own.

## CURRENT SCREENING AND ASSESSMENT PRACTICES

Despite acknowledgment among many researchers that people with dementia should cease driving at some point during the disease, there is no universally accepted test or standard that defines when driving should stop (Lincoln, Radford, Lee, and Reay, 2004). Who should test, how extensive it should be, and what constitutes a valid test are many of the questions that remain without definitive answers. This section reviews current screening practices including the differences in State policies related to driving assessment.

### **Screening for Driving Safety: What Tests Should Be Used and Who Is Responsible?**

#### ***Screening Processes***

Although research provides insights about why driving is difficult for those with dementia, it has yet to determine what degree of cognitive impairment constitutes an unacceptable risk (Vegega, 1990). As a result, many clinicians have sought methods by which fitness to drive may be determined. Much of the literature surrounding this question focuses on the Mini-Mental State Examination (MMSE) and additional neuropsychological tests to rate cognitive ability and estimate driving fitness from the results (Adler et al., 2000; Lincoln et al., 2004). However, the MMSE was not designed to be, nor has it been validated as, a predictor of driving safety; and indeed studies have shown it to be inconclusive at predicting level of crash risk (Dobbs et al., 1998; Fox, Bowden, Bashford, and Smith, 1997; Lincoln et al., 2004; Shua-Haim and Gross, 1996) and also that it fails to evaluate perception, attention, and motor skills, three areas thought to be essential to competent driving (Reger et al., 2004; Vegega, 1990). Uc et. al (2004), in assessing navigation and safety errors in comparing a sample of 32 people with probable AD with 136 neurologically normal adults, concluded that drivers with AD made more errors than the normal group on a route-following task that placed demands on driver memory, attention, and perception.

Other tests besides the MMSE have been used in assessments of driving fitness. The Clinical Dementia Rating (CDR) scale is used by neurologists to classify Alzheimer's disease severity. The scale is based on categories that include memory, judgment, problem solving, and personal care. In 2000 the American Academy of Neurology (AAN) released a review recommending that Alzheimer's patients with an impairment level of CDR 1 should not drive an automobile. In addition, it recommended that individuals with a CDR of 0.5 be referred for a professional driving evaluation as they may pose a serious traffic safety problem (Dubinsky, 2000). It should be noted that the AAN is currently reviewing its guidelines.



The Useful Field of View test (UFOV) has also been used to detect cognitively impaired drivers. This test measures speed of mental processing when the attention of an individual is divided, as it often is during driving. The test was used during the Maryland Pilot Older Driver Study conducted by NHTSA in 2003 as one of a number of tests to determine driving ability (National Older Driver Research and Training Center, 2003). The Gross Impairment Screening tool (GRIMPS), developed by the NHTSA, has also been used for driver evaluation of individuals with dementia. While the CDR, UFOV, and GRIMPS have not yet been validated for this purpose, researchers are using these tools in studies of cognitive and perceptual factors in aging and driving performance. Rinalducci, Mouloua, and Smither (n.d.) observe that changes in older drivers might best be measured using neurological measures and the UFOV.

However, neuropsychological tests have been found to be no more reliable than the MMSE, despite the fact that they can measure specific areas of cognitive ability, including visual-spatial skills, attention, and choice reaction time. Such tests measure the ability to perform nonspecific tasks, while driving involves task-specific processes that are learned through practice (Withaar, Brower, and van Zomeren, 2000). It is thought that only through a combination of tests can driving abilities be evaluated in a valid way (Hunt, 2003; Lincoln et al., 2004; Reger et al., 2004). Cognitive tests alone are not sufficient to determine fitness to drive. It is essential to develop some battery of tests that can distinguish safe drivers, those who are unsafe, and individuals with dementia who need further evaluation. Such a test would reduce the number of individuals needing further evaluation and would result in less cost for screening programs (Lococo and Staplin, 2005a).

Some researchers uphold on-road driving assessments by experienced driving evaluators as the gold standard to evaluate driving abilities (Wang, Kosinski, Schwartzberg, and Shanklin, 2003). The DriveABLE Program, developed by Dr. Allen Dobbs at the University of Alberta, is an example of an evaluation program based on eight years of research on the driving abilities of those with mental impairments (Dobbs et al., 1998). The program consists of two phases, starting with in-office testing of cognitive abilities and proceeding to in-car testing when necessary.

Snellgrove (2005) reports on a new cognitive screening instrument, the Maze Task, developed to assess the competence of drivers with mild cognitive impairment (MCI) or early dementia. In a study of 115 community-dwelling older people, 50 percent of those with MCI failed the task and 75 percent of those with early-stage dementia failed. This task correlates with known measures of attention, visuoconstructional skills, and executive functions of planning and foresight and underscores the concern related to safe driving among people with early-stage dementia or MCI.

Some argue that individuals with dementia who need driving evaluations should be assessed multiple times in multiple settings (Lococo and Staplin, 2005a). This is believed to be necessary to counteract the “good day/bad day” behavior of Alzheimer’s disease; evaluators must assure that competency is constant and not the result of an individual having a good day. Advocates of simulator use believe that the simulator more easily addresses that concern. Driving simulators that score safety error are also believed by some researchers to be effective, and some studies have shown them to correlate directly to driving evaluators’ assessments (Szlyk et al., 2002). Such simulators have multiple advantages in that they require less training for staff and do not put evaluators in cars with potentially dangerous drivers. Concern has been raised, however, about the simulators’ ability to replicate the vehicle environment accurately. They also induce motion sickness in some test-takers.

