Florida Department of Elder Affairs

Florida Dementia Friendly Transportation Research Project

6/30/2010
Submitted by:
Orlando Health, Inc. and Carlin Rogers Consulting LLC
Executive Summary

Background

The Florida Alzheimer Disease Initiative (ADI), including its state sponsored Memory Disorder Clinics and the ADI Advisory Committee, has been actively engaged in the issues of transportation challenges for individuals with dementia, since the early 1990s. Monitoring research developments, establishing a policy position on these issues, as well as other important actions taken by key stakeholders, has put Florida at the cusp of program development in this emerging area. Our demographics, with an estimated 502,000 Floridians with probable dementia and 25% of our licensed drivers currently over the age of 60, require us to look carefully at the entire continuum of senior transportation for this special needs population.

When considering the challenges of drivers with dementia, we are also aware that the same cognitive or physical decline which will require a driver with dementia to stop driving at the point when warning signs begin to appear will also make it extremely unlikely that they will be able to make a successful transition to many types of alternative transit services. As their cognitive skills decline over time, these individuals require more supportive transportation services, in order to maintain connectivity with their community and their ability to live independently for as long as possible.

2008 was a seminal year in Florida for this topic. The Department of Elder Affairs commissioned a study to look specifically at dementia friendly transportation. A statewide survey of transit providers and the aging network was conducted, best practices were searched and a set of tip sheets were created to meet the education needs of providers and their families. An important part of this project was the development of a definition of dementia friendly transportation:

“Going beyond senior friendliness, a transportation service that considers the special needs of passengers with all stages of memory loss.”

This was also the year when Governor Crist signed Silver Alert into law. These two actions became the springboard for the current project.

2010 Project

Research forums were conducted with professional and caregiver audiences across the state of Florida to explore the two overlapping topics of Silver Alert and dementia friendly transportation services. Discussion on alternative transportation resources and educational requirements for transit providers, caregivers and volunteers were specifically included. Several of the tip sheets developed in the first project were included to test reaction to their content and utility. Participants shared many excellent ideas about distribution strategies for materials related to both topics.
Overarching findings from the project include:

- The high frequency with which both professional/volunteer service providers and family members are dealing with the unique challenges of providing safe transportation to individuals with dementia: every day and with every ride.
- The need for reliable escorted transportation to fill a critical gap in the transportation services profile for communities.
- The utility of the information (tip) sheets reviewed during this project, for professional and volunteer drivers as well as family members.
- The divergence of viewpoints between this subset of professionals and caregivers interviewed in the project. Professionals rely on family members to a high degree to deal with issues of driving cessation and arrangements for transportation services. Family/friends of persons with dementia do not rely on transportation services to any degree, in large part because reliable services which can provide dementia friendly transportation do not generally exist in their area.
- The Silver Alert program is a valued support structure which provides an important safety net for families. Memory Disorder Clinics should be seen as key participants in efforts to prevent occurrences and reoccurrences of Silver Alerts.

An important finding of the project indicates that one area of particular focus should be on seniors living alone. Assumptions that a familial support network will assist with critical transitions away from driving or toward alternative transportation options may not be realistic solutions for some.

As a result of both group discussion and individual written surveys, a series of recommendations have been prepared which center on four action areas:

- Silver Alert: traditional and nontraditional messaging strategies are seen as valuable.
- Dementia friendly transportation: distribution of tip sheets and visibility of the issue via select websites. Program expansion to include more transit options geared toward travelers with dementia should be considered.
- Training curriculum: Development of an in person training program for transit providers should be considered by the Department of Elder Affairs, as well as the development of a specialty certification process.
- Information: The template for transportation services developed for this project should be provided to each Community for a Lifetime in Florida. A regional transportation profile and a cataloging system for transportation alternative services which was developed for this project should assist regional community planners and other interested parties to determine necessary actions in their respective communities. Particular attention should be paid to the categorization of transportation alternative services as a means to gain a better understanding of the true availability of options.

Strategies to increase visibility of these topics will strengthen the support system for our most vulnerable seniors with special needs. Further research is needed in this area, as is work with early stage dementia travelers themselves.
Acknowledgments

We would like to recognize the invaluable efforts of the research team and our local partners in the conduct of this project. Without their generous contribution of time and effort, this project would not have reached so many parts of the great State of Florida. This collaboration and commitment on the part of so many individuals and organizations is a direct reflection of the importance of the issues before us.

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
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We would also like to recognize the hard work and diligent efforts of the project team engaged in this task.

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<tr>
<th>Name</th>
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Florida Dementia Friendly Transportation Research Project

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Section I. Introduction and Background

Today there is growing recognition about the special circumstances of people with dementia and their ability to drive safely. When they can no longer drive, which is a predictable result of the disease process, their ability to access and utilize appropriate transportation options is of great concern to passengers, families and transit providers alike. Demographic shifts toward greater numbers of seniors driving and/or relying on alternative forms of transportation have drawn our communities, our planners, our seniors and their support networks, into discussions about how to address these issues. Safety concerns are paramount.

Project History

In 2008, the Department of Elder Affairs and Carlin Rogers Consulting undertook a Dementia Friendly Transportation project that included a telephone survey of Florida transit providers and aging services providers, a report on transportation alternatives for persons with dementia, and the development of fact sheets related to transportation alternatives for Individuals with dementia. This project included numerous recommendations for creating more dementia friendly transportation services in Florida. Key findings from the project included:

1. The need to increase visibility for specialized transportation services for passengers experiencing cognitive declines
2. The need for training for both paid and volunteer drivers
3. The need for development of a strategy for distribution of existing resources and information

A significant outcome was a definition of dementia friendly transportation: “Going beyond senior friendliness, a transportation service that considers the special needs of passengers with all stages of memory loss.” This description developed in Florida, is helping stakeholders (providers, seniors and families) around the nation to begin dialogue and program development on these important topics.

One of the recommendations from the 2008 effort was that focus groups be conducted in various locations around the State to further develop these strategies, through face to face discussion with a sample of individuals and organizations dealing with these matters on a regular basis. Such groups would provide an important opportunity to pilot test materials prior to distribution throughout the State. The 2008 project provided a strategic foundation for the current initiative.
Relevance and Call to Action

25% (3,794,846) of our State’s licensed drivers are 60 years of age or older¹. As the prevalence of dementia is directly related to the aging of the population,² Florida’s demographics force us to address the issue of dementia friendly transportation sooner rather than later. With 4,396,017 seniors 60 years of age or older, and over 502,000 cases of probable Alzheimer’s disease³, Florida must take the lead in addressing these important challenges.

At least 20% of people with dementia who live in the community are living alone, with estimates reaching 44% in some geographic regions⁴⁵. Moreover, about 30% to 45% of persons with dementia continue to drive for approximately three to four years following diagnosis⁶. The concern is not simply that individuals with dementia should or should not drive, but that driving skills predictably worsen⁷. Florida has over one million seniors who live alone and 445,154 who live in rural areas⁸. Transportation issues are most problematic with both of these groups.

The recently enacted Florida Silver Alert system has taught us about the frequency of transportation crises which may confront drivers with dementia.

Statewide Strategic Assets

Florida’s Alzheimer Disease Initiative (ADI) network and its 15 State sponsored Memory Disorder Clinics are fully engaged in the issue of drivers and dementia. They have become proactive as a direct result of a statewide strategy session sponsored by the Alzheimer’s Disease Initiative Advisory Committee in June of 2005. An outcome of this sentinel event was the acceptance of an Ethics Based Policy on Driving

¹ 2009 Florida State Profile, Department of Elder Affairs website http://elderaffairs.state.fl.us.
³ http://elderaffairs.state.fl.us/english/pubs/stats/County_2009projection/2009CountyProfile_Projection.html
⁸ 2009 Florida State Profile, Department of Elder Affairs website, IBID.
Safety and Progressive Dementia\textsuperscript{9} which was adopted by the ADI network, including its Memory Disorder Clinics (MDC) and the Department of Elder Affairs. As a result of this policy establishment, each Memory Disorder Clinic is now contractually obligated to take active steps with their clients on these issues. This programmatic obligation reaches approximately 5,000 new patients throughout the State of Florida each year. Some MDCs also provide education regarding dementia and driving to their regional network of providers.

More recently, a related white paper\textsuperscript{10} was developed which addresses the concept of mandated reporting of drivers with dementia to the Department of Highway Safety and Motor Vehicles, as has been proposed legislatively in previous years.

Several Memory Disorder Clinics have addressed issues of driving wellness with their patients and families through participation in CarFit\textsuperscript{11} events. When staff discusses the difficult issues of driving cessation with a patient and/or family, counsel and advice regarding transportation alternatives is also provided. Safety issues abound for dementia individuals who are passengers in vehicles as well.

In early 2000, The Florida At Risk Driver Council (FADC) was created to serve in an advisory capacity to the Florida Department of Highway Safety and Motor Vehicles. It produced a report\textsuperscript{12} for the Florida Legislature which made recommendations for policy and practice in the areas of prevention, education and early recognition; assessments; remediation and rehabilitation; and alternative transportation. The Council brought together key stakeholders to address the issues of older driver safety with a common voice. This consortium of statewide partners has been recognized as a national model by the Government Accounting Office\textsuperscript{13}. Other states have modeled similar groups after Florida’s early efforts.

There is increasing interest in mobility issues for clients or residents with dementia, on the part of senior centers, community care centers, independent living centers, and the aging and dementia network of the State of Florida in general, as many providers and families are struggling with these challenges every day.


\textsuperscript{10} White Paper “Question of Mandating Florida Physicians to Report Drivers with Dementia”, Leilani Doty, University of Florida, dotyL@neurology.ufl.edu

\textsuperscript{11} Driver vehicle fitness program www.car-fit.org

\textsuperscript{12} “The Effects of Aging on Driving Ability”, February, 2004 www.flhsmv.gov/ddl/atriskdriver.pdf

Section II. Senior Transportation and the Challenges of Memory Loss

A Review of Literature and Key Issues

Mobility is essential for independent living. “Age and health and disability status influences choice of transportation options. As age increases and health and disability status declines, most choose family or friends as alternative transportation.”

No single solution can meet all mobility needs of all seniors; a wide range of services and systems are necessary. Alternative transit information tends to be very fragmented, however, and can be very difficult for seniors or their family members to obtain. There are certainly pieces in place, but rarely is it easy to find them in any kind of coordinated fashion. Transportation alternatives that include public transportation, volunteer networks, biking, and walking, are not well integrated in Florida. In this regard, we are not unique: other states face similar issues.

Community mobility is vital because of the opportunities that it unlocks. Seniors unable to provide their own transportation often face extremely limited lives. Research indicates that non-driving seniors make 2/3 fewer trips than drivers do.

Ongoing research and programs dealing with driver skill assessment and driving cessation issues are available now, thanks to a national focus on senior transit users over the past 20 years. The first major national study addressed the issue of cognitive performance related to driving, but omitted cognitive problems when discussing alternatives to the automobile (or as a passenger in a private vehicle). The report did recognize the important contribution of volunteer and family networks in providing trips to seniors. Even now, few projects address the special training needs of informal caregivers such as family and friends, and of transportation providers regarding strategies for dealing with a vehicle passenger with dementia.

Having a cognitive disability does not mean that you stop traveling; it just requires careful planning to ensure safety, comfort and enjoyment for everyone. Paratransit eligibility is not simply a matter of whether or not a person has a disability, but instead relates to whether or not an individual can use the transportation entity’s fixed route system safely. Historically, paratransit has focused on

14 AARP Virginia Member Survey 2007: Transportation Needs Assessment
16 Transportation Research Board National Research Council Special Report 218 “Transportation in an Aging Society Improving mobility and Safety for Older Persons”, Volume 1, 1988
physical challenges rather than impairments in cognitive abilities. Attention to cognitive challenges is now needed as well.

**Discussion of Special Needs of Drivers with Dementia**

Individuals with some form of progressive dementia, must, at some point, stop driving.\(^{18}\), \(^{19}\), \(^{20}\) Getting lost while driving can be life threatening.\(^{21}\) In a recent study by Hunt and colleagues of 207 media reports of lost drivers with dementia over a ten-year period, seventy drivers were not found, 32 were found dead, and 116 were found alive, of whom 35 were injured. Twenty of the reports in this study were from Florida.\(^{22}\)

This significant loss of independence and freedom makes people with dementia, dependent upon others to meet or support their transportation needs. As the disease progresses, confusion, forgetfulness, wandering and behavior problems can complicate all activities of daily living (ADLs) and instrumental activities of daily living (IADLs), including transportation. Individuals and organizations providing transportation services to persons with dementia face unique challenges. Moreover, the provision of transportation services to persons with dementia may be targeted as specialized services; but they also may be in mainstream programs and services intended for a general population. Therefore, increased awareness of the passenger with dementia will benefit all providers, whether they have specialized services or not.

A unique aspect of this disease is that individuals lose insight: they may think they are going to one location (e.g., home) when in fact they have not lived at that address for many years. They may not recall that a ride has been arranged for them and therefore, not be ready. They may not want to go and resist attempts to get into a vehicle.

Drivers, whether family members, volunteers or professional drivers need to be able to understand, anticipate and manage a wide array of problems which may develop\(^{23}\). Most importantly, they need to understand that “problems” which may occur are a direct result of the disease process and

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not a result of a passenger with dementia being “mean spirited”. Most insidious of all, as most dementias are not formally diagnosed or if formally diagnosed, just not revealed, a transit driver or family member may not know they are dealing with an uncooperative passenger with dementia and therefore take actions that may lead to harmful consequences.

Driving cessation support groups\textsuperscript{24} and resources\textsuperscript{25} have been developed in recent years to assist with the transition from driver to passenger\textsuperscript{26,27}. These interventions are targeted toward family members to help them communicate with impaired drivers throughout the process of driving cessation.\textsuperscript{28}

**Florida’s Silver Alert Program**

Silver Alert began to emerge shortly after the introduction of the national AMBER (America’s Missing: Broadcast Emergency Response) Alert plan used to locate missing and abducted children. By late 2008, 17 states had enacted Silver Alert policies, with more expected as national grant funding became available in 2009.\textsuperscript{29} Carr, Muschert, Kinney, Robbins, et. al (2010) examined the 17 existing state Silver Alert and related policies.\textsuperscript{30} These authors stress the need to examine the efficacy of these programs and to carefully weigh the benefits of stringent surveillance mechanisms against the potential loss of civil liberties for those who are subjects of Silver Alert.