### ***Who Conducts the Screening***

When nothing more than basic cognition tests are done, a physician is usually responsible for the testing. However, physicians generally dislike being designated the “licensing gatekeeper” (Skinner and Stearns, 1999). They also express concern about the potential to disrupt the rapport they have established with patients and cite insufficient time during the office visit to discuss driving (Silverstein and Murtha, 2001). Where no other provisions are in place, responsibility for assessment typically shifts between the Department of Motor Vehicles (DMV) and licensed medical practitioners (Skinner and Stearns, 1999). When asked, individuals with dementia mentioned both themselves and their family members as better evaluators of their driving abilities than their physicians (Adler et al., 1999; Adler and Kuskowski, 2003). Ott et al. (2005) studied a cross-section of 50 drivers with mild dementia and compared clinicians’ safety assessments with those of a professional driving instructor. The researchers noted that while clinicians who were especially trained in dementia assessment were the most accurate predictors among the range of clinicians (62 to 78%), clinicians’ assessments alone was not adequate to determine driving competence with mild dementia. McKenna, Jefferies, Dobson, and Frude (2004) also provide useful insight regarding a cognitive battery to predict who will fail an on-road driving test, demonstrating 100 percent accuracy for subjects less than 69 years old; more research is needed with older age samples, however. Their cognitive assessment tool, the Rookwood Driving Battery, is described in McKenna et al. (2005).

When the decision to stop driving is made, Adler and Kuskowski (2003) found that, among those they surveyed, the physician was most often identified as the decision maker. In September 2003, the American Medical Association (AMA), in conjunction with the National Highway Traffic Safety Administration, published a *Physician’s Guide to Assessing and Counseling Older Drivers* (see Wang et al., 2003). In this manual, the importance of driver evaluation is discussed, including what the AMA sees as the ethical

obligation of physicians to assess drivers for the safety of society. The AMA asserts that, in the case of a known unsafe driver, the threat to the public safety outweighs considerations of the doctor-patient relationship.

The *Physician's Guide* recommends two brief tests for conducting a driving evaluation. The Trail-Making Test, Part B (only), and the Clock Drawing Test (CDT) with the Freund Clock Scoring for Driving Competency are considered by the AMA to be useful in identifying people who should be referred to a specialist for more in-depth screening (Wang et al., 2003). Freund et al. (2005) report that the CDT is a reliable, valid, time-effective screening tool for primary-care physicians to use in identifying at-risk drivers in need of further evaluation.

However, primary care physicians may not be the best qualified to evaluate driver safety for individuals with dementia. Brown, Ott et al. (2005) found that general practitioners' assessments of drivers' ability matched those of a qualified driving evaluator just 72 percent of the time. The same study showed that only experienced neurologists who were able to conduct full patient evaluations were able to predict driver safety with accuracy comparable to that of the driving evaluator.

When an evaluation calls for an in-depth screening, patients might be referred to a driver rehabilitation specialist (DRS). These are professionals who specialize in assessing driver ability and implementing strategies to increase driver safety. They also make recommendations about when and where individuals should drive, or whether driving should cease altogether (Wang et al., 2003). Such evaluations are most effective when the examiner has the complete medical history of the individual being assessed (Marottoli, 1998), but the history may not be available because of issues related to doctor/patient privilege or the patient's unwillingness to cooperate. Some occupational therapists also provide similar evaluation and counseling services. The American Occupational Therapy Association (AOTA) recently launched an Older Driver Initiative aimed at increasing the number of occupational therapists (OTs) who offer driving therapy and evaluations. (AOTA [2004] describes the OT's role in driving and transportation alternatives for older adults.) An initial evaluation session can cost up to \$500, however, and Medicare, Medicaid, and private insurance companies often do not cover the cost of these services.

Some States mandate driver screenings, either upon diagnosis and referral by a physician or when the driver reaches a specified age. The effectiveness of such practices remains to be studied extensively in the United States. Currently, responsibility for recognizing driver impairment lies chiefly with the impaired drivers themselves and their family members, a risky situation given that dementia patients often lack the insight to evaluate their own abilities and their caregivers may not understand the implications for community mobility of an Alzheimer's diagnosis (Silverstein and Murtha, 2001). For

example, Adler, Rottunda, and Kuskowski (1999) found that 43 percent of caregivers surveyed believed that the driver with dementia would be able to continue driving throughout the course of the disease. While it is true that many older adults begin to modify their driving as their abilities decline (Brayne et al., 2000), individuals with Alzheimer's disease are often unable to recognize the loss of their abilities (Molnar, Eby, and Dobbs, 2005; Wild and Cotrell, 2003).

## **Monitoring Driver Safety: When Is the Time for Driving Cessation?**

### ***Monitoring Those with Degenerating Abilities***

Monitoring, like assessment, often falls to the primary-care physician. Patients with dementia are routinely evaluated to determine the progression of their disease during regular office visits. Maslow (2004) notes that serious medical conditions may coexist with dementia. Some of these, such as diabetes, should by themselves prompt discussion about driving, yet this subject is not typically discussed during physician office visits. Moreover, many older people have multiple chronic health conditions and may take several medications for them, another reason for concern about critical driving skills (Lococo and Staplin, 2005b). However, physicians do not often refer patients for driving competency assessment, nor are they present during actual driving evaluations. In their discussion of the CanDRIVE research initiative, Molnar, Byszewski, Marshall, and Manson-Hing (2005) make similar observations regarding physician assessment of fitness to drive in Canada. Middleton, Westwood, Robson, and Kok (2005) in the UK report on the AGILE project (AGed people Integration, mobility, safety, and quality of Life Enhancement through driving) review a new modular, older-driver assessment system co-funded by the European Union (See also Middleton et al., 2003). Thus, the topic of driving skill assessment is a concern that is being raised across the globe.

Departments of Motor Vehicles see drivers periodically at the time of license renewal (unless renewal is by mail or through the Internet). Researchers in Australia are working on a model license-reassessment program for older drivers in their country (Fildes et al., 2001). In a report on Medical Advisory Board activity for NHTSA prepared by Lococo and Staplin (2005a), 20 DMV jurisdictions indicated that they train their licensing personnel on how to observe for impairing conditions, with four of the jurisdictions having specialized training in impairments in older adults (Szlyk et al., 2002).

As noted previously, 1 in 10 people over 65, and nearly half of those over 85, have Alzheimer's disease or a related form of dementia (Alzheimer's Association, 2005). This has prompted five jurisdictions—the District of Columbia, Illinois, New Hampshire, Oregon, and Pennsylvania—to implement age-based testing as a way to screen for high-risk drivers. In these programs, the start age of screening varies from a mandatory test at age 75 in Pennsylvania to random selection starting at age 40 in Pennsylvania. Other jurisdictions shorten the renewal cycle for older drivers while still others eliminate the option to renew by mail, necessitating in-person visits.

Lococo and Staplin's (2005a) report for NHTSA contains recommendations concerning how often people with dementia should be reevaluated. These include multiple on-road evaluations in different areas to be conducted every three to six months. Adoption of such a program would have significant implications for people with dementia and their families, especially with regard to the cost in money and time involved in multiple-day testing.

In California, Delaware, Nevada, New Jersey, Oregon, and Pennsylvania, physician reporting is required for drivers who are medically impaired and may suffer a loss of consciousness. States that encourage or allow physician reporting, but do not make it mandatory, are Alabama, Arizona, Arkansas, Colorado, Connecticut, Florida, Georgia, Idaho, Iowa, Illinois, Kentucky, Maine, Maryland, Michigan, Minnesota, Montana, Nebraska, New Hampshire, New Mexico, North Carolina, North Dakota, Rhode Island, West Virginia, Wisconsin, and Wyoming. The remaining States may not encourage reporting, or they may consider it a violation of patient/doctor privilege.

### ***Compliance with Driving Assessments***

In a study by Adler, Rottunda, and Kuskowski (1999), 46 percent of licensed drivers with dementia of the Alzheimer's type reported that they would be reluctant to discontinue driving based solely on a physician's advice. Eighteen percent of drivers and 32 percent of their caregivers believed it was the physician's responsibility to determine when the patient was no longer able to drive safely, but the majority believed that the individual with dementia should make that determination. Some observers worry that even if impaired individuals do initially comply with driving assessments, the disease progression might cause them to forget their decision and attempt driving. Anecdotal evidence supports this concern, but no validation study has yet been done (Sainz, 2004). Officials working in State transportation departments have also expressed concern regarding the lack of uniformity in driving regulations from State to State. It is thought that some retirees may relocate to States with less stringent licensing procedures in an effort to maintain community mobility longer (Bener, 2005). This would be an especially dangerous practice for drivers with dementia, given the importance of periodic assessment of driving skills.

## **State Policy Affecting Community Mobility: Variability across the Country**

### ***State Programs***

Licensing drivers is within the States' authority. Although the American Association of Motor Vehicle Administrators (AAMVA) recently began a project, in cooperation from the NHTSA, to develop model guidelines for State DMVs, currently 51 separate sets of regulations define licensing procedures across the States and the District of Columbia. An example of the variety in these regulations can be found in

driver-reporting laws that apply to physicians. Currently, 6 States require some level of physician reporting. Some are very specific about the types of conditions that can be reported, but others provide little guidance. Twenty-two States have some sort of protocol for physicians to report voluntarily but do not require it. Five States encourage self-reporting, and 44 States allow a family member to report an impaired driver. States also follow up on these reports in a number of ways; all notify the individual that they have been reported, and most give the option of contesting a report stating that the driver is unsafe. Driver notification is most commonly done by mail, and significant time can elapse between reporting and notification.

Following are examples of several current programs. The first six require physician reporting while the last three employ alternate methods, including reporting by the individual driver or by nonmedical personnel. For more information regarding specific State regulations, the appendix of the *Physician's Guide to Assessing and Counseling Older Drivers* (Wang et al., 2003) contains a State-by-State quick reference guide to licensing and renewal procedures. The Web site of the American Association of Motor Vehicle Administrators contains a similar guide as well as a summary of the activities of the various State medical advisory boards. That more-than-400-page report was prepared by TransAnalytics, LLC. (Staplin and Lococo, 2003).

### **California**

Physicians in California are specifically required to report all patients diagnosed with Alzheimer's disease. In the absence of a diagnosis of any disorder that is characterized by lapses in consciousness, they are not required to report unsafe drivers, although they are authorized to do so if they feel it is in the public's best interest. Physicians are protected from any legal liability for reporting conditions that are required by law. The California DMV is responsible for notifying and following up with reported drivers. Follow-up involves a driving evaluation and determination of an appropriate course of action, which may include revocation of the license or ordering periodic reexaminations. The California DMV also accepts reporting from other sources, including individual drivers and their family members.

### **Oregon**

Oregon is in the process of phasing in a statewide, mandatory, medical-impairment-based reporting system that requires medical personnel who qualify as primary care providers to report people with functional or cognitive impairments that cannot be corrected or controlled by surgery, medication, driving modifications, or adaptive techniques. Physicians, law enforcement officials, family members, and friends may also report drivers who are unsafe because of their medical conditions. The license of the reported individual is immediately suspended, and, for individuals with dementia, a medical file and driving record are sent to the State Health Office to determine if the individual is safe to drive. The individual may request the opportunity to demonstrate fitness to drive via written and on-road tests.

**Delaware**

Physicians in Delaware are required to report all citizens who are subject to loss of consciousness due to disease of the central nervous system. Failure to file a report is punishable by a fine of \$5 to \$50. Drivers are notified of the report, and their licenses are suspended until further examination takes place. Legal immunity is available to the reporting physician. The Delaware DMV also accepts reports from courts, other DMVs, police, and family members, and it protects the identity of all reporters. If the DMV receives questionable reports, they are sent to the Delaware Medical Advisory Board for evaluation.