As programs are new and there is great variation in how the programs are implemented and managed, it may be premature to examine efficacy. It is more useful at this time, to first understand how different states are addressing the challenges of persons with dementia who wander and become lost and may meet with catastrophic outcomes. The Congressional Research Service issued a report in May 2009 that highlighted the experiences of eleven states, including Florida, with existing state alert

systems in place for locating missing adults. The following information is from Table B-3, p.34-35 of that report.  

In 2008, Governor Charlie Crist signed Executive Order 08-211 establishing the Florida Silver Alert Plan after amending Section 937.021 of the Florida Statutes. The amended law requires local law enforcement to establish procedures for taking reports of missing adults, and to allow reports of missing adults to be made to the Florida Department of Law Enforcement (FDLE) Missing Endangered Persons Information Clearinghouse (MEPIC). The alert system was implemented in October, 2008. It is administered by FDLE/MEPIC in coordination with the Florida Department of Elder Affairs, the Florida Department of Transportation, and the Florida Department of Highway Safety (which includes the Florida Highway Patrol). The FLDE/MEPIC activates the alert on highway road signs after specified criteria are met; in addition, local law enforcement agencies may issue a Silver Alert locally in coordination with the media. The target population is a missing person age 60 or older who has an “irreversible deterioration of intellectual faculties (i.e. dementia),” as verified by law enforcement officials, and under extraordinary circumstances for a missing person age 18-59 who has an “irreversible deterioration of intellectual faculties.” Vangilder (2010) introduces a term, throwaways to refer to missing persons whose caregiver does not make an effort to recover him or her, and notes that adults are allowed to leave home, however, persons with mental impairments may not have the capacity to determine how to return home or know if being away from home is in their own best interest.  

Of direct relevance to this current project on transportation alternatives is Executive Order 08-211 which specifies that the Florida Department of Elder Affairs is to actively share information about the existence of the Silver Alert plan with key advocacy groups, service providers, and other organizations or agencies serving the state’s older adult population. Increased awareness by professionals, advocates, and the larger community, of concerns for wandering behavior among persons with cognitive impairments who may become lost will be helpful not only during the search and rescue response, but also in taking preventative steps toward minimizing future occurrences. Such steps relate to specialized driving assessment, driving cessation support, appropriate transportation alternatives, knowledge of community programs such as adult day services, and home safety modifications.

Florida has had 179 alerts issued since implementation in 2008, of which 32 have occurred between January 1, 2010 and May 19, 2010. Florida has created a multidisciplinary advisory committee comprised of state agency representatives, advocacy leaders and others who are reviewing the Silver Alert infrastructure here in Florida and the efficacy and outcomes of our actions to protect vulnerable seniors who become lost while driving.

33 10/08/08 – 5/19/10, per Florida Department of Law Enforcement correspondence, 5/25/2010
34 Email correspondence with Florida Department of Law Enforcement..
Section III. Alternative Transportation Services

This section discusses the spectrum of alternative transportation services which includes the important topic of escorted transportation.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>ADA paratransit</td>
<td>Complementary service to fixed route transit. Used by passengers who cannot use fixed route or rail. Eligibility criteria exist.</td>
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<tr>
<td>Adaptive devices</td>
<td>Transit services that can accommodate assistive equipment such as wheelchairs, walkers, canes, etc.</td>
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<tr>
<td>Curb to curb</td>
<td>Passengers are picked up and dropped off curbside</td>
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<td>Demand response</td>
<td>Transportation appointment set with provider and vehicle arrives as scheduled. May be either an individual or a group ride</td>
</tr>
<tr>
<td>Dementia friendly transportation</td>
<td>Going beyond senior friendliness, a transportation service that considers the special needs of passengers with all stages of memory loss</td>
</tr>
<tr>
<td>Door through door</td>
<td>Service provided across the threshold of passenger address and destination</td>
</tr>
<tr>
<td>Door to door</td>
<td>Service provided to entryway of pick-up and drop-off addresses.</td>
</tr>
<tr>
<td>Escorted transportation</td>
<td>Assistance/supervision provided by companion who may stay for the duration of the trip</td>
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<tr>
<td>Fixed route</td>
<td>Established route and stops at designated locations only</td>
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<tr>
<td>Paratransit</td>
<td>See “demand response” above. Vehicles may include small busses, automobile or vans.</td>
</tr>
<tr>
<td>Senior friendly transportation</td>
<td>Meets the 5 “A” criteria: availability; acceptability; accessibility; adaptability; affordability</td>
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<tr>
<td>Travel training</td>
<td>Orient new passengers in how to use system, routes and requirements (appointment setting, monies, etc)</td>
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<tr>
<td>Volunteer transportation</td>
<td>Service that utilize volunteers to transport passengers, in whole or in part</td>
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Applicability to General Population

A Government Accounting Office study conducted in 2004 identified five federal departments that administer fifteen programs which support transportation disadvantaged seniors. National data indicate that some types of needs are not being met, including those trips: (1) to multiple destinations or for purposes that involve carrying packages; (2) to life-enhancing activities, such as cultural events; and (3) in rural and suburban areas. The report shows that most federally funded transportation trips are

35 Beverly Foundation  www.beverlyfoundation.org
36 Transportation-Disadvantaged Seniors  Efforts to Enhance Senior Mobility Could Benefit from Additional Guidance and Information, GAO-04-971, August 2004
provided to increase seniors access to federal programs, such as Medicare. The report notes that “For those seniors who do not have access to these support structures (ability to drive; informal network of family, friends to drive; access to transportation from public or nonprofit sources; sufficient income; good health) or who live in non urban areas, some mobility needs—especially those related to life-enhancing activities—may not be met.”

Florida has a nationally recognized system of paratransit services. The Commission on Transportation Disadvantaged (TD) exists for individuals who are unable to utilize fixed route public transit and who live within an established geographic corridor. Eligibility criteria include persons who because of a mental or physical disability, income status, or age, are unable to transport themselves or to purchase transportation privately and are, therefore, dependent upon others to obtain access to healthcare, employment, education, shopping, social activities, or other life-sustaining activities, or children who are handicapped, high risk, or at risk. Florida law requires a coordinated approach to provision of services which are provided with public resources. The program tracks the services they provide. To assist seniors in accessing transportation services, the Commission for the Transportation Disadvantaged has established a website and toll-free telephone system. The senior calls the toll-free number and is connected to the Community Transportation Coordinator in the county where the individual lives. The local Community Transportation Coordinator asks a series of eligibility questions in order to qualify the senior for transportation services.

In 2009, the Department of Elder Affairs provided funding for 4.1 million trips to eligible seniors who were among the 819,000 Floridians served.

Consideration for Dementia Passengers

As we learned in the original 2008 study, transit providers report problems that happen when a passenger with dementia gets off at the wrong stop. The person is at risk in unfamiliar territory. An escort would be able to prevent this vulnerable person from possibly becoming a victim of crime. However, arranging for an escort is the passenger’s responsibility. Unfortunately, this is not a common practice.

Door-to-door transportation includes passenger assistance between the vehicle and the door of the passenger’s home or other destination. This represents a higher level of service than curb-to-curb, yet not as specialized as “door-through-door” service, where the driver actually provides assistance into and out of the home or destination. Some experts have suggested that “arm through arm” or “chair in the home to chair in the destination” be considered as criteria for dementia-friendliness.

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38 IBid, pg 21.
39 Community Transportation Association 2008 Community Transportation State Leadership Award
40 Florida Commission for the Transportation Disadvantaged 2009 Annual Performance Report, pg.97. www.dot.state.fl.us/ctd
41Attributed to Katherine Freund, CEO, ITN America (nd).
42Attributed to Helen Kerschner, CEO, Beverly Foundation (nd).
Even with door-to-door service, sometimes the passenger with dementia convinces the driver that they were supposed to get off at a different stop. To prevent this from happening, drivers must receive sensitivity training on disabilities. This training, if available, varies widely. Paratransit drivers are required to provide door-to-door service to the location showing on the driver’s manifest—no variances allowed. Nevertheless, what about those people with a cognitive disability who are no longer capable of negotiating the public transit service alone? Who is going to assist them in arranging for an escort or door-to-door transit or provide for their safety en route?

Volunteer, private and non-profit services also provide transportation. The most complete list of available services in Florida can be found at the Florida Department of Transportation Safe Mobility for Life website.  

The Beverly Foundation’s (2008) framework for application of the impact of ten warning signs of dementia on senior transportation is provided below:

<table>
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<th>Warning Signs</th>
<th>Transportation Impact</th>
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<tr>
<td>Memory loss</td>
<td>Can’t remember ride time or appointment</td>
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<td>Difficulty performing tasks</td>
<td>Has a problem making transit arrangement</td>
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<td>Problems with language</td>
<td>Is unable to communicate with driver</td>
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<tr>
<td>Disorientation to time/place</td>
<td>Gets lost after transit drop-off</td>
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<tr>
<td>Poor or decreased judgment</td>
<td>Has difficulty paying fare</td>
</tr>
<tr>
<td>Abstract thinking</td>
<td>Is unable to navigate route changes</td>
</tr>
<tr>
<td>Misplacement of things</td>
<td>Leaves belongings in vehicle</td>
</tr>
<tr>
<td>Changes in mood/behavior</td>
<td>Becomes agitated for no reason</td>
</tr>
<tr>
<td>Changes in personality</td>
<td>Becomes suspicious of driver</td>
</tr>
<tr>
<td>Loss of initiative</td>
<td>Does not want to get in or out of vehicle</td>
</tr>
<tr>
<td>Misplacement of things</td>
<td>Leaves belongings in vehicle</td>
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Understanding what the warning signs of dementia mean for transportation providers is a critical step toward meeting the community mobility needs of this unique population. The goal is that communities identify the best options for riders; not that all providers need to accommodate all riders.

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43 www.safeandmobileseniors.org.
Section IV. Project Description

Project Scope

The Florida Dementia Friendly Transportation Research Project addresses the special transportation needs of individuals with or suspected of having Alzheimer’s disease (AD) or other memory disorders. Whether it is due to dementia, age related frailties or the lack of appropriate transportation options, many older adults need very personalized and supportive transportation to remain active, independent and socially connected to their communities. The overarching mission of the project is to enhance public safety awareness by researching dementia friendly transportation alternatives which are not only safe and reliable, but supportive to both affected seniors and their families. The project builds on previous work (2008) to identify best practices and to make recommendations about resource distribution. This initiative is designed to explore options and resources needed to provide dementia friendly transportation in Florida’s communities.

Project Objectives

1. Update literature review from 2008 project
2. Host a minimum of six (6) research forums for data collection and discussion purposes
3. Distribute, collect and analyze written survey instruments from forum participants
4. Develop conclusions and recommendations related to dementia friendly transportation and to Florida’s Silver Alert program.

Project Approach

Four community partners in Florida agreed to serve as local hosts for research forums. In person sessions were designed to explore topics regarding dementia friendly transportation, Florida’s Silver Alert system and to discuss resource distribution strategies. These particular partners were selected because they met the following criteria:

a. Demonstrated interest in senior transportation matters
b. Proven track record with previous initiatives and projects
c. Ability to reach out to the broader community and involve partners as appropriate
d. Represent a mix of urban, rural and suburban areas and diverse populations.
e. Participants in Communities for a Lifetime
The communities were Orlando, Tallahassee, DeFuniak Springs and Miami. Participating organizations included two State sponsored Memory Disorder Clinics (Orlando Health Memory Disorder Clinic and University of Miami Memory Disorder Clinic) and two Senior Centers (Tallahassee Senior Center and Life Enrichment Senior Center (DeFuniak Springs). Research forums were scheduled with both professionals and caregivers in each community. Each research forum was scheduled for a two hour time block. The mix of communities represents urban, suburban and rural areas in Florida. An experienced facilitator and recorder team, Drs. Helen Kerschner and Cheryl Svensson, conducted each session. The project director, Fran Carlin-Rogers, served as session observer and staff director. Each location was afforded the opportunity to have outside observers at their session as well.

Forum participants were invited by the local host organizations and were contacted either in person or by Email. A target of 8-10 participants per group was established to ensure an appropriate size to facilitate group discussion; in view of that goal, approximately 10-15 individuals were contacted as potential participants for each group.

A script for both caregivers and professional groups was developed to ensure consistency among sessions. The focus of discussion at each research forum was to explore local perceptions of the special transportation needs of persons with dementia. Each was designed to solicit group discussion and to provide each participant with an opportunity to complete a written survey instrument. This strategy afforded each participant with the opportunity to participate publically as a part of the larger group and also to share information and recommendations privately.

This individual exercise with participating professionals allowed us to collect demographic and exposure information, to explore opinions about driving challenges, critical travel destinations for persons with dementia and perceptions of transportation service levels. The availability of adequate transportation services for people with dementia was also probed, as was the role of necessary/available transportation assistance, transportation training and Silver Alert.

The survey instrument tailored for caregivers/family/friends covered many of the same topic areas, such as driving decline, transportation service needs and availability and query about destination needs. Awareness of Florida’s Silver Alert system was included as well.

A Spanish caregiver forum was scheduled in Miami. To support this particular session, Spanish speaking translators were provided for both the facilitator and the recorder. The research forum script was given to the translator in advance, in order to ensure adequate preparation. The written caregiver survey was translated into Spanish for use in this particular session.
Data Collection

Detailed notes of group discussion were recorded for each research forum. Written individual surveys were distributed and collected during each session as well. For each forum, summaries were created and results aggregated for professional and for caregiver groups. The overall thematic directions for both groups are presented below.

Forum Participation

<table>
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<th>Community</th>
<th>Date</th>
<th># Professionals</th>
<th># Surveys Returned</th>
<th># Caregivers</th>
<th># Surveys Returned</th>
<th>Subtotal Participants</th>
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<td>12</td>
<td>12</td>
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<tr>
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<tr>
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<tr>
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<td><strong>23</strong></td>
<td><strong>23</strong></td>
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</tbody>
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Section V: Research Forum Discussion

Analysis of Research Forums with Professionals

Profile of Participants

Forty two professionals participated in the research forums. The groups included thirty one females and eleven males. While the majority (55%) of participants was under age fifty, a large number (45%) were age fifty to sixty four. Only one participant was older than sixty four years of age. The top two professional fields represented within the group were aging and transportation. Other professions represented included public safety, dementia support, human services, law enforcement, planning, hospice, and clinical rehabilitation. In addition to participating in discussions, each of the participants completed a brief written survey.