**New Jersey**

New Jersey statutes require all physicians to report to the DMV any patients who experience a recurrent loss of consciousness, but the regulations do not specifically mention individuals with dementia. The license of the reported driver is then scheduled to be revoked, but that driver may request due process in an administrative court. While the physician is provided with legal immunity, the State offers no legal protection or anonymity to other reporters. The police, family members, other DMVs, and courts may also report unsafe drivers, but the report must be signed and anonymity is not protected.

**Nevada**

In Nevada, physicians must report patients who experience any disorder characterized by a lapse of consciousness, but the regulations do not specifically mention individuals with dementia. The DMV notifies the reported driver by mail and may suspend that driver's license. Legal immunity and protection are given to the reporting physician. Family members, the courts, other DMVs, and the police are also permitted to submit reports, and all are granted anonymity if it is requested.

**Pennsylvania**

Pennsylvania law requires all physicians or people authorized to diagnose or treat disorders and disabilities to report any condition that may affect driving safety to the Pennsylvania Department of Transportation (PENNDOT) within 10 days of diagnosis. Alzheimer's disease is specifically mentioned as a reportable condition. PENNDOT then notifies the individuals and asks them to submit specified medical forms in order to determine their fitness to drive or need for assessment. The State provides that no civil or criminal actions may be brought against any person or agency for providing the information required. PENNDOT also accepts reports from courts, other DMVs, police, emergency personnel, family members, caregivers, and neighbors. While all reports must be signed, the department protects the identity of the reporter.



## **Illinois**

Illinois physicians are encouraged to inform patients of their responsibility to report to the Secretary of the State any medical condition that may affect their ability to operate a motor vehicle safely. The driver is notified of the referral and required to submit a medical report. The DMV determines if further action is needed. Illinois accepts reporting from courts, other DMVs, law enforcement officials, members of the Illinois medical advisory board, National Driver Register, Problem Driver Pointer System, Secretary of State, management employees, the Federal Motor Carrier Safety Administration, and driver rehabilitation specialists. Because Illinois is not a mandatory reporting State, there is no legal protection for reporters.

## **Florida**

Florida law allows any person with knowledge of a licensed driver's mental or physical driving impairment to submit a report to the Department of Highway Safety and Motor Vehicles (DHSMV). After notifying the driver in writing, the department investigates the report and takes action if it appears to be warranted. The law provides that no report can be used as evidence in any civil or criminal trial or proceeding, and anonymity is available.

## **Kansas**

Kansas law allows physicians to provide information concerning the mental or physical condition of any patient only if patients sign a form authorizing the release of such information to the State DMV. Upon such notification, the DMV informs the individual via a written referral. Physicians who submit a report in good faith are protected from civil actions for damages, but all such reports must be signed and anonymity is not preserved since affected drivers may request copies.

## **Maryland**

The Maryland Motor Vehicle Administration (MVA) works with physicians, family members, and people with Alzheimer's to ensure they are on the road safely for as long as possible. Currently, the MVA's Medical Advisory Board reviews more than 13,000 drivers per year. Medical conditions referred to the board for investigation include any disorder that impairs the ability to make decisions or produces any kind of confusion.

When taking medical histories of patients with dementia, Maryland physicians are asked to review their driving histories as well. Physicians are also encouraged to request relevant information from family members. Physician concerns are then reported in writing to the MVA, which may order screening tests to determine the fitness to drive of the person with Alzheimer's, including an on-road test. Maryland law grants immunity to any physician reporting in good faith.

If the person with Alzheimer's has no treating physician, family members may contact the Motor Vehicle Administration to request an evaluation. A phone call or letter from a family member is sufficient to initiate a review, and the report is kept confidential. The Medical Advisory Board asks for a short description of the driving problems or incidents that are of concern. The family member's referral initiates a request for more information on the driver's medical condition from a doctor, family members, and from that driver.

### ***Fatality Prevention***

Currently, there is no information concerning the effectiveness of fatality-prevention programs. Most are too new for such statistics to be gathered. (For example, Oregon's law was passed in 2003, and implementation was only completed in 2005.) However, a study by Grabowski, Campbell, and Morrissey (2004) examined the efficacy of State licensing regulations by looking at all fatal crashes in the United States during the years 1990–2000, as identified by the Fatality Analysis Reporting System. The study determined that State-mandated vision and road tests, and more frequent license renewals, were not effective in reducing fatality rates among older drivers. Only in-person license renewal had any effect on driver fatality, and then only for the oldest drivers (those 85 and older). This effect may be due to driver self-assessment that causes those in the 85-and-older population group not to attempt to renew their licenses. This could possibly result in safe drivers being taken off the road too soon due to a desire to avoid the process of license renewal (Grabrowski et al., 2004).

### ***The Effect on Individuals with Dementia***

Most of the programs described above reference the need for periodic monitoring of drivers with dementia. States whose driving laws specifically mention Alzheimer's disease include California and Pennsylvania. Oregon's laws refer to individuals with cognitive impairments, while the District of Columbia, Florida, Georgia, Iowa, Kansas, Kentucky, Nebraska, Nevada, North Dakota, Rhode Island, South Carolina, Utah, and Virginia all reference the need to monitor those with some degree of mental disease or impairment. All of these descriptions could include the individual with dementia. A report submitted to the DMV in these States would most likely require review and, in some instances, could be heard by the State Medical Advisory Board.

The second part of this literature review focuses on what happens when the driver with dementia moves into the passenger seat. What happens to the person's ability to get around in their community and continue engaging in quality-of-life activities after driving cessation?

## COMMUNITY MOBILITY

A national travel survey referenced in a 2004 report (U.S. General Accounting Office, 2004) concerning the community mobility of older people found that 90 percent of trips taken by older people are by automobile, either as passengers or drivers. For the remaining trips, 8 percent were walking and 2 percent were on public transportation. For most individuals, however, driving expectancy is significantly less than life expectancy. On average, men outlive their ability to drive by 6 years; women outlive their driving ability by 10 years (Foley, Heimovitz, Guralnik, and Brock, 2002). Research suggests that more than 600,000 people 70 and older stop driving each year and become dependent on others to meet their transportation needs. Poor vision, memory impairment, and an inability to perform one or more activities of daily living are common reasons for older people to stop driving. This section examines transportation options for seniors, and discusses the specialized community mobility needs of the individual with dementia. This section is not meant to be exhaustive. Readers who wish to read more about community transportation options are referred to the Transit Cooperative Research Program (TCRP) at [www.tcrponline.org](http://www.tcrponline.org).

### **Current Status of Community Mobility for Nondrivers: What Are the Options?**

#### ***Community Mobility for the Nondriving Elder***

According to a 2001 report from the National Household Travel Survey conducted by the U.S. Department of Transportation's Bureau of Transportation Statistics, and the Federal Highway Administration, 21 percent of seniors 65 and older do not drive. Moreover, people 85 and older are especially likely to be nondrivers (U.S. General Accounting Office, 2004).

Currently, 15 Federal programs contain provisions for the mobility needs of disadvantaged seniors (see list in Appendix A). These programs are considered senior accessible if they are designed specifically for seniors, if seniors are included in the eligible population, or if they offer reduced fares for the elderly (U.S. General Accounting Office, 2004). These programs are generally overseen by Area Agencies on Aging (AAAs), which can also guide States in assessing seniors' transportation needs. However, most AAAs only modestly address senior mobility on the statewide level, citing their perception that local agencies make a higher priority of other programs for seniors.

On February 24, 2004, President George W. Bush signed Executive Order 13330 (Bush, 2004). This executive order established the new Interagency Transportation Coordinating Council on Access and Mobility, which was charged with coordinating 62 separate Federal programs in nine departments that provide funding for human services transportation. The latter is defined in the order as any of the broad range of programs designed to meet the needs of transportation-disadvantaged populations, including the elderly, individuals with disabilities, and those with low incomes. The coordinating

council established the United We Ride initiative to implement the executive order. This initiative is intended to eliminate duplication and ultimately to lower operating costs for transportation providers. People in need of transportation are also expected to benefit from enhanced transportation options and higher quality of services. The United We Ride initiative is also in the process of developing a Transportation Technical Assistance Clearinghouse, which will offer resources for transportation providers to improve their accessibility and staff training.

According to the U.S. General Accounting Office (GAO) (2004), the needs of older people who depend on public transportation are not being met, but there is little information about the extent of these unmet needs. Though 75 percent of nondrivers 75 and older reported satisfaction with their community mobility resources, it is believed that these seniors obtain transportation largely from family members and friends. Seniors without access to family members or those living in nonurban areas are likely to have unmet needs that are greater than those of older people who live near family members. A 2001 AARP report referenced by the GAO (2004) found that senior nondrivers accepted rides from other people more than any other transportation option.

### ***Community Mobility for the Nondriving Older Person with Disabilities***

Two Federal departments are primarily responsible for addressing mobility needs among older individuals with disabilities: the Department of Transportation (DOT) and the Department of Health and Human Services (HHS). The DOT offers targeted funding to State and local jurisdictions to develop and run transportation programs via Formula Grants for the Elderly and Persons with Disabilities, Formula Grants for Other Than Urbanized Areas, Urbanized Area Formula Grants, and Capital Investment Grants. The DOT also oversees the enforcement of the Americans with Disabilities Act (ADA) as it relates to transportation. Under the civil rights legislation, public transportation must accommodate people with disabilities. Where fixed-route bus service exists, for example, public transportation operators must also provide paratransit services. However, this applies only to areas already served by fixed-route transit and does not affect areas that have no or limited public transportation. Initiatives like United We Ride are attempting to address these shortcomings.

Medicaid provides health care benefits that include transportation to medical appointments. Approximately \$1.8 billion are spent annually to provide about 110 million trips, costing about \$16 per trip, according to the AARP study previously mentioned (GAO, 2004). Because Federal law permits them to do so, the States have adopted many different approaches to Medicaid access requirements. These range from comprehensive programs to those that rely on local private services. In addition, due to the new program of Medicaid waivers intended to encourage home and community-based services, two thirds of the States have implemented programs that provide for essential trips (such as for grocery shopping) to be paid for with Medicaid dollars.

It should be noted that Medicare does not provide transportation help for individuals with disabilities except for emergency transportation in an ambulance. This restriction is a source of controversy among transportation advocates, who argue that many emergency trips to the hospital could be avoided through increased access to preventive care at the doctor's office. Similarly, emergency trips may be used inappropriately for nonemergency episodes.

The Department of Transportation has published rules regarding the scope of public transportation services in an effort to make them more accessible to people with disabilities. Nevertheless, some still cannot use these facilities or the ADA paratransit system currently in place. Because it is limited to "curb-to-curb" service, ADA paratransit rules do not necessarily specify provision of support to would-be users who have cognitive impairments. These rules do not require the availability of a responsible person to assist the disabled individual at their destination. More comprehensive services are commonly referred to as "door-through-door" services and are not generally offered directly by Federal programs. The U.S. Administration on Aging is currently conducting a study of the benefits and costs of door-through-door services.