Participants described their primary roles as professionals with terms such as coordinator, representative, collaborator, planner, educator, paratransit provider, customer service, service intake, faith community transit provider, senior transit coordinator, volunteer transit provider, grant giver, community educator, crime prevention specialist, citizens safety services.

The majority of professionals (67%) said they had positions in which they came in contact with or worked with people with dementia. Their involvement included: having a family member or friend with dementia (29%), working with dementia patients periodically (40%); working with dementia patients every day (26%). Other areas of involvement included driving people with dementia, counseling or helping drivers with dementia, planning transit alternatives, educating caregivers, and providing driver assessments.

Only 26% of the participants were born in Florida. Other states where two or more of the professional participants were born included: Ohio, Michigan, Pennsylvania, Kentucky, New York and North Carolina.

Part 1 Dementia and Transportation

The discussion in Part I of the research forums with professionals addressed dementia friendliness in transportation, working with people with dementia, challenges, transportation needs, expanding information and understanding, and a review opportunity for several tip sheets including a passenger information sheet, travel tips for caregivers, and travel tips for drivers. Part I required approximately one hour of time.
1A. Dementia Friendly Transportation

Chart #1 and Chart #2 in the Appendix (What is Dementia Anyway and Dementia Friendly Definition) were displayed in each of the research forums with professionals. The comment was made that we all know drivers with memory loss, and that at some point they will need to stop driving because of the nature (or progression) of their disease.

**Question:** What do you believe can be done to support drivers with early stage dementia who exhibit some of these (see slide) characteristics? Professionals made suggestions such as the AARP driver course, a note pad in the car to write where you’re going, and family or friends to look after you. Some said that they really didn’t know what to do.

**Quotable Quotes**

“My friends called to tell me that my aunt (who lives in Miami) was going the wrong way on a road so we went down, picked her up and brought her back to live with a cousin here in town.”

“I lost my parents early, but I had an older sister who shouldn’t have been driving…so when my sister’s car broke down we didn’t repair it.”

“My mom is eighty-two years old. She had an accident not so long ago. This past mother’s day she drove my brother and me to a restaurant and made a couple of crazy turns. She lives alone in a rural area and if I take the keys, she would have to move in with one of the kids.”

**Question:** What does public transit do for people who don’t drive? While some professionals focused on taking away the keys; others tended to see it as presenting the opportunity to provide training to dispatchers, to DMV personnel, or to the family. Several commented that when people don’t drive they need transportation options.

**Quotable Quotes**

“They are the customer. There is no way we can take away the keys.”

“You need to train the dispatchers with educational programs…training is essential and the police need the training first.”

“The DMV will do an evaluation and a driving test if you refer someone to them.”

“There are two things to consider. One is liability and the second is to go to the website DMV.gov to get an evaluation for someone.”

“You should advertise the transportation services that are available.”

“The person whose keys are taken away must have choices, and options, and the means to get to services.”

“As far as public transportation goes, the drivers need training to recognize dementia and what to do.”
**Question:** What is your opinion about providing some guidelines for promoting dementia friendliness of a transportation service? The idea of defining dementia friendliness and having some dementia friendliness guidelines for transportation services was appealing to professionals. Some saw it as information needed for training and others suggested it could be used as information for evaluation, awards, or recognition.

**Quotable Quotes**

“It considers special needs of passengers with memory loss.”
“It increases awareness of the needs of dementia patients.”
“It suggests need to respond with kindness, care, and compassion.”
“It gives the transportation services a way of expanding application questions.”
“Training is needed for all stages (especially higher levels) of dementia.”
“The state has a lot of recognition programs, and maybe this could be recognition for those who make the grade.”
“We could add it to the company guidelines...and then if you win you could use it in your advertising.”
“We need criteria to evaluate it. Then it could be used as an incentive, as an award, or as recognition.”
“Everyone should be aware of dementia friendliness.”

**1B. Working with People Who Have Dementia**

Professionals participating in the research forums indicated that their work in some way involves working with people with dementia, and several indicated that they care for someone with dementia. The majority (67%) indicated that they work with dementia patients every day or periodically, more than a quarter (29%) said they have a family member or friend with dementia, and several said that they drive people with dementia to destinations. They also identified a variety of problems they face in working with people with dementia.

**Quotable Quotes**

“The biggest problem is that they think they can drive, but they can’t.”
“We can request a DMV test, but we wish the doctors would be more involved.
“The police only get involved when there is an accident.”
“We need to educate the law enforcement about the stages of dementia...this could be added to elderly abuse courses that are required.”

**1C. Challenges (in working with people who have dementia)**

**Question:** What are the greatest challenges in working with people with dementia? Professionals identified a variety of challenges in working with people with dementia. These included:

- denial on the part of the caregiver and the patient
• lack of awareness of the changes that take place in dementia patients
• understanding and assessing the level of dementia
• appreciating the responsibilities of caregivers
• resolving confusion about where to go for help
• service availability (especially transportation and home based and community services)
• depression of dementia patients
• law enforcement collaboration
• reaching a rational decision with a person with early stage dementia
• finding services in rural areas
• the reaction and response to law enforcement
• lack of preparation on the part of the person with dementia and the family
• the person with dementia wandering when the children live far away and the police don’t know who to contact
• the family caregivers because they work themselves to death and want to do it all

Quotable Quotes

A Policeman: “I didn’t know how to cope. A man was talking about a space ship and I didn’t know how to get him into the office.”
An Educator: “It’s hardest on the family.”
A Planner: “I watched the impact on my wife and her family and they didn’t want to accept it.”
A Sheriff’s Deputy: “I had to pick up an older woman going the wrong way on a bridge and her family lived in Tennessee. She was confused…I thought she was drunk…”
A Hospice Worker: “It’s hardest on the caregivers when trying to get them (the person with dementia) to do something because logic doesn’t work and I don’t have a lot of experience.”

Specific challenges related to transportation included: transportation when a senior cannot drive and isolation because they cannot access transportation options.

1D. Transportation Needs (of someone with dementia)

Professionals were given a list of service and support needs and asked to rank them in order of importance. Their choices, in order of their selections were: #1 health care, #2 home care, #3 housing, #4, transportation, #5 life enriching activities, #6 nutrition services, and #7 social services. Perhaps transportation was not higher on the list because a majority (67%) of the professionals selected family members as a transportation alternative in the community that meets the transportation needs of people with dementia. Interestingly, a large number of professionals (45%) identified friends and neighbors while under a third (31%) identified ADA paratransit services.

Question: In your professional opinion, what is the greatest transportation need of someone with dementia? Participants identified a number of transportation-related problems faced by persons with dementia including: not knowing what is out there, transportation for companionship – not just medical, ensuring safety and well being, maintaining a social life with friends, and avoiding isolation. Their
comments also included driver safety issues such as not knowing when to stop driving and needing a person or driver to ride with them. Professionals also identified a wide range of transportation needs.

- a transportation service that provides an escort who will wait and stay until they get home.
- a transportation service that provides escort services for those with dementia
- a transportation service that helps keep them safe
- a transportation service that provides communication with a dementia person who lives alone
- a transportation service that offers one place to call (e.g. one stop shop)
- a transportation service that provides 24/7 service
- a transportation service that meets basic needs
- a transportation service that gives freedom to older people to get out where and when they want to go
- a transportation service that provides respite for the caregiver
- a transportation service that gives freedom to older people to get out where and when they want to go
- a transportation service that provides communication with a dementia person who lives alone
- a transportation service that offers one place to call (e.g. one stop shop)
- a transportation service that provides 24/7 service
- a transportation service that meets basic needs
- a transportation service that gives freedom to older people to get out where and when they want to go
- a transportation service that provides respite for the caregiver
- a dementia education program for transportation providers because drivers don’t know how to help

**Quotable Quote**

“We aren’t mind readers so the family must tell us what they need. Even the family can be in denial so for transportation needs, they must tell us.

“If they have Alzheimer’s and still drive there will be an accident. Public transit needs escorts. We require an escort if there is dementia and the drivers tell us when they need one. “

“Escorted services are essential, so they can be integrated into the community.”

“So many times, dementia sneaks up on a family. They need information about warning signs and help in making a plan for early intervention.”

The need for the availability of transportation was mentioned by several professionals as were volunteer driver programs.

**1E. Understanding the Challenges (of providing transportation)**

**Question:** What do you believe could be done to enhance the understanding of other professionals about the challenges of providing transportation to people with dementia? Most professionals suggested education, information, and training. Below are some of their suggestions.

- It should be known that dementia is terminal and is a medical diagnosis as important as dialysis...and don't limit services because of dementia
- Information that helps people understand that a person with dementia can be socially competent but they are not good decision makers
- Education of professionals (sensitizing through dementia simulation)
- Education about the limitations of transportation services
- Education in small groups
- Community education to understand all services provided
- Educate the doctors that the patients live in the real world and they need resources; must learn to partner with other agencies
• education on dementia and coordination of transportation services
• education and facilitator training in the community. Alzheimer’s support groups…but it depends on the location…not at senior centers with active seniors because they won’t come…We moved our training to Friendship House…a caregiver support center
• it could be provided through PSAs that make people aware that dementia is a problem and includes the names of those in agencies who can help
• it could include an intervention plan for families…the early dementia red flags
• 211 for transportation

**Quotable Quote**

“Someone needs to provide education and information on dementia for all the public. The scope of the problem in Florida, how it affects all agencies, and the need for support should be discussed. It should include information about all the signs and stages and tidbits of what to look for (e.g. how to give up the keys, tools to get others to help you). There should be information on the websites and other locations.”

“We need to be proactive and raise dementia to an ADA status (such as in European countries)”

**Question:** Do drivers need training in providing transportation to people with dementia? Suggestions were made such as training once a year that all the drivers have to go through, training for bus and paratransit drivers; and sensitivity training; increase the PSAs to get the information started; put it on buses, billboards, and news sources.

**1F. Passenger Information**

**Chart #2** in the Appendix (**Passenger Information Tip Sheet**) was displayed in each of the Research Forums with Professionals.

**Question:** What does the chart tell you? While some professionals thought the Passenger Information Sheet would be helpful, others did not. Many of them had suggestions for enhancing it.

**Positive Comments**

• provides information on patient with dementia
• a checklist
• like customer intake and trip information
• a symbol of safety
• helpful for identifying a person’s transportation situation and needs
• would help them get home from adult day or senior centers

**Negative Comments**

• has a lot of personal information
• from a law standpoint it is good to have the information but the person might not use it
• too much responsibility for the driver.
Suggestions

- simplify it with a diagnosis and phone number and wear it; It becomes a safety issue if the bad guys get the information
- a bar code with all the information on it would be good
- make it look like a ticket to ride
- put the emergency contact information in a database
- carry a card, and swipe it
- it might include something on medications.

Quotable Quotes

“There is too much information for each trip if it’s on the person, he or she will be targeted…it’s like a sign ‘take advantage of me’.”

“From a law enforcement perspective, it provides easy access of information.”

“Grandpa wouldn’t use it at all because of the labels; seems like it would be for a 5 year old.”

“Drivers must be caring….not just push the button, open the door and push them out.”

“There are Paratransit (programs) that gather that information so the drivers would be confused…it would be too much; a bus driver would not use it; simplify it and pin it on to the person.”

Question: How would you suggest it be displayed? Many of the professionals said that the passenger Information Sheet should not be displayed on the person. Their suggestions were:

- a person would not wear it if it were visible
- could be in the pocket
- who would fill it in?
- it would increase vulnerability and the person would be a target
- less information would make possible to keep in pocket
- it is not an example of dignified information what is needed is to partner a person with a driver one to one
- drivers already have this as intake information
- tagging means you objectify a person and take away autonomy
- the driver is not always with the patient, so the driver should not keep the card
- It could be a bracelet because a bracelet is part of a national registry
- the person should not wear the information on the outside
- It would be important to keep the information updated
- with a certain type of wanderer you need a card with a type of transportation link on the back side
- maybe have it as bar code the information on the drivers license.

Quotable Quotes

“You need door through door service. Education of the transportation providers is essential. This might help.”

“The caregiver must recognize the limitations of the transportation service. This might help.”
**Question:** What is one method or location you would suggest for its distribution? They did have a variety of suggestions:

- partner with something that already exists (e.g. the medical bracelet)
- connect with safe return so you don’t have to reinvent the wheel.
- agencies should step up and do it; not as a state agency policy
- doctors’ offices
- hospice
- senior centers
- websites
- sent as information from the police chief that goes down through the ranks
- taxi companies
- special locations where you can post information
- in utility company bills
- the chamber of commerce
- county fairs (a really big event in Florida)
- the city police.
- via cell phones with ICE (In Case of Emergency).
- whoever provides transportation must be the one to have it

### 1G. Tips for Helping Caregivers (with transportation)

**Chart #3** in the Appendix (Tips for Helping Caregivers with Transportation) was displayed in each session with professionals.

**Question:** What does the chart tell you? Many professionals raised questions about information on the chart (who will do the checklist? Who can really assess the transportation needs? Are there solutions available?). Others found the information helpful and still others had suggestions for strengthening it.

- would be helpful for providers and caregivers
- information on the patient with dementia and possible solutions
- a good idea, but I don’t think all of them should be on the card.
- should be a card for reference.
- a good idea to help train drivers
- older people still want independence
- is not for professionals, it is for family members
- is a conscious raising tool that all dementias are not the same
- a good idea to train drivers
- would work in small towns but not in big cities.

**Quotable Quotes**

“Travel assessment is individualized. You could use those that apply and find a solution.”

“It’s a good idea but it should be a phone checklist because the first contact is on the phone. If you’re on the phone you can listen and hear if the person has cognitive issues.”
“There is an expert on dementia who trains the drivers. The training is funded by memory disorder clinics in Florida. It is a tool that would help them.”

“It’s a good idea, but I don’t think all of them should be on the card. It should be a small card for reference.”

“It’s important to get information to the public on all levels. For instance, my wife now hears things on TV about dementia and realizes her grandfather did have dementia.”

“The person who needs the education will not remember. Maybe you could use Jitterbug…you push the button and they find them.”