### ***Factors in Community Mobility***

Federal transportation programs are designed to target seniors most at risk of having unmet transportation needs related to deficiencies in six major areas: ability to drive; availability of an informal network of family or friends who drive; access to transportation provided by nonprofit community institutions; access to public transportation; adequate income; and good health. Seniors who are transportation disadvantaged are likely to have particular difficulty with transportation to multiple destinations, life-enhancing trips (e.g., visits to spouses in nursing homes or cultural events), and trips to nonurban areas (U.S. General Accounting Office, 2004).

The growth of the 85-and-older population is projected to occur largely outside of centralized areas that have public transportation already in place (Koffman, Raphael, and Weiner, 2004). The majority of the growth is expected to occur in rural areas and in recently established suburbs that have yet to set up reliable and easy-to-use public transportation. Some organizations have also begun to consider the mobility and service needs of residents of "frontier communities," so-called because they are completely removed from such direct services as respite care and adult day care. They are classified as being at least 60 miles and/or 60 minutes from the nearest market center and, thus, many critical health and social services. The Alzheimer's Association is one organization attempting to identify and provide services for remote populations with the convening of the first "Frontier Conference" in 2005.

## **Transportation Programs for the Nondriving Older Person: Options and Shortcomings**

### ***Current Programs From Transportation Service Providers***

The Federal government has traditionally provided transportation to and from the services it provides, usually by partnering with local agencies and nonprofit organizations that already provide services and funding the expansion of these services (U.S. General Accounting Office, 2004).

### ***Supplemental Transportation Programs***

The term “supplemental transportation programs” or “STPs” was coined to encompass both formal and informal programs (Beverly Foundation, 2001a). The Beverly Foundation suggests that such supplemental transportation programs effectively meet the requirements of its “5 A’s of Senior Friendly Transportation”: availability, accessibility, acceptability, affordability, and adaptability (Beverly Foundation, 2001b). (See Appendix B for further information on the 5 A’s). STPs exist in many communities across the country, often using volunteer drivers to transport riders to locations that are not covered by Federal rules, such as medical appointments. The importance of these trips to older people’s independence and dignity is often repeated. One example of a long-standing STP is the Independent Transportation Network (ITN), which originated in Westbrook, Maine. The ITN is currently involved in a national rollout called *ITNAmerica*, with programs developing in Orlando and Santa Monica.

### ***Program Efficacy***

Groups such as AARP have conducted surveys in which as many as 75 percent of respondents 75 and older respond positively when asked if they are “satisfied with their mobility” (Koffman et al., 2004). However, the U.S. General Accounting Office (2004) found—through interviews with Federal officials, evidence from nationally published research, and reports from local aging service providers—that seniors who are successful in meeting their transportation needs are often doing so with help from their families or by living in transit-rich cities. The GAO also found that seniors who rely on alternate modes of transportation often have difficulty making trips for which the car is better suited, including life-enhancing trips, and that all community mobility needs are less likely to be met for older people living in suburban or rural areas.

A 2003 Brookings Institution report (Rosenbloom, 2003) indicates that those who are unable to drive are often unable to use public transit services as well. The author determined that older Americans are likely to give up walking before they cease driving, further evidence that they would be unable to use public transportation. Since the average man will outlive his driving ability by 6 years, and the average women by 10 years, this can result in a substantial amount of time without viable transportation options (Foley et al., 2002). Even though some older people can sometimes use special transit services, most prefer to ride in a car with a friend or family member.

Special transit services typically have limited availability. They operate only during regular transit-service hours, and there are residential distance requirements (e.g., within three quarters of a mile of a regular transportation route) for one to be considered for services. The Brookings Institution report (Rosenbloom, 2003) found that many who did live near existing bus routes were still ineligible for services due to the eligibility requirements of the service provider.

Finally, the Brookings Institution report (Rosenbloom, 2003) concluded that although most communities host small, specialized paratransit services operated by nongovernmental agencies, these usually serve only a very small proportion of the elderly population, and will serve a smaller proportion as the older population grows. They will likely not be a viable strategy for addressing the community mobility needs of older individuals with dementia.

### **The Community Mobility Needs of the Person with Dementia: Specialized Needs of a Vulnerable Population**

Individuals with dementia are often unable to use public transportation systems if they are no longer able to drive safely (Rosenbloom, 2003). Those who become lost, easily confused, or cannot reason through complex situations while driving are usually unable to navigate public transportation systems that involve reading maps and schedules and understanding transit routes.

Little is known about what would make it possible for the individual with dementia to use public transportation. Studies to evaluate public transportation use by people with dementia have not yet been done (O'Neill and Dobbs, 2004). According to a case study carried out by Adler and colleagues (2000), transportation for those with dementia must involve as little waiting as possible, as well as hours and routes with few restrictions. Public transportation, however, offers none of these features. Applying the concepts of travel training and mobility management, such as is done for individuals with certain disabilities, might be a useful strategy for people with dementia, particularly those in the early stages of the disease process.



## **IMPLICATIONS FOR PROGRAM AND POLICY**

A goal for all people, including people with dementia, is to maintain their community mobility. A starting point for thinking about policy related to community mobility and dementia is to consider the policy framework for older adults crafted by the United States Department of Transportation (2003). That framework includes:

- New roadway designs that better accommodate the needs and limitations of older drivers and pedestrians, along with land use that minimizes auto dependence and facilitates aging in place.
- Vehicle safety systems designed to protect fragile older occupants, better understanding of the interaction between older drivers and vehicle systems, and use of new technologies to meet the needs of older drivers and passengers.
- Better understanding of factors that place older drivers at increased risk; more effective procedures for identifying, assessing, training, rehabilitating, and regulating functionally limited drivers; better understanding of how to enable people with functional disabilities to walk safely (see Dunbar, 2000).
- Public transportation systems that facilitate wider use by older people, including one-call-does-it-all mobility managers; evaluation and promulgation of best practices; elimination of programmatic barriers to coordinated delivery of transportation services; and intercity travel that is more elder-friendly.
- Formation of State and local action plans to develop safe transportation for an aging populace.
- A comprehensive campaign to educate older people and their caregivers on how to identify unsafe older drivers; information for community service groups to equip them to address the safe-transportation needs of older people.
- Research on the effects that loss of mobility can have on the quality of life of older people, on the potential for related health-care costs, and on ways to reduce the transportation problems of older people through technological and other solutions.