Question: **How should it be distributed?** Participants suggested that it could be distributed in health and service settings such as doctors’ offices, hospice, senior centers, memory disorder clinics, AAA’s, senior organizations, support groups, and caregivers themselves. They also suggested the Department of Highway Safety and Motor Vehicles, transportation services, law enforcement agencies, the internet, and that drivers could give it to their passengers. One participant suggested that it be prepared as a tri-fold brochure which could be put in the mail for families. Other suggestions for distribution were:

- senior Expo
- Car Fit events
- first responders
- faith communities
- Bi-monthly publications
- website;
- Florida assn for senior centers
- Department of Transportation
- seniors.org
- special locations where you can post information
- utility company bills
- chambers of commerce
- county fairs (a really big event in Florida)
- planning commission
- cell phones with ICE (In Case of Emergency).

1H. **Tips for Drivers (of passengers with dementia)**

**Chart #4** in the Appendix (**Tips for Drivers of Passengers with Dementia**) was displayed in each of the research forums with professionals.

**Question: Is this a good piece of information?** Most of the professionals said they thought it was important information, and addressed all stages of dementia, but some suggested that perhaps we did not need a new tool and if it were distributed it should not replace driver training. A tip sheet was presented which included dementia warning signs, transportation challenges, and suggested solutions. Most participants saw it as a much stronger tip sheet. Several said that they liked the shorter version
better, that consolidating them into one made it most useful, and that it could be a good training tool for drivers and clients.

**Quotable Quotes**

“Yes it’s good but you need to be wary of certain things...like if the passenger asks to get off at a certain place.”

“Drivers have many passengers in their vehicle and can’t focus on one.”

“At the bottom of the tip sheet it should say, ‘when in doubt call....’.”

“We give these trainings to our drivers because it’s scary to drop off passengers who are at home alone.”

“Hospice training includes four hours of Alzheimer’s training and most of this is part of it.”

“The police need training on dementia otherwise they might use a Tazer to get people out of a vehicle.”

**Question:** How would you suggest we get it into the hands of family members, friends, volunteer drivers, and/or transportation services? Professionals made a number of suggestions. One even suggested that it become a part of driver license testing for young adults. Other suggestions were:

- driver training programs
- transportation services
- drivers and caregivers
- The DMV
- AARP
- Florida Safety Council
- Use it as a sticker in the transportation vehicle so both passenger and driver could read it...
- Use as handouts for people in transit
Part 2 Silver Alert

The professionals discussed Silver Alert for approximately forty minutes. The participants were asked how they learned about Silver Alert and what they thought about it, related materials that might be helpful in informing people about it, ways to prevent recidivism, and ways to give greater publicity to Silver Alert.

2A. Awareness and Attitudes

Chart #5 in the Appendix (Silver Alert E-Mail Message) was displayed in each of the groups.

Question: Have you ever heard of Silver Alert? The majority (71%) of the research forum professionals said that they had heard about Silver Alert, although only 50% of those in the rural area said they had heard about it. They said they learned about it from the news, TV, memory disorder clinics, highway signs, human service agencies, senior centers, AAAs, conferences, the Alzheimer’s Disease Initiative (ADI) and law enforcement.

Question: What do you think about Silver Alert? The definition of Silver Alert was read to some of the participants who used the following words to describe it: helpful, enlists the community in recovery, and an increasing problem for older people. One person raised the question, “Why only driving?”

Quotable Quotes

“I did not think it would be effective, but it is.”
“It is a good to find someone who is lost.”
“I’ve seen it work twice so it’s a good idea.”
“It’s a good idea but I’m not sure how effective it is.”
“It’s good. I think there should be e-mail messages.”
“You go to the DMV and put medical information on the file. Why couldn’t you put dementia information on it?”
“I think the e-mail message would be helpful but I would want a picture of the model and color of the car.”
“I’d actually like to take this chart home with me...I want to use it with my staff tomorrow!”

2B. Preventing Silver Alerts

Participants discussed Silver Alert prevention, follow up, and avoidance of recidivism.

45 N.B., group number was small.
Question: What could be done to support drivers in early stage dementia to avoid a Silver Alert?

**Quotable Quotes**

“In the beginning it should be discussed with the family for safety reasons.”

“It’s getting the keys, not the license that we see with Silver Alerts.”

“You have to take the mode away...it’s up to the family/caregivers to take the car.”

*Note: One participant who is a guardianship judge, notes that the family may face civil liability if a vehicle is removed from a senior who has not be declared to be incapacitated; the suggestion was made that a policy change is needed in this area.*

“I think you should explain to the caregivers that if there’s an accident someone may die, and they will lose their inheritance, and even with good insurance there is liability.”

“The family waits for someone else to make the decisions. They need to have the discussion and take the keys and the car, but not the license.”

“Occupational Therapists are certified to assess behind the wheel driving and can do assessments which might help with prevention. They should be covered by insurance.”

“Inform people about the circumstances for a Silver Alert.”

Question: What type of follow up is needed after the event? Most of the participants suggested that someone should take away the keys, disable the car, sell the car....or all three. One suggested using a GPS to locate anyone who might have caused a Silver Alert.

**Quotable Quote**

“A three person committee should do a case review.”

“There should be a tag to the med review (DHSMV Medical Review) board so people can’t drive.”

“You must take the car, not just the keys; it’s not law enforcement’s responsibility to take the car. ...only to take the license.”

“Some one who is in contact on the daily basis should be the person to report.”

“Take the registration and then go to insurance company and let them know. The insurance will become very expensive.”

“You need to get neighborhood associations involved in neighborhood watch programs for older people who live alone.”

Question: What do you think could be done to prevent recidivism? As was the case with the preceding question, most of the participants suggested that someone should take away the keys, disable the car, and sell the car...or all three. Other suggestions were to get an On-Star system installed, use GPS for tracking, require drivers to use a Lifesaver bracelet, or require people who have had previous Silver Alerts to carry a cell phone or a chip that can track movements.
2C. Expanding Information about Silver Alerts

The 36 research forum participants who rated the level of awareness of Floridians about Silver Alert gave it fairly low ratings. On a scale of 1 to 5 with 1 being low, 11% rated the awareness level as 1; 36% rated it as a 2; 36% rated it as a 3; and 17% rated it as a 4. No respondent gave it a 5 rating.

*Question: How can we communicate Silver Alerts and information about the Silver Alert program?* In addition to the usual distribution methods, several participants mentioned technology such as twitter, facebook, you tube, cell phones, and linking to law enforcement. One person commented, “We need more success stories in the media.” Other suggestions included:

- news groups
- doctor’s offices
- memory clinics
- senior expos
- Billboards
- public service announcements
- paid advertisements
- local law enforcement
- media facilitated by law enforcement
- Statewide resources
- transit drivers
- the motoring public
- a sign on the Lynx Bus
- utility bill inserts
- senior centers and retirement facilities
- posters in hospitals, emergency rooms, and doctors’ offices
- DMV offices
- movie theatres
- milk cartons
- local news channels, both TV and Radio
- in staff training
- churches
- civic groups
- social security offices
- mass e-mails
- text messages
- mall security
- cable TV
- truck stops.

*Quotable Quotes*

“Memory clinics should be a conduit of information since they deal with the first warning signs of dementia.”
“Does this come up on the bottom of the TV screen when “One Life To Life” is on? It should! “What is needed is a campaign to highlight Silver Alert it in the media.”
“Lamar electronic signs company operates state wide and they often help with public service information.

One participant commented that there are many communication methods in place to communicate information about Silver Alert including 30 second PSA shots; educating caregivers on how to take the keys; and law enforcement training for all in Florida.

A success story was shared by a participant in Miami who had seen an announcement of a Silver Alert on a variable message sign in I-95 and then saw the announcement on TV as soon as she arrived home.

Several individuals agreed with the person in one group who felt strongly that successful recoveries in a Silver Alert situation should be shared as well as community alerts.

Lessons Learned From Professionals

As was mentioned earlier, all professionals completed a brief written survey. The results of their comments make several important points about transportation for people with dementia with respect to the types of transportation alternatives professionals think are appropriate; the most adequate transportation alternatives that meet the needs; the types of assistance that are needed; and the types of transportation alternatives and types of assistance that are available.

- Only one professional identified persons driving themselves as the most useful transportation service in getting persons with dementia where they need to go.
- The greatest number of professionals completing the survey identified a volunteer driver service and family members (79% and 69% respectively) as the most useful transportation service in getting persons with dementia where they need to go.
- The greatest number of professionals completing the survey selected family members and friends and neighbors (67% and 45% respectively) as the transportation alternatives that could adequately meet the transportation needs of people with dementia. Only 19% selected a volunteer driver service which could be related to the limited number of volunteer driver programs in areas in which the forums were held.
- Perhaps one of the most enlightening assessments by professionals was their ratings of needed services and available services. The chart below shows their ratings of six types of services.
The chart suggests that, from the professional’s perspective, the two least needed services (curb-to-curb and door-to-door) were some of the most available services, while the three most needed services were the least available services.

The survey results suggest that professionals who participated in the research forums believe:

- That people with dementia are not using transportation services for getting themselves where they need to go.
- That family members and friends, and volunteer driver services can be useful in getting them where they need to go.
- That while volunteer driver programs may be a useful alternative, they may not be as available as other transportation alternatives.
- That while assistance in the form of escort or attendant, door-through-door, and travel training transportation services are the most needed types of assistance, they appear to have limited availability to people with dementia and their caregivers.

Two important results of the survey suggest that: (1) people with dementia will need high level of assistance; and (2) people with dementia will not be able to access a high level of assistance which can enable them to access transportation services. It is interesting to note that professionals assume that: (a) people with dementia will have family and friends to drive them; and (b) people with dementia will not need to drive.

**Comment**

One professional summed it up very well, when she said: “As the future comes on, we are all going to be seeing more and more of this.”

A social worker commented about the important role of caregivers: “I wish they all had them. I am working with someone now whose daughter is here for five days. She is very involved, but only here for a short period because her home is in Maine.”
It is often falls to the role of caregivers (family members, friends, and neighbors) to serve an important role in providing transportation and helping care receivers access transportation options that meet their needs. However, to perform an assistance role in helping care receivers access appropriate transportation services, those services must be available. It is equally important to be aware of the fact that a large number of people with dementia live alone and do not have caregivers.

People with dementia who do not have caregivers, do not have the caregiver transportation option, and may discover that if appropriate transportation options are not available, driving their automobiles may be their only means of getting where they need to go. Access to volunteer driver programs, the help of friends, or to paid specialty services may be an essential option for such individuals.

In the case of Silver Alert, it is difficult to know about the probability of neighbors or friends calling and reporting a problem such as wandering or bad driving, or if those neighbors or friends would be in a position to initiate the Silver Alert process. And finally, one can only wonder if it would take a Silver Alert or a crash to make them stop driving. And when they do stop driving, it is difficult to imagine how they would be able to get where they need to go.

**Report on Research Forum with Caregivers**

**Profile of Participants**

Twenty three caregivers participated in the research forums. Eighteen were female and five were male. They ranged in age from under age fifty to age seventy-five plus with 34% under age sixty five and 65% age sixty five plus. Half (50%) of them belonged to support groups; and while 78% said their current health status was excellent or good, the remaining 12% said their health status was only fair. The number of years caregivers had provided support ranged from 1 to 15 with an average of seven years.

A spouse was the primary care receiver followed closely by parent. Other care receivers included grandparents, friends and neighbors. More than half (57%) of those being cared for lived in the same household as the caregivers. The average age of the care receivers was seventy-eight.

One caregiver forum was comprised solely of a married couple, one of whom was a care receiver and the other, a care giver. This intimate group turned out to be a fabulous session, as we had a wonderful opportunity to explore the transportation challenges of this family unit. We learned a great deal from these two generous participants.

The most frequent words caregivers used to describe themselves were caregiver, or caregiver for my mom or my husband, a friend, a grandmother. Other words included helper, volunteer, or volunteer driver. They identified their responsibilities as knowing where to get information, trying to make the person with dementia happy, finding an Alzheimer’s group, doctor visits, spiritual care, and preservation of dignity by not taking them where they would feel threatened.
34% of the caregivers were born in either Florida or New York. Other locations of birth included Massachusetts, Indiana, Pennsylvania, Louisiana, and Missouri, Georgia, and Arkansas. Two of the participants in the Spanish focus group were born in Cuba, one in Spain, and one in Venezuela.

In addition to participating in discussions, each of the participants completed a brief written survey.

**Part 1 Dementia and Transportation**

The discussion in Part I of the Caregiver Research Forums addressed general issues related to dementia, challenges of being a caregiver, sources of information for caregivers, needs of care receivers, transportation challenges, and several tip sheets including a passenger information sheet, travel tips for caregivers, and travel tips for drivers. Part I required approximately one hour of time.

1A. What is Dementia

**Chart #1** in the Appendix ([What is Dementia Anyway](#)) was displayed in each of the Caregiver Research Forums. When asked if this information would be helpful, most of the caregivers responded that it would, especially in the early stages.

**Quotable Quotes**

“It could be very important. I did not know anything was wrong at first…I was in denial.”
“Your daughter first saw the problem and asked, What’s wrong with dad? I could have used the information to explain his dementia to her.”
“This should be required for the general population. It should not be necessary to wait for the problem to occur to understand it.”
“It’s good public information for everyone, for example memory loss and loss of initiative.”
“All those words on the chart…they all apply.”
“The first sign of dementia was when he got lost driving.”

**Story**

About 10 years ago, my husband took his car and was gone for two hours. I called the police but they said they couldn’t do anything because he was gone too short of a time. At 2:00 a.m. he came walking home. He had left the car. I sold his car and hid the keys to my car and he stopped driving after that. He wasn’t happy about it though.
**Great Idea**

We bought a GPS seven years ago so we could track where he walked. He has a wire around his neck and I can follow him on the computer. Now I can relax.

Suggestions for distribution of the dementia chart included: the media, newsletters, TV ads (like they do with depression, ads like they use to sell medicine,) health care providers, quarterly newsletters, doctors’ and neurologists offices, and the AARP magazine.

1B. Challenges (in being a caregiver)

**Question:** What is the most difficult challenge you face as a caregiver? More than half of the caregivers said the person for whom they care had gotten lost, and a number said they needed help with caregiving or respite. Several people mentioned that their care receivers wore a bracelet as a person with dementia which makes it possible for police to return them home. They also identified a variety of other challenges:

- reasoning (because no short term memory)
- logic (don’t understand the consequences)
- communication with outsiders (trying to get them to understand what is dementia)
- keeping up morale (because of caregiver and care receiver depression)
- time for life
- vigilance (watching over her because she wanders)

_Quotable Quotes (from caregivers of patients in late stage dementia)_

“My husband is healthy from the neck down…and it is hard to dress him because he does not understand and does not have language skills now. The physical part of my work is the hardest.”

“My problem is to move him. I don’t have enough strength to move him. He is like a dead weight. I get some help with his bath and to toilet him…and then he is back in bed.”

“There is just not enough time for my own life. I have no life.”

“When he comes back from something (adult day care) if something is where it always was it is fine. If something is out of place, he puts it somewhere like in the freezer.”

“I don’t know what he wants or how he feels...because he cannot speak or walk now. When he grimaces on his face...I give him a Tylenol.”

1C. Sources of Information (for Caregivers)

**Question:** Where do you get your information about how to help someone with dementia? Many of the caregivers said they used the internet and received information from sites such as Web MD and local resource information. They also identified sources such as: the care receiver’s doctor, memory disorder clinics, senior centers, the Alzheimer’s support groups, long term care facilities, caregivers newsletters, friends, Easter Seals, University of Miami REACH program, and hospice outreach for respite.
Caregivers also said they purchased books (e.g. The Thirty-Six Hour Day), picked up fliers at the doctor’s office books, participated in teleconferences, and used the phone book. Several said they simply learned on the job.

Quotable Quotes

“I am in two support groups and my husband goes to Easter Seals. At first I couldn’t manage, but the facilitator helped me. A REACH program from the University of Miami helped me get to the information about Easter Seals.”

“Fourteen years ago, my husband was diagnosed with Alzheimer’s. I read about it in the news and called and got into a group for early stage patients, and the social worker sent me to Easter Seals adult day care. I read to learn about it.”

“I had to go to work so I looked in the phone book to find an adult day care near by. It wasn’t good for my husband because when I picked him up they said don’t come back because he wanders. So I went to Easter Seals.”

“I don’t have time to attend conferences. I could do teleconferencing if it were recorded.”

1D. Needs of Care Receivers

Question: In your opinion, what are the biggest needs of the person with dementia for whom you help or care? Caregivers identified health care, life enriching activities and housing as the top three service and support needs of care receivers. Although several caregivers identified transportation needs including: transportation for socialization, safety in transportation service delivery. One reason that transportation may have been fairly low on their list of service and support needs, may be that the caregivers were the transportation providers. Participants also identified a number of other needs including transportation. General needs included

- a caregiver who “knows” the right thing to do
- socialization
- someone to communicate with and trust
- medications that have routine schedules…with no changes
- friends and fellowship
- music therapy (e.g. Lawrence Welk music)
- continued respect
- understanding and normalcy
- dependable and informed caregiving assistance.
- being a good listener
- paying attention; patience

Quotable Quotes

“He doesn’t have any necessities. He is bed ridden and is cared for. It’s the caregivers who suffer and need help.”
“I need someone to help me care for my husband.”
“My husband needs to be bathed and moved in bed...so I need respite”
“The transportation services are always good. They pick up on time and return on time, but on Saturdays I drive him around Miami. He likes it because once he said ‘how pretty’.”

1E. Transportation Challenges

Caregivers said that none of their care receivers drove a car, and sixty-five percent said they relied on themselves to provide transportation for their care receiver. The top two destinations of their care receivers were the doctor and visits with family and friends. Other less frequently identified destinations were the adult day center, grocery shopping. Several caregivers said they relied on other family members and friends; and a few said they used ADA paratransit or volunteer driver services as transportation alternatives. Participants also said that they knew of transportation alternatives in the community but wouldn’t or couldn’t use them because: the person they cared for wasn’t capable of using them; the services were difficult to get to, were limited, were not dependable, or had erratic schedules.

Question: What is one thing that caregivers (and others) who drive people with dementia need to know?

Caregivers made several suggestions.

- emergency contact information
- the exact condition of the care recipient
- the problems that the care recipient has
- that the driver needs to remain calm and protective
- that the personality can change immediately as a result of behavior change
- that there may be the need for a personal escort even if there is a driver
- It is important to make conversation and talk to them to distract them.

Question: What is Your biggest challenge in providing transportation to someone with dementia?

Participants identified their challenges as:

- finding a place to park which would be easy to walk from
- arriving early for pick up so they won’t wander off
- timing with respect to getting to the destination without confusing them
- finding an escort or volunteer to help with the patient in the car
- taking them somewhere and keeping them on task
- getting them to appointments on time
- getting in and out of the vehicle because the mind does not tell the feet what to do
**Quotable Quotes**

“It was a blessing that I could drive.”

“I would never let my mom go on public transportation with anyone else. She would not be able to do it. My mother would be afraid.”

“I was a sailor’s wife and was always the primary driver. So it isn’t difficult to be the driver.”

“If I didn’t drive, I would never call a taxi. It’s too expensive in a rural area. I would sell the house and move to town and use my friends for transportation. Or, I would move close to my daughter.”

A recurring question asked in more than one research forum was: “Are there any escort programs available?”

**1F. Passenger Information Tip Sheet**

Chart #2 in the Appendix (The Passenger Information Sheet) was displayed in each of the caregiver research forums. While most of the caregivers did not use alternative transportation services, many of their comments about the information sheet included concerns regarding its content as well as how it should be displayed.

**Positive Comments**

“If it were an ID, then it would be perfect.”

“This would be good for someone if they were at the level where they could be put on a bus...but I question the safety with so much information.”

“If the person is alone, they need the information, maybe on a wrist band.”

“The Alzheimer group has a bracelet so in the early stages this information would help.”

“My mom would feel safe and in control. I would fill it out for her.”

“This would give me security knowing that my mom would get where she needs to go.”

“This would help lower the fear that goes with dementia.”

“They could laminate and wear it like a conference badge.”

“It would be helpful around the neck because it would identify a person as having dementia.”

**Negative Comments**

“Mom would lose it or fumble with it all the time.”

“All dementias are different and this might be helpful for some but not for everyone.”

“How do you do it so someone bad doesn’t get the information?”

“How do you do it so it stays on them?”

“This could be a problem because they would remove it or tear it off.”

“My husband had a bracelet and that could help because I could leave him in the mall while I shopped.”
When asked where the Passenger Information Sheet should be made available, caregivers made the following suggestions: doctor’s offices, senior centers, adult day care facilities, hospitals, social service agencies, caregiver support groups, the office of elder affairs, Alzheimer’s projects, Medicare and Medicaid offices, and transportation services. Suggestions also were made to make it available as an online downloadable image.

**1G. Travel Tips for Caregivers**

**Chart #3** in the Appendix (Ideas for Caregivers) was displayed in each of the caregiver groups. There were several positive comments about the chart which has the purpose of helping with travel situations. Some comments included specific recommendations and other addressed specific needs. At the same time, some caregivers said it would not help them because they had help from family members or their care receivers were in later stages of dementia and unable to travel. It should be mentioned that several caregivers linked the chart with the Safe Return program.

**Quotable Quotes**

“*I think they’re all helpful. My mom has all the problems, but I think the escort would help if it were the same person; prepayment would help.*”

“*If the caregiver realizes there is a problem, then this would help.*”

“I wish I had had these suggestions earlier.”

“I like the idea of prepaying for transportation because my mother cannot handle money

“I didn’t need it. I had help from family.”

“They would help get my mother to hair appointments and bridge, but not to the doctor.”

“Their value depends on the level of dementia of the care recipient.”

“This is helpful, but the progression is unpredictable...there are good and bad days...they respond unpredictably.”

“This will not help with late stages of dementia.”

“I have difficulty caring for my mother myself…I can’t imagine the driver knowing all this.”

Several suggestions of locations for distribution included: churches, senior centers, public transportation providers, support groups organized by the Alzheimer’s Association, support groups at family life centers in churches, church newsletters, senior center newsletters, police departments; clinics, and doctors’ offices.

**1H. Travel Tips for Drivers**

**Chart #4** in the Appendix (Travel Tips for Drivers of People with Dementia) was displayed in each of the Caregiver research forums. As was the case with previous charts, caregivers said that its usefulness depended on the level of dementia. At the same time they were generally positive about the travel tips.

**Quotable Quotes:**

“It’s a good way to be reminded about what to do with a person with dementia when driving them.”
“The back seat is a good idea.”
“It could be used to educate taxi drivers.”
“I’ve come the conclusion that patience, patience, patience is the answer. When I get frustrated I realize that I bring it on with my own expectations.”
“Language competency might help in the beginning, but not now...it’s too late.”
“I would look for a driver of dementia clients who has taken training and understands these tips.”

**Exchanges**

**Facilitator:** “What about playing music while driving?”

**Caregiver:** “I’d rather talk than have music”.

**Care Receiver** “I’d rather have music.”

**Facilitator:** “What about sitting the passenger in the back seat?”

**Caregiver:** “He has now become a backseat driver who sits in the front seat.”

**Care Receiver:** “I’d never sit in the back seat because I own the car as much as she does.”

Several suggestions of locations for distribution included insertion in a resource book for seniors, doctors’ offices, senior centers, churches, and residential facilities. Additional suggestions were made to ensure that the Tips would be prepared in an inexpensive manner, that they should be free (with the government or insurance company as the sponsor), and that they could be an element in driver certification training.

**Part 2 Silver Alert**

The caregivers discussed Silver Alert for approximately forty minutes. The topic was introduced with discussions about driving and giving up the keys. Then, caregivers were asked how they learned about Silver Alert and their attitudes about its value, dementia and Silver Alert, ways to prevent recidivism, the value of expanding Silver Alert to include wanderers, and ways to give greater publicity to Silver Alert.

**Chart #5** in the Appendix ([Silver Alert E-Mail Message](#)) was displayed in each of the caregiver sessions.

**2A. Drivers with Dementia**

Caregivers had many stories about their experience with drivers with dementia.
### Quotable Quotes

“My mother drove across the median and drove three blocks the wrong way...it should be reported to the DMV and take away the keys.”

“It is important to set boundaries to limit driving (e.g. to the grocery store).”

“Sign up for adult day care for socialization.”

### Stories

“Unfortunately, my mom kept passing the (driving) test.”

“Grandpa would not give up the keys. He would go out driving and get lost. One day, the car was parked in the yard and it just burned up. We don't know how it happened, but it solved grandpa’s driving problem. It's sad, some people are so stubborn...but my husband was real good. He gave up the keys on his own.”

“My father drove himself to the clinic on Sunday thinking he had an appointment. I was taking my wife to church and just happened to go that way...I don’t normally go that way...and saw my dad in the hot Florida sun just sitting on the curb waiting to get into the clinic. So I stopped my car...asked my dad what he was doing...and he said he was waiting for the clinic to open. I said “Dad, It's Sunday, the clinic isn't open. “ So my wife drove my dad to his home and I followed in my dad’s car. When we got home, my dad said “What are you doing with my car?” And I said...”what are you doing with my wife?”

“I will be 90 at the end of the year. I am planning and training to give up my keys, because I don’t believe anyone over 90 should drive. I’m actually learning the bus routes with a friend who uses public transportation. I live on a bus route...and I like to walk a lot.”

### 2B. Giving Up the Keys

While caregivers in one group were universally committed to taking away the keys, other caregivers identified a variety of ways of getting their care receiver to give up their keys.

#### Quotable Quotes

“I took the keys from my husband.”

“I kept the car but do not let her drive.”

“Another caregiver uses mom’s car to take her to appointments.”

“My brother drives my mom’s car and so she can't drive it.”

“My husband drove over the curb so I started driving. I told him I wanted to start learning to drive.”

“He chose to give up his keys. I am so glad because it was not a problem for us...or for me.”

One care receiver who participated in the discussion made the following comment about giving up his keys.
“I didn’t go to the DMV to get my license renewed, but to get a picture ID. I feel fine with it. There was no charge and I don’t have to renew it.”

2C. Awareness and Attitudes about Silver Alert

Fewer than 65% said they were aware of the Silver Alert program, and 73% said they had never seen an e-mail alert. Those who knew about it said they had seen a Silver Alert on the news or highway sign or they had heard about it at work or from a friend. For the most part, caregivers expressed positive attitudes toward Silver Alert, and many identified it as a parallel to Amber Alert. They suggested expanding information about Silver Alert through news programs, news copters, bus and taxi drivers; interstate truck drivers with CBs; gas stations. Many suggested that both caregivers and the general public were the primary beneficiaries.

*Quotable Quotes:*

“I would have felt much safer if this had been in effect when my husband was missing.”

“I think the police need to be trained and educated in dementia because when my husband was missing (when he wandered away) the police handcuffed him and put him on the floor of the police car when they brought him back.”

“I think this will be most beneficial in the beginning stages.”

2D. Preventing Silver Alert Recidivism

Although none of the caregivers had experienced a Silver Alert with their care receiver, they had expressed concern about people with dementia continuing to drive. While some caregivers suggested the need to limit driving, most comments suggested a universal theme that their keys and their car should be taken away from them.

*Question:* What do you think could be done to prevent a recurrence of a Silver Alert? Some said that it would be important to take away the keys or add restrictions, but others suggested assistance and counseling.

- the DMV should revoke the license
- either give away the car or burn it
- provide an escort
- have the doctor explain that the person is no longer able to drive
- have someone at home to watch them and drive for them
- the family needs to be nearby; should take their drivers license
- the adult children should know if there is a Silver Alert
- the information about a Silver Alert should go to the doctor and then to the family
2E. Expanding Publicity about Silver Alert

Caregivers suggested that both public and private information and communication sources be used to publicize Silver Alert. While public entities such as police and fire departments were mentioned, for the most part they suggested private entities such as paid advertisements, PSAs, billboards, and the like. Below is a list of many of their suggestions.

- public sources including websites
- local and state police
- public transportation facilities
- media outlets including TV and radio stations
- doctors offices
- case managers
- newspapers
- support groups
- bus stations
- convenience stores
- memory disorder clinics
- signs on highways
- Wal-Mart information board
- Face-book
- twitter tweets
- pharmacies
- the Senior Resource Book
- newspapers
- senior events
- churches and senior ministries
- newsletters

Lessons Learned from Caregivers

The Caregiver Research Forums tended to include people who were supporting family members of friends at advanced stages of dementia. In all cases, they did not use community transportation alternatives. While their discussions provided critical information regarding a better understanding of many of the topics addressed in this project, they did not address the needs, challenges, and opinions of people who lived alone and did not have family or friends as caregivers.

In the Spanish speaker caregiver group in Miami, one individual spoke about the difficulty encountered if a driver does not speak the same language as the passenger.