Action steps are delineated for each of these items in the US DOT (2003) report and in Eberhard (2004). However, steps related specifically to people with dementia have not yet been identified. That is clearly an area where leadership is needed among Alzheimer's professionals, advocates and other concerned citizens. The first step is to acknowledge that while a diagnosis of dementia does not mean that the individual must immediately stop driving, it does mean that the person will need to stop driving before long, and that plans should be in place when that time comes.

Below are gaps and barriers to an effective transportation and community mobility approach that will help people with dementia to remain in their communities for as long as possible. The list is not exhaustive, however it addresses some of the most crucial elements of transportation for people with dementia.

## **Current Policy Gaps: The Community Mobility Needs of Individuals with Dementia**

### ***Public Transportation***

In many areas, public transportation, including paratransit, is not a viable option for individuals with dementia, particularly because independent travel is not feasible for them. Half of all older adults cannot use public transportation because it does not exist in their communities (Bailey, 2004). Public transportation depends on Federal, State, and local government funding to operate. Maintaining the current public transportation system requires \$14.8 billion in capital investments annually, while improvement would most likely require close to \$43 billion annually (Bailey, 2004). It is hoped that planned coordination within the United We Ride initiative will result in savings that will help curtail these rising costs.

### ***Screening and Assessment***

One set of elements for determining driving risk is screening and assessment. Screening can be described as the detection of a possible problem; assessment determines the extent and likely causes of the problem. While regular screening and driving assessment are important for the safety of both the general public and the individual driver with dementia, these activities can place a large financial burden on the patient and family (on top of the emotional burden they are likely to be experiencing). While most driver evaluation programs offer full assessment and screening procedures, the cost of such assessment is usually about \$300 (Wang et al., 2003), and many insurance providers will not cover these evaluations (Hunt, 2003). Moreover, such assessments are intended to be conducted multiple times for people with degenerative diseases such as dementia.

### ***Licensing Policy Proposals Affecting Individuals with Dementia***

Currently, 51 separate assessment procedures are in place across the nation to determine fitness to drive. Increasingly, licensing agencies and stakeholder groups are calling for a more uniform system of driver evaluation (Lococo and Staplin, 2005a). A uniform system would include consistent reporting and licensing criteria for drivers with certain medical conditions, thereby reducing abuse of the system (such as drivers obtaining a license in a State with less stringent policies and using it in a stricter State.). Such a system would also promote communication between licensing agencies and support services and help to reduce confusion about who should be referred for help (Bener, 2005). Recommended elements of a national assessment system include detailed physician reports with a complete patient medical history, a battery of cognitive tests, a driver interview with a trained evaluator, an on-road assessment, and finally evaluation by the local Medical Advisory Board of cases that cannot be determined through cognitive tests or driver evaluations (Lococo and Staplin, 2005a).

Dementia-specific licensing procedures have also been proposed. There is some controversy regarding the idea of a graduated de-licensing system for those with degenerative diseases (Fain, 2003; Fitten, 2003). Such a program would not revoke licensing privileges all at once but instead would gradually restrict driving privileges. For example, geographically restrictive licenses allow individuals with dementia to drive only in familiar areas near their homes. Driving tests would be conducted in this area to verify their safety (Lococo and Staplin, 2005a). Many who work with people with dementia, however, have expressed concern about these kinds of proposals. Individuals with dementia can become lost even in areas with which they are familiar, and they may have difficulty with unexpected driving situations, such as detours or road construction (Hunt, 2003; Silverstein, Flaherty, and Tobin, 2002).

### ***Proposed Initiatives Beneficial to Individuals with Dementia***

While nondrivers in the early stages of dementia may find it possible to use other forms of transportation, the loss of cognitive abilities that results in unsafe driving also commonly makes it difficult for the affected individual to use public transportation. The individual with dementia usually needs door-through-door services that place an escort at each end of the trip. These options are quite costly, however. In most services, for example, the cost of driver salaries can be as much as 50 percent of the total program budget (Kerschner, 2005). Therefore, many stakeholders now look to volunteer programs to provide transportation for this group of special-needs individuals. The success of such programs depends on resolving insurance liability concerns for volunteer drivers and securing insurance at reasonable costs, providing effective volunteer management, raising funds to cover operational costs and driver reimbursement, and volunteer recognition (Kerschner, 2005). Notwithstanding such challenges, many communities throughout the country already use volunteer programs to aid in older people's mobility (Beverly Foundation, 2001b).

### ***The Benefits of Mobility Managers***

Because older adults, and especially those with dementia, typically require a combination of public and private modes to meet all their transportation requirements, there is a growing need for local specialists knowledgeable about the network of services offered in their area. During forums and focus groups conducted for the 2003 Department of Transportation older person mobility report, the request was made frequently for a central source of help with transportation planning. This sort of service, well known in the disability network, would be invaluable to caregivers of individuals with dementia, as it would eliminate a vast amount of planning on their part (U.S. Department of Transportation, 2003). The Elder Care Locator service available through Area Agencies on Aging could potentially provide information about and referrals to local travel trainers and mobility managers.

In addition to planning daily trips, mobility managers could also be a referral resource for physicians and the Department of Motor Vehicles for people who have lost their ability to drive (Cutler, 2005). These mobility managers could possibly help create a mobility plan, not unlike a financial, legal, or end-of-life plan, that would help the individual with dementia make the transition to being a nondriver. Some research suggests that a formal mobility plan can ease the emotional distress of the individual during the process of driving cessation (Bauer and Rottunda, 2003) while providing caregivers with resources before the actual driving cessation. Liddle, McKenna, and Broome (2004) concur and note from their own work in Australia that a range of resources is needed to improve awareness of and planning for driving cessation, to provide support and education during the transition, and to maintain safety and lifestyle following retirement from driving.

### **Barriers to Improving Mobility: The Effects of Current Regulations**

#### ***Volunteer Liability***

Currently, many regulations are in place that can make it difficult for nonprofit organizations to use volunteers in providing transportation to vulnerable populations. In 2005, Helen Kerschner of the Beverly Foundation presented information regarding some of these restrictions at a White House Conference on Aging listening session (Kerschner, 2005). Kerschner noted that liability in the event of a crash is a major perceived problem facing volunteer drivers, and some are not able to purchase insurance for use in their volunteer capacity. Nonprofit organizations that rely on volunteer drivers often pay large fees to insure their drivers, resulting in increased costs to clients. In response, Kerschner made two policy recommendations: first, to implement a national policy extending the Good Samaritan law so that it limits liability to volunteers who give rides to seniors and, second, to encourage the insurance industry to cover programs and volunteer drivers who provide senior-friendly transportation.

### ***Physician Liability***

Physicians are concerned about liability at many points during the process of driver evaluation. Some States do not protect physicians who report potentially dangerous drivers to their State Department of Motor Vehicles (National Older Driver Research and Training Center, 2003). Such gaps in protection make it possible for the patient who was reported to sue the physician for revealing confidential information, despite the fact that it was done in the best interest of the patient and of the public's safety. In addition, some physicians are reluctant to discuss driving issues with patients because they do not want to be held liable for the patient's subsequent actions. In the event of a crash the physicians fear being held liable because they had failed to keep the driver off the road. These issues impair the ability of physicians to help potentially unsafe drivers receive evaluations.

### ***Policy Summary***

Addressing the policy gaps and barriers surrounding the transportation and mobility needs of people with dementia will be a long-term effort. As future research and pilot projects explore the issues noted throughout this document, decision-makers will have greater knowledge to affect change and to assure that people with dementia are able to maintain safe mobility while preserving their dignity and quality of life. The framework for action found in the vision laid out for a future transportation system in the document, *Safe Mobility for a Maturing Society: Challenges and Opportunities* (USDOT, 2003) will certainly benefit persons with dementia as well. Clearly, the general strategy steps need to be taken before the specialized needs can be addressed. Getting people talking together from federal agencies, Congress, states, counties, municipalities, health and social service agencies, and the private sector is a necessary strategy for the sustainable community interventions needed to address the mobility needs of this vulnerable population.

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## APPENDICES

### Appendix A

#### *15 Key Federal Programs for Transportation Aid*

The U.S. General Accounting Office has identified 15 key Federal programs that aid in the transportation of disadvantaged older adults:

1. **Independent Living Services for Older Individuals Who Are Blind:** provide transportation to programs and services and for general needs to blind people 55 and older.
2. **Community Services Block Grant Programs:** provide general trips to low-income people via taxi vouchers and bus tickets.
3. **Social Services Block Grants:** provide trips to medical or social services to populations identified by the States as being in need.
4. **Grants for Supportive Services and Senior Centers:** provide trips for older adults to program services and medical appointments, as well as general trips, through contact with local service providers or via their own vehicles.
5. **Program for American Indian, Alaskan Native, and Native Hawaiian Elders:** provides the specified populations with access to program services, medical services, and general trips with the programs purchasing their own vehicles.
6. **Medicaid:** provides people eligible for Medicaid services with transportation to medical appointments, usually through reimbursement to transportation providers.
7. **Rural Health Care Services Outreach Program:** gives medically underserved populations transportation to health-care services through transit passes and program vehicles.
8. **Senior Community Services Employment Program:** helps low-income seniors access employment opportunities through reimbursement for transportation.

9. **Capital and Training Assistance Program for Over-the-Road Bus**

**Accessibility:** facilitates general trips for people with disabilities by purchasing lift equipment and providing driver training.

10. **Capital Assistance Program for Elderly Persons and Persons with**

**Disabilities:** provides assistance with general trips by purchasing vehicles and contracting for services with existing providers.

11. **Capital Investment Grants:** provide funds for programs for the general public to take general trips by giving to bus and bus-related capital projects.

12. **Job Access and Reverse Commute:** provides low-income people with transportation to employment by expanding existing services or establishing new ones.

13. **Nonurbanized Area Formula Program:** provides the general public with general trips through capital and operating assistance for existing programs.

14. **Urbanized Area Formula Program:** provides the general public with general trips through capital and operating assistance for existing programs.

15. **Veterans Medical Care Benefits:** provides low-income or disabled veterans with access to healthcare services through mileage reimbursement or via contracts with service providers.

## Appendix B

### **The 5 A's of Senior Friendly Transportation**

- Availability:** Transportation exists and is available when needed (e.g., transportation is at hand, evenings and/or weekends).
- Accessibility:** Transportation can be reached and used (e.g., bus stairs can be negotiated; bus seats high enough; van comes to the door; bus stop is reachable).
- Acceptability:** Deals with standards relating to conditions such as cleanliness (e.g., the bus is not dirty); safety (e.g., bus stops are located in safe areas); and user-friendliness (e.g., transit operators are courteous and helpful).
- Affordability:** Deals with costs (e.g., fees are affordable; fees are comparable to or less than driving a car; vouchers or coupons help defray out-of-pocket expenses).
- Adaptability:** Transportation can be modified or adjusted to meet special needs (e.g., wheelchair can be accommodated; trip chaining is possible).

*\* The 5 A's of Senior Transportation were developed by the Beverly Foundation, 2001*



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