“Speaking English is out of the norm here.”
This same group also spoke about the importance of law enforcement training regarding these issues. One group participant spoke about an experience when her husband, who suffers from Alzheimer’s and becomes easily confused and agitated, had an encounter with the police.

“They shouldn’t be treated as a criminal.”

“If they call a Silver Alert, they (police) need to understand what they are dealing with, just as they would know they were dealing with a child when they are working an Amber Alert.”

In the course of the research forum activities, project staff discussed the challenges faced by people with dementia who live alone and do not have immediate access to a caregiver. Questions addressed if and when they should give up their keys, how they get to the doctor, to the store, to life enriching activities, and to the grocery. It is important to know how they are able to schedule (and remember) their appointments for transportation services, and how anyone would know if they got lost when driving their car. We could only speculate about the probability of their neighbors or friends calling and reporting a problem such as wandering or bad driving, or if those neighbors or friends would be in a position to initiate the Silver Alert process. It was difficult to imagine that they would be able to or that someone would be available to encourage them to give up their keys in the early stages of dementia. And finally, we could only wonder if it would take a Silver Alert or a crash to make them stop driving.
Section VI. Summary of Findings from Research Forums, Recommendations and Suggested Near Term Actions

Silver Alert

1) Public awareness campaigns should be developed to educate both family members and professionals who interact with seniors. There is a demonstrated need to increase visibility of this valuable program.

2) Target audience should be seen as family/friends; general public and professionals who are called to serve senior constituents.

3) Rural areas, which may lack variable message signs (VMS), face special challenges in spreading the word of an alert to the motoring public. Communication strategies in these areas should include additional specialized avenues such a reverse phone trees, as is done now in Washington County.

4) Message strategies, both traditional (print and electronic media sources) and nontraditional, should be utilized to get the word out. Consideration should be given to the use of: cell phone alerts; social media such as Twitter, Face book alerts; paid advertisements including billboards in key locations; notification to key stakeholders including media outlets, truck drivers, bus drivers, Alzheimer support groups, retail outlet community bulletin boards, pharmacies, church newsletters, etc.

5) Key participants in Silver Alert prevention should include Memory Disorder Clinics since they are dealing with the at risk population, are engaged in education about transportation issues and may be a referral agency after a Silver Alert has occurred.

6) A community resources linkage, after a successful recovery has been made following a Silver Alert, is important. Referral to the Florida DHSMV Medical Advisory Board\textsuperscript{46} for a case review of driver ability should be considered as a pathway to safety. Alternatively, case review authority in situations of Silver Alerts could also be delegated to a State sponsored Memory Disorder Clinic with recommendation to DHSMV for action.

7) A Silver Alert information kit should be provided to first responder agencies and community partners who may be recipients of referrals after a Silver Alert recovery. The kit should contain a selection of the tip sheets utilized in this project, as well as local community resource information. The intended audience would be family members of a Silver Alert wanderer.

8) The database from the Florida Department of Law Enforcement on Silver Alert cases should be queried to determine how many of the cases to date involve individuals who live alone.

\textsuperscript{46} Or appropriate state licensing authority for out of Florida drivers.
**Dementia Friendly Transportation**

1) Update the DoEA website to bring visibility to dementia friendly transportation and to provide access to existing resources, such as the tip sheets used as “charts” in the forums. Improve a user’s ability to find these resources easily. They could, for example be listed as a featured topic.

2) Provide linkage or materials to Area Agencies on Aging and Florida Memory Disorder Clinics with a request to include information on their websites as well.

3) Work with Florida Department of Transportation to add a section on dementia friendly transportation to their website on senior transportation. A linkage to existing resources on the DoEA website could be made, as well as information about other key resources.

4) Focus group participants were strongly in favor of guidelines to promote dementia friendly transportation. The Department may wish to consider developing a pilot program to encourage transit providers to evaluate the dementia friendly level of services they provide or to link with services which may specialize in such services.

5) A state sponsored certification process for dementia friendly transportation providers or individuals would contribute significantly to the importance of this issue among transit providers, volunteer driver programs and other interested parties. This would also provide an essential level of assurance of service appropriateness to family members and travelers themselves which may encourage use of alternative transportation options where available. Development of such a program would be consistent with Florida’s Communities for a Lifetime initiative.

6) Consider additional research on the issue of transportation challenges of persons with dementia who are living alone.

**Training**

1) A standardized training program should be provided for drivers (paid and volunteer) who are transporting passengers with dementia. Training curriculum development and provision of training sessions should be a goal. This activity could serve as a component of a formal certification program, but also should be available as educational materials for individuals as well.

2) Access to existing resources vetted during this project by community providers should be made available. Several of the resources reviewed by forum participants were deemed to be a high value by professionals and families alike.

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47 Caregivers: Passenger Information Tip Sheet; Travel Tips for Caregivers; Travel tips for Drivers
48 Professionals: Passenger Information Tip Sheet; Tips for Helping Caregivers with Transportation; Tips for Drivers of Passengers with Dementia)
General

In view of the preponderance of seniors in Florida who live alone, estimated to be 22.95% of those 60+ statewide in 2009,\(^49\) it is important to consider the topics of special needs of drivers with dementia and of dementia passengers, with seniors who do not have family support available to them. Professionals clearly view family involvement as an essential element to safe transport practices and an essential in the prevention of Silver Alert situations, and yet, this support structure is not available to over 1 million elder Floridians who live alone. Further community review of this important area is warranted.

Overview of Regional Data Summaries

Statewide and regional data summaries have been prepared in an effort to profile existing services. Data has been gathered from a variety of sources in an attempt to demonstrate services that may be available to local citizens. Categories have been applied to listings of transportations alternatives in an attempt to accurately reflect service types.

These profiles were used in preparation for the conduct of the research forums as a way to give the research team a better understanding of the local area conditions. As it turned out, the group discussion during the forums themselves turned out to be much more personal than regional in nature. While the data summaries performed a useful function during the course of this project, they could serve as an important springboard for further discussion.

Regional Data should be shared with local Community for a Lifetime leadership and/or other local leadership (e.g., Area Agency on Aging Directors or Transportation consortium leaders) for their information and discussion. Particular attention should be brought to the categorization of transportation alternatives.

The template developed in this project may also be useful for other regions in Florida.

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\(^49\) Department of Elder Affairs 2009 Florida State Profile.
Section VII. Description of Service Delivery Models

Escorted Transportation Services

When memory loss and Alzheimer’s disease force a senior to stop driving, those same memory challenges may make it impossible to access a bus service, a curb-to-curb paratransit service, or taxi service without extra assistance. In some communities, the person providing transportation assistance will take the person to the door, help them access the vehicle or stay with them at the destination...or do all of those things.

There is very little published literature on the role of a transportation escort. However, there is growing interest in what is known as door-through-door transportation and in the role of paid escorts, volunteer escorts, and volunteer drivers for meeting “supportive transportation” needs. A 2000 national study of Supplemental Transportation Programs (STP) by the Beverly Foundation50 queried respondents about door-to-door service and volunteer drivers. The study produced data that 75% of the respondents involved volunteer drivers and 72% could provide door-to-door service. The conclusion is that quite frequently the volunteer drivers are in fact also volunteer escorts.

In some instances, paid attendants or escorts can be provided to people with dementia. Paying people to serve as ride escorts can pose a major expense for a transportation program. Some transportation services are meeting the need for escorts by mobilizing volunteers. Those volunteers serve the escort role in a variety of ways:

- family members who extend their caregiving role to assisting with transportation;
- friends and neighbors who are recruited by the rider to act as escorts;
- volunteer drivers who not only drive but also provide “supportive transportation” services;
- community based volunteers who have assignments as volunteer escorts

Transportation Models for Consideration

Several communities around the country offer door-to-door and escort transportation programs that could provide useful models for consideration. The transportation service descriptions below demonstrate that there are many ways to organize a program for improving senior’s access to transportation. Volunteer driver programs appear to be a cost effective way of providing expanded services to special needs passengers, such as a client with progressive dementia.

- Brevard Alzheimer’s Foundation Located in Melbourne, Florida, the Foundation is the county’s top adult day center. It recently developed a new arm of services called Joe’s Club Transportation. This service expands its traditional door-to-door transportation by

50 www.Beverly Foundation.org
offering transportation to persons with dementia and thus provides relief to caregivers by meeting their needs in addition to the care receiver’s needs for transportation. The program provides transportation to doctor’s offices, dentists and other health related medical appointments. It includes a fleet of five handicap-accessible vans, has delivered over 300 clients for more than 2,200 trips in less than 100 days. The service begins with an assessment registration, a visit by a social worker to assess needs and identify services to both the caregiver and care receiver.

- **Community Services Agency Volunteer Transportation Program** Located in Mountain View, CA, the agency has a volunteer transportation program that supplements its other services. The program provides escorted transportation and shopping assistance. The volunteers normally provide rides using their own vehicles, mainly to medical appointments and shopping, but in some instances the volunteers will accompany a person on the ADA paratransit service.

- **Elder Services of Merrimack Valley, Inc.** Located in Merrimack, Massachusetts the pilot program combines through-the-door transportation furnished by a volunteer who also acts as the older person’s medical advocate, if the person wants an advocate. When playing the advocate role, the volunteer sits with the older person when the doctor or other medical professional explains what the older person needs to do and helps interpret information to the medical personnel, to the older person, and to family members.

- **GADABOUT Transportation Services, Inc.** Located in Ithaca, NY, GADABOUT provides door-to-door transportation service to seniors and disabled older adults in both urban and rural areas. The program contracts with social services department to provide escorts for riders.

- **Independent Transportation Network** A national membership model of rides given to seniors and those who are visually impaired, in private automobiles, 24 hours per day. Rides are provided either by volunteer or paid drivers who assist passengers door through door and with bundles or bags. Communities define service areas and provide unrestricted rides within those areas. This networked model has 16 affiliates operating in 12 states: two are located in Florida: Orlando and Sarasota.

- **MATP (Medical Assistance Transportation Program)** Located in Allegheny County PA, MATP’s clients must request to bring an escort when scheduling trips. MATP will authorize escorts only when the rider is physically or behaviorally incapable of traveling alone or the effect of medical treatment causes temporary incapacity. Escorts must be at least 18 years old.

- **Mountain Empire Older Citizens, Inc.** Located in Big Stone Gap, Virginia, the program offers a variety of services tailored to the individual requirements of riders. Higher level
services are identified through caseworker assessments. Clients who are especially frail are eligible for one-on-one service with a driver who transports and accompanies them to appointments, the pharmacy, or shopping.

- **TRIP (Transportation Reimbursement and Information Program)** Located in Riverside, CA, TRIP targets frail seniors and people with disabilities who have no other form of transportation available and who would be homebound and unable to access health services or otherwise provide for their daily needs if they did not have TRIP. Within the TRIP program, the agreement for transportation is made between the rider and driver. And, while the program is described as providing door-to-door transportation, many drivers act as escorts and even assist riders with activities of daily living.

- **Ride Connection** Located in Portland, Oregon, it is common for some Ride Connection partners to mobilize volunteers to act specifically as escorts for frail riders being transported on a vehicle driven by someone else. For example, if a vehicle is bringing more than one person to a destination, the escort may help one person into the building while the driver is operating the lift for another rider. The escort may also help obtain directions from a rider without the driver needing to be distracted. Some Ride Connection partners have volunteer couples, one of whom drives while the other acts as an escort. Offering opportunities to couples is said to help with recruitment. Ride Connection also provides a Concierge service in which volunteers ride on vehicles and provide information as well as physical escort assistance to seniors and disabled.

It is evident that a variety of organizations sponsor escort programs and the volunteers play a variety of important roles. These include going to the door, going through the door, staying with the rider on the vehicle, staying with the rider at the destination. They also include a variety of destinations, such as medical appointments, shopping, recreation, and personal business.
Section VIII. Conclusions

There have been several important lessons learned during the conduct of the Florida Dementia Friendly Transportation Research Project.

We have seen:

- The high frequency with which both professional/volunteer service providers and family members are dealing with the unique challenges of providing safe transportation to individuals with dementia: every day and every ride.
- The need for reliable escorted transportation to fill a critical gap in the transportation services profile for communities.
- The utility of the tip sheets reviewed during this project, for professional and volunteer drivers as well as family members.
- The divergence of viewpoints between this subset of professionals and caregivers. Professionals rely on family members to a high degree to deal with issues of driving cessation and arrangements for transportation services. Family/friends of persons with dementia do not rely on transportation services to any degree, in large part because reliable services which can provide dementia friendly transportation do not exist in their area.
- The Silver Alert program is a valued support structure which provides an important safety net for families. Memory Disorder Clinics should be seen as key participants in efforts to prevent occurrences and reoccurrences of Silver Alerts.
- It is important to consider the particular situation of seniors who live alone. For this group of over one million Floridians, conventional strategies and solutions may not be effective at all.

The development of a regional transportation profile and the development of a categorization system for transportation alternative services is a useful planning tool for communities to gain a better understanding of the array and scope of services available to seniors.

Several action steps have been suggested in the areas of:

- Silver Alert: traditional and nontraditional messaging strategies, including reverse 911 call trees
- Dementia Friendly Transportation: distribute Tip Sheets; increase visibility of issue through features on select websites
- Training: create an educational training program for service providers, consider development of a specialty certification process
- Information: provide regional transportation template to participating communities and to each Community for a Lifetime for their use

Further research is needed to learn more from Florida seniors who live alone and from early stage dementia travelers themselves.
Section IX. Report Distribution Opportunities

Distribution of this report to key stakeholders and interested parties will contribute to the visibility of the topic of dementia friendly transportation and to a better understanding of the Florida Silver Alert program. The Department of Elder Affairs should consider distribution of this report to the following entities, organizations and individuals:

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Related Party</th>
</tr>
</thead>
<tbody>
<tr>
<td>Florida Department of Elder Affairs</td>
<td>Highlight on website and list with other research reports</td>
</tr>
<tr>
<td></td>
<td>Alzheimer Disease Initiative Advisory Committee</td>
</tr>
<tr>
<td></td>
<td>Memory Disorder Clinics</td>
</tr>
<tr>
<td></td>
<td>Aging Disability Resource Centers/ Area Agencies on Aging</td>
</tr>
<tr>
<td>Silver Alert Network</td>
<td>Advisory Committee</td>
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<td>Communities for a Lifetime</td>
<td>Community Liaisons</td>
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<td>Aging Network</td>
<td>Florida Council on Aging</td>
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<tr>
<td>Florida Department of Highway Safety</td>
<td></td>
</tr>
<tr>
<td>Florida Department of Transportation</td>
<td>Safe Mobility For Life Program and website</td>
</tr>
<tr>
<td></td>
<td>Safe Mobility For Life partner coalition</td>
</tr>
<tr>
<td></td>
<td>Commission on Transportation Disadvantaged</td>
</tr>
<tr>
<td></td>
<td>Community Transportation Coordinators</td>
</tr>
<tr>
<td>Metropolitan Planning Organizations/Transportation Planning Organizations</td>
<td>MPO Advisory Committee</td>
</tr>
<tr>
<td></td>
<td>Miami Dade Urbanized Area MPO</td>
</tr>
<tr>
<td></td>
<td>METROPLAN Orlando</td>
</tr>
<tr>
<td></td>
<td>Capital Region MPO</td>
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<td>Okaloosa-Walton TPO</td>
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<td>Alzheimer Association Florida Chapters</td>
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<td>Independent Alzheimer Providers</td>
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<tr>
<td>Research Forum Local Sponsors</td>
<td>Orlando Health Memory Disorder Clinic (Orlando)</td>
</tr>
<tr>
<td></td>
<td>Winter Park Health Foundation (Winter Park)</td>
</tr>
<tr>
<td></td>
<td>Tallahassee Senior Center (Tallahassee)</td>
</tr>
<tr>
<td></td>
<td>Life Enrichment Center (DeFuniak Springs)</td>
</tr>
<tr>
<td></td>
<td>University of Miami Memory Disorder Clinic (Miami)</td>
</tr>
<tr>
<td>Interested Parties</td>
<td>Public Transit systems</td>
</tr>
<tr>
<td></td>
<td>AAA Auto Club South</td>
</tr>
</tbody>
</table>

The significant value of the Tip Sheets reviewed in this project has been demonstrated. These educational tools should be made available as a standalone educational tool for professionals and families, as well as being featured in training curricula.
Section X. List of Appendices

Tip Sheets Reviewed by Forum Groups:

1. What is Dementia Anyway?
2. Passenger Information Sheet
3. Tips for Helping with Travel Situations
4. Tips for Drivers of Passengers with Memory Loss
5. Challenges & Scenarios
6. Definition of Dementia Friendliness
7. What is Dementia Anyway (re-discussed)
8. Silver Alert: What Is it?

Regional Transportation Profiles

1. Statewide
2. Leon County/Tallahassee
3. Miami Dade County/Miami
4. Orange County/Orlando
5. Walton County/DeFuniak Springs

General Resource Information on Senior Transportation

Survey Instruments: Professionals & Caregivers
## Chart #1: What Is Dementia Anyway?

<table>
<thead>
<tr>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Loss</td>
</tr>
<tr>
<td>Difficulty Performing Tasks</td>
</tr>
<tr>
<td>Problem with Language</td>
</tr>
<tr>
<td>Disorientation to Time &amp; Place</td>
</tr>
<tr>
<td>Poor or Decreased Judgment</td>
</tr>
<tr>
<td>Problem with Abstract Thinking</td>
</tr>
<tr>
<td>Misplacing Things</td>
</tr>
<tr>
<td>Changes in Mood/Behaviors</td>
</tr>
<tr>
<td>Changes in Personality</td>
</tr>
<tr>
<td>Loss of Initiative</td>
</tr>
</tbody>
</table>

*Adapted from Alzheimer Association Warning Signs of Dementia, 2008*
Chart #2: Passenger Information Sheet

**FRONT**

Passenger Information Sheet

*a travel companion for people with memory loss*

**BACK**

Passenger Information Sheet

Appointment Date: ________________

Travel Information:

- Pick Up Time __________________
- Destination __________________
- Destination Phone # __________
- Destination Address: __________

Passenger Information:

- Name ________________________
- Phone # ______________________
- Address: _____________________
- Emergency Contact: __________

Transit Provider Phone # __________

Special Passenger Notes to Tell Your Driver:

- ______________________________
- ______________________________
- ______________________________

Pre-Trip Passenger Checklist

- ____Complete Passenger Information sheet for each trip you take
- ____Pack travel bag (water, cell phone, etc)
- ____Visit restroom before you leave
- ____Take this sheet with you
- ______________________________
- ______________________________
Chart #3: Tips for Helping With Travel Situations

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Transportation Scenarios</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Loss</td>
<td>can’t remember time of appointment for ride</td>
</tr>
<tr>
<td>Difficulty Performing Tasks</td>
<td>problem making transit appointments</td>
</tr>
<tr>
<td>Problem with Language</td>
<td>unable to communicate with driver</td>
</tr>
<tr>
<td>Disorientation to Time &amp; Place</td>
<td>might get lost after transit dropped off</td>
</tr>
<tr>
<td>Poor or Decreased Judgment</td>
<td>could have difficulty handling money in stores or paying fares;</td>
</tr>
<tr>
<td>Problem with Abstract Thinking</td>
<td>may not be able to navigate changes in routine</td>
</tr>
<tr>
<td>Misplacing Things</td>
<td>might leave things behind on vehicle/at destination); require reminders</td>
</tr>
<tr>
<td>Changes in Behaviors</td>
<td>could become agitated for no obvious reason</td>
</tr>
<tr>
<td>Changes in Personality</td>
<td>might become suspicious of driver</td>
</tr>
<tr>
<td>Loss of Initiative</td>
<td>may not want to get in/out of vehicle</td>
</tr>
</tbody>
</table>

**Solutions**

Enroll your family member in a Safe Return or similar program.  
Consider accompanying passenger (or providing a companion).  
Complete the Passenger Information Sheet for every trip taken alone.  
Communicate any changes in travel plans to provider.  
Consider a passenger travel bag (water, cell phone etc.).  
Urge passenger to use facilities before departure (in case of long trip).  
Consider possibility of making a “trial trip” with passenger yourself.  
Explore options of pre paying travel costs, to avoid need for cash.  
Know “assistance capacity” of transit service (e.g. will it provide necessary physical assistance if needed?).
Chart #4: Tips for Drivers of Passengers with Memory Loss

- Be sensitive to the individual needs of your passengers.
- Understand that passenger challenges are not directed at you: they are part of the disease process.
- Be patient with repetitive stories. Be patient...Be patient!
- Your passenger may exhibit varying moods and abilities from one day to another.
- Passenger should be assisted to the specific destination (the doctor’s office, not just the address).
- Be wary if your passenger asks to get off at a destination other than what is scheduled. They may mix up locations or time events. Check the passenger destination sheet if available to you.
- Be aware of cultural and language diversity….be sensitive to others.
- Check that passenger seatbelts are worn properly for the duration of the trip.
- A passenger with memory loss may be much safer if seated in the back seat of a vehicle...this eliminated the chance to “fiddle” with vehicle controls.
- You may need to engage the child safety locks in rear doors of a passenger vehicle to prevent untimely door openings.
- Soothing music may calm an agitated passenger.
- Above all else, keep your sense of humor!
Chart #5: Challenges & Scenarios

<table>
<thead>
<tr>
<th>Five Challenges</th>
<th>Five Transportation Scenarios</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Loss</td>
<td>can’t remember time of appointment for ride</td>
</tr>
<tr>
<td>Problem with Language</td>
<td>unable to communicate with driver</td>
</tr>
<tr>
<td>Disorientation to time &amp; and place</td>
<td>might get lost after transit dropped off</td>
</tr>
<tr>
<td>Changes in Mood/Behaviors</td>
<td>could become agitated for no obvious reason</td>
</tr>
<tr>
<td>Changes in Personality</td>
<td>might become suspicious of driver</td>
</tr>
</tbody>
</table>

**Tips for Drivers of People with Dementia**

Understand that passenger challenges are not directed at you: they are part of the disease process.

Your passenger may exhibit varying moods and abilities from one day to another.

Your passenger may require more assistance and have help through the destination door one day.

Be wary if your passenger asks to get off at a destination other than what is scheduled. They may misremember locations or time events. Check the passenger destination sheet if available to you.

Soothing music may calm an agitated passenger

Above all else, keep your sense of humor!

Be patient…Be patient…Be patient!
Chart #6: Definition of Dementia Friendliness

A transportation service that considers special needs of passengers with all stages of memory loss.
Chart #7: What Is Dementia Anyway?

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Loss</td>
<td>Difficulty Performing Tasks</td>
<td>Problem with Language</td>
<td>Disorientation to Time &amp; Place</td>
<td>Poor or Decreased Judgment</td>
<td>Problem with Abstract Thinking</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misplacing Things</td>
<td>Changes in Mood/Behaviors</td>
<td>Changes in Personality</td>
<td>Loss of Initiative</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chart #8: Silver Alert – What Is It?

The Statewide Silver Alert is a plan to aid local law enforcement in the rescue or recovery of a missing elderly person who suffers from irreversible deterioration of intellectual faculties and is driving a car.

Example of A Silver Alert

![Silver Alert Example](image)
## Transit Profiles

### Florida Statewide Transportation Profile

<table>
<thead>
<tr>
<th>Florida Statewide Profile</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population Profile</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total all ages</td>
<td>19,058,404</td>
<td>100%</td>
</tr>
<tr>
<td>Age stratification:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 60</td>
<td>14,662,387</td>
<td>76.90%</td>
</tr>
<tr>
<td>60+</td>
<td>4,396,017</td>
<td>22.92%</td>
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<tr>
<td>70+</td>
<td>2,416,021</td>
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</tr>
<tr>
<td>85+</td>
<td>494,463</td>
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</tr>
<tr>
<td>Male 60+</td>
<td>1,960,882</td>
<td>44.61%</td>
</tr>
<tr>
<td>Female 60+</td>
<td>2,435,135</td>
<td>55.39%</td>
</tr>
<tr>
<td>Probable Dementia #</td>
<td>502,631</td>
<td>11.50%</td>
</tr>
<tr>
<td>Severe Dementia Estimate</td>
<td>117,730</td>
<td>23.42%</td>
</tr>
<tr>
<td>Estimate of mild/moderate dementia</td>
<td>384,901</td>
<td>76.60%</td>
</tr>
<tr>
<td># Drivers 60+</td>
<td>3,794,846</td>
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<td>Seniors living alone</td>
<td>1,608,916</td>
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</tr>
<tr>
<td>Non white population</td>
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</tr>
<tr>
<td><strong>Transportation Data</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statewide Total Traffic Fatalities &amp; Injuries (all ages)</td>
<td>215,371</td>
<td></td>
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<tr>
<td><strong>Transportation Resources</strong></td>
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<td></td>
</tr>
<tr>
<td>Potential Transportation Disadvantaged population</td>
<td>7,164,641</td>
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<tr>
<td>Transportation Disadvantaged: DoEA funded trips</td>
<td>4,143,453</td>
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<tr>
<td>Unmet trip requests by county</td>
<td>1,057,419</td>
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<tr>
<td># Transportation Disadvantaged population served</td>
<td>819,500</td>
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<td><strong>Other Information:</strong></td>
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<td>Silver Alert activations (16.5 months)</td>
<td>179</td>
<td></td>
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<tr>
<td>CFAL communities</td>
<td>121</td>
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<tr>
<td>Memory Disorder Clinics</td>
<td>15</td>
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<tr>
<td>Volunteer Driver programs</td>
<td>n/a</td>
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<tr>
<td><strong>Statewide Transit Resources</strong></td>
<td>16</td>
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<tr>
<td>Ambulance (Land/Air)</td>
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<tr>
<td>General Medical</td>
<td>9</td>
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</table>
Leon County/Tallahassee Transportation Profile

<table>
<thead>
<tr>
<th>Leon County/Tallahassee</th>
<th>Number</th>
<th>Percentage</th>
<th>Size Category</th>
<th># in Cat.</th>
<th>Rank in Cat.</th>
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</thead>
<tbody>
<tr>
<td>County Population Profile</td>
<td></td>
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<tr>
<td>Total all ages</td>
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<td>Age stratification:</td>
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<td>60+</td>
<td>35,945</td>
<td>13.0%</td>
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<td>70+</td>
<td>16,565</td>
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<td>85+</td>
<td>3,599</td>
<td>1.30%</td>
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<tr>
<td>Male 60+</td>
<td>15,936</td>
<td>44.30%</td>
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<tr>
<td>Female 60+</td>
<td>20,009</td>
<td>55.70%</td>
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<tr>
<td>Probable Dementia #</td>
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<tr>
<td>Severe Dementia Estimate</td>
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<tr>
<td>Estimate of mild/moderate dementia</td>
<td>2,687</td>
<td>76.47%</td>
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<tr>
<td># Drivers 60+</td>
<td>33,991</td>
<td>16.70%</td>
<td></td>
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<tr>
<td>Seniors living alone</td>
<td>8,696</td>
<td>24.2%</td>
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<tr>
<td>Non white population</td>
<td>8,235</td>
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<td>City ranking</td>
<td></td>
<td></td>
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<tr>
<td>City: Total Traffic Fatalities &amp; injuries</td>
<td>n/a</td>
<td>n/a</td>
<td>75,000+</td>
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<td>6</td>
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<tr>
<td>City: Drivers 65+</td>
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<td>County ranking</td>
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<tr>
<td>County: Total Traffic Fatalities &amp; injuries</td>
<td>n/a</td>
<td>n/a</td>
<td>200,001+</td>
<td>23</td>
<td>3</td>
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<td></td>
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<td>Trans Resources</td>
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<tr>
<td>Potential Transportation Disadvantaged population</td>
<td>84,192</td>
<td>30.63%</td>
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<td>Unmet trip requests by county</td>
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## Leon County/Tallahassee

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# Miami Dade County/Miami Transportation Profile

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<td>48,540</td>
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# Orange County/Orlando Transportation Profile

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<td>340,370</td>
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<tr>
<td>Memory Disorder Clinic in County</td>
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<tr>
<td>Public Transit</td>
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<tr>
<td>Paratransit</td>
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<tr>
<td>Taxi/Livery</td>
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<td>Home Care</td>
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<td>Bus (regional)</td>
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<td>Airport Van</td>
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<tr>
<td>General</td>
<td>2</td>
<td></td>
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<tr>
<td><strong>Statewide Medical Services</strong></td>
<td>16</td>
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</tbody>
</table>
## Walton County/DeFuniak Springs Transportation Profile:

<table>
<thead>
<tr>
<th>Walton County/DeFuniak Springs</th>
<th>Number</th>
<th>Percentage</th>
<th>Size Category</th>
<th># in Cat.</th>
<th>Rank in Cat.</th>
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<tbody>
<tr>
<td><strong>County Population Profile</strong></td>
<td></td>
<td></td>
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<tr>
<td>Total all ages</td>
<td>59,370</td>
<td></td>
<td></td>
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<td>Age stratification:</td>
<td></td>
<td></td>
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<tr>
<td>60+</td>
<td>14,666</td>
<td>24.70%</td>
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<tr>
<td>70+</td>
<td>7,849</td>
<td>13.20%</td>
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<tr>
<td>85+</td>
<td>1,301</td>
<td>2.20%</td>
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<tr>
<td>Male 60+</td>
<td>6,833</td>
<td>46.60%</td>
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<tr>
<td>Female 60+</td>
<td>7,833</td>
<td>53.40%</td>
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<tr>
<td>Probable Dementia #</td>
<td>1,503</td>
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<tr>
<td>Severe Dementia Estimate</td>
<td>344</td>
<td>22.88%</td>
<td></td>
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<tr>
<td>Estimate of mild/moderate dementia</td>
<td>1,159</td>
<td>77.11%</td>
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<tr>
<td># Drivers 60+</td>
<td>12,621</td>
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<td>Seniors living alone</td>
<td>3,254</td>
<td>22.19%</td>
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<tr>
<td>Non white population</td>
<td>800</td>
<td>5.50%</td>
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<td><strong>Transportation Data</strong></td>
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<tr>
<td>City ranking</td>
<td>n/a</td>
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<td>3,000+</td>
<td>124</td>
<td>33</td>
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<tr>
<td>City: Total Traffic Fatalities &amp; injuries</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
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<td></td>
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<tr>
<td>City: Drivers 65+</td>
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<tr>
<td>County ranking</td>
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<tr>
<td>County: Total Traffic Fatalities &amp; injuries</td>
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<td>50,000+</td>
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<td>County: Drivers 65+</td>
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<tr>
<td><strong>Trans Resources</strong></td>
<td></td>
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<tr>
<td>Potential Transportation Disadvantaged population</td>
<td>18,419</td>
<td>31.87%</td>
<td></td>
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<td>Transportation Disadvantaged: DoEA funded trips</td>
<td>6,896</td>
<td>8.82%</td>
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<td>Unmet trip requests by county</td>
<td>199</td>
<td>n/a</td>
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<td># Transportation Disadvantaged population served</td>
<td>7,185</td>
<td>39.01%</td>
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<td><strong>Other Information:</strong></td>
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<tr>
<td>Silver Alert activations (16 months)</td>
<td>0</td>
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<td>CFAL community?</td>
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<tr>
<td>Memory Disorder Clinic in County</td>
<td>No</td>
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<tr>
<td>Public Transit</td>
<td>No</td>
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<tr>
<td>Paratransit</td>
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<tr>
<td>Volunteer Driver programs</td>
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<tr>
<td>Walton County/DeFuniak Springs</td>
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<tr>
<td><strong>Intercounty Services</strong></td>
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<tr>
<td>Medical/General</td>
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<tr>
<td>Medicaid/ADA/publically funded</td>
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<td>Home Care</td>
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<td><strong>Statewide Medical Services</strong></td>
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General Resource Information on Senior Transportation

Florida Specific Resources

Safe and Mobile Senior is the virtual front door for information about senior transportation. It includes links to a multitude of issues related to road users, vehicles, laws and transportation alternatives by county.  www.SafeandMobileSeniors.org

Florida Department of Elder Affairs provides access to Area Agencies on Aging for caregiver assistance through elder help lines. Call toll-free 1-800-96ELDER (1-800-963-5337) or contact website: http://elderaffairs.state.fl.us/

Florida GrandDriver® program provides access to driver safety information resources and alternative transportation information at the Florida Department of Highway Safety and Motor Vehicles, Division of Driver Licenses at: http://www.floridagranddriver.com

Florida Senior Safety Resource Center includes information about alternative transportation and driver skill information. http://www.fssrc.phhp.ufl.edu/

National Resources

The National Center for Senior Transportation (NCST) was established in 2006 to increase transportation options for older adults and enhance their ability to live more independently within their communities. Based in Washington, DC, the NCST is administered by Easter Seals in partnership with the National Association of Area Agencies on Aging through a cooperative agreement with the U.S. Department of Transportation, Federal Transit Administration (FTA). The National Center for Senior Transportation has become a portal of information regarding senior transportation in general. http://seniortransportation.easterseals.com

The Department of Health and Human Services has caregiver resources available at Elder Locator with information on the Internet designed to assist family members and caregivers of older adults. Contact website:

http://www.eldercare.gov/Eldercare/Public/Home.asp
http://www.eldercare.gov/Eldercare.NET/Public/Resources/Caregiver.aspx
The U.S. Administration on Aging (AoA) website at: <http://www.aoa.gov> offers valuable information for caregivers, including informational links, articles, and other resources. Caregiver resources on the AoA site include:

Provides caregivers and professionals information about the National Family Caregiver Support Program, including where you can turn for support and assistance, and providing services to caregivers


http://www.aoa.gov/aoaroot/(S(o1gxfqv4sk0zuleqeftdzg55))/aoa_programs/hcltc/caregiver/index.aspx

The Alzheimer’s Demonstration Program.

http://www.aoa.gov/AoARoot/(S(kqjjupfdd2cgxm45n5svsk55))/AoA_Programs/HCLTC/Alz_Grants/index.aspx

Aging Internet Information Notes are intended to empower users to explore Internet resources. Effort is made to include links with information useful to consumers and professionals. More than 60 aging topics are in the series.

<http://www.aoa.gov/prof/notes/notes.asp>

The Eldercare Locator provides the linkage to local elder help lines across the U.S. Call toll-free at 1-800-677-1116 or visit the Eldercare Locator website: http://www.eldercare.gov

Easter Seals – Project ACTION: Accessible Travelers’ Database lists providers of accessible transportation services throughout the U.S., including public transit and private bus companies, van rentals, travel agencies, shuttle services, etc. If planning to travel with someone who may become agitated or who needs physical assistance, see “Transportation Solutions for Caregivers” for ideas. Contact website:

http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2_trans_care


This Physician’s Guide to Assessing and Counseling Older Drivers was developed by the American Medical Association in cooperation with the National Highway Traffic Safety Administration.


Your Road Ahead: A Guide to Comprehensive Driving Evaluations
This guidebook describes the benefits of having a comprehensive driving evaluation from an occupational therapist with specialized driver evaluation training.

http://hartfordauto.thehartford.com/UI/Downloads/Your_Road_Ahead.pdf

National initiatives, coordinating programs and information are streamlining the system of transportation services for older adults. The needs of adults with cognitive problems vary greatly from the physical challenges that Americans with Disabilities Act (ADA) programs cover. Many riders deal with both physical and cognitive changes.

Easter Seals, Project ACTION – Accessible Community Transportation In Our Nation: You Can Ride

Site offers various resources, as well as training and technical assistance, in an effort to make the ADA work for everyone, everyday. A 1-800-659-6428 line to answer questions about ADA rights and responsibilities, direct callers to additional resources and help members of the disability and transportation communities address diverse accessibility issues. Training and technical assistance staff teaches individuals and communities how to build, use, and strengthen accessible transportation. Local communities host training events for Project ACTION to address specific topics. A Clearinghouse of over 90 free print, video and audio resources on numerous topics including:

Easter Seals Project ACTION http://www.projectaction.org

Easter Seals, Project ACTION – Transportation Solutions for Caregivers: A Starting Point

U.S. Department of Health and Human Services, Administration on Aging: “Promising Practices in the Field of Care giving” at:

http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2_trans_care

Caregiver Transportation Toolkit, “Transportation Solutions for Caregivers: A Starting Point”, which includes a video, informational booklet and a list of helpful products and resources for family caregivers. Issues addressed in the toolkit include difficulty getting into and out of a vehicle, providing physical assistance (wheelchair transfers, proper body mechanics, etc.) and both preventing and dealing with dementia-related behaviors.

Easter Seals, Primary Contact: Lisa Peters - Beumer

230 West Monroe Avenue, Suite 1800

Chicago, IL 60606


http://www.nhtsa.gov/people/injury/olddrive/CommMobilityDementia/index.htm

Alzheimer’s Association

‘Coach Broyles’ Playbook for Alzheimer’s Caregivers’

Tackle the challenges of caregiving with this free football style “playbook” by Frank Broyles, former Athletic Director of the University of Arkansas Razorbacks. The Playbook is an engaging how-to-guide written for those who care for someone with Alzheimer’s. Coach Broyles cared for his late wife Barbara, who had Alzheimer’s disease.

http://www.alzheimersplaybook.com/

Supplemental Transportation Programs for Seniors

AAA Foundation for Traffic Safety & the Beverly Foundation

Website: http://www.seniordrivers.org/STPs/index.cfm

Website Resource for those who wish to start supplemental transportation programs for seniors (STP’s). STP’s are community level entities to provide seniors with alternative forms of transportation. The website has suggestions for creating a program, a list of existing programs by state, and PowerPoint.

Passenger Service and Safety (PASS)

The PASS Driver Certification Program ensures that community transportation drivers have current expertise in passenger assistance techniques and sensitivity skills appropriate for serving persons with disabilities. PASS program is designed as a three-day Train-the-Trainer to certify trainers who can then train drivers or as a two-day Driver program in which our instructors train your drivers. Community Transportation Association of America (CTAA) – Len Cahill

http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=35&print=yes
CTAA Rural Transit Assistance Program (RTAP) Driver Training Module


“Understanding the Capabilities/Needs of Special Passengers”

Interviews with people with a disability who share their transportation assistance needs and dispel misconception. Topics include spinal cord injury, mental retardation, visual impairments, hearing impairments, neuromuscular conditions, epilepsy and seizure disorders, Alzheimer’s disease and aging.

“Safe Transport of the Public under the ADA”

Stresses good passenger relations and focuses on the driver’s responsibility for learning safe and courteous responses to varied circumstances. Topics include: Your job is more than driving and working with passengers with mobility, communication, visual and other impairments.

“Trading Places – Assisting Passengers with Special Needs”

Designed to help drivers, dispatchers, and managers gain the skills and knowledge to provide sensitive, caring and safe transit services to elderly or disabled passengers. The module’s approach to learning is at times light-hearted, but the underlying message is serious—drivers must prevent problems as well as be able to respond to a wide variety of mechanical and personal demands from passengers who need special assistance.

‘Problem Passengers, Challenging Situations’

Designed to help drivers and other personnel who deal directly with the public recognize, avert, and control disruptive behaviors. Applying the principles featured, drivers make professional choices that communicate with the problem passenger without letting a situation get out of hand and jeopardizing the safe transport of others.

Into the Other Lane: Driving and Dementia. Produced by Terra Nova Films.

http://www.terranova.org/Into_The_Other_Lane.aspx

Real-life stories about when and how to deal with the emotional issue of giving up driving. This two-part DVD presents a compassionate, yet realistic, portrait of the many issues faced by persons with dementia, (and their caregivers) when a decision has to be made about giving up driving.
Survey Instruments

Transportation & Dementia

Professionals Survey
This survey is being conducted with professionals who work with or assist people with memory disorders and should require about 10 minutes to complete.

PART I - YOUR PROFILE
(Please Check (✓) or Complete Response)

1. YOUR GENDER: □ Male □ Female

2. YOUR AGE: □ Under Age 50 □ Age 65 – 74
□ Age 50 – 64 □ Age 75+

3. YOUR PROFESSION: In which of the following professions do you work?
□ aging
□ human services
□ transportation
□ dementia support
□ public safety
□ other (please specify ____________________)

5. YOUR INVOLVEMENT: What types of involvement do you have with people who have dementia? (check all that apply)
□ have a family member or friend with dementia
□ work with dementia patients every day
□ work with dementia patients periodically
□ drive people with dementia to destinations
□ counsel/help drivers with dementia
□ other (please specify) ____________________

PART II - DEMENTIA-RELATED INFORMATION
(Please complete information if you hold a professional position that requires you to work with or support people with memory disorders.

6. WARNING SIGNS: Do you work with any persons who exhibit any of the following behaviors related to dementia? (please check all that apply)

□ Memory loss
□ Difficulty performing familiar tasks
□ Problems with language
□ Disorientation to time and place
□ Poor or decreased judgment
□ Problems with abstract thinking
□ Misplacing things
□ Changes in mood or behavior
7. **Service & Support Needs:** How would you rank the following needs of the family member or friend for whom you help or care. *(start with the most important)*

<table>
<thead>
<tr>
<th>Rank</th>
<th>Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Health Care</td>
</tr>
<tr>
<td>2</td>
<td>Housing</td>
</tr>
<tr>
<td>3</td>
<td>Home Care</td>
</tr>
<tr>
<td>4</td>
<td>Nutrition Services</td>
</tr>
<tr>
<td>5</td>
<td>Transportation Services</td>
</tr>
<tr>
<td>6</td>
<td>Social Services</td>
</tr>
<tr>
<td>7</td>
<td>Life Enriching Activities</td>
</tr>
</tbody>
</table>

Please rank from 1 *(most important)* to 7 *(least important)*

8. **Driving Decline:** Do you work with any persons who exhibit any of the following behaviors related to driving decline? *(please check all that apply)*

- [ ] Easily distracted while driving
- [ ] Other drivers often honk horns
- [ ] Incorrect signaling
- [ ] Scraps or dents on car, mailbox, or garage
- [ ] Riding the brake
- [ ] Driving at inappropriate speeds
- [ ] Not anticipating potential dangerous situations
- [ ] Bad judgment on making left hand turns
- [ ] Delayed response to unexpected situations
- [ ] Confusing the gas and brake pedals

9. **Driving Assessment:** Have you ever heard of specialized driver assessments for people with dementia or other cognitive limitations?  [ ] yes  [ ] no

10. **Destinations:** Which of the following do you believe are the most challenging travel destinations for a person with dementia to get to? *(please check only three destinations)*

    - [ ] the doctor
    - [ ] specialized health center
    - [ ] grocery shopping
    - [ ] adult day center
    - [ ] social services
    - [ ] beauty shop
    - [ ] senior center
    - [ ] visit family & friends
    - [ ] don’t know
    - [ ] other  ___________________ *(please specify)*

Florida Dementia Friendly Transportation Research Project
11. TRANSPORTATION What types of transportation services do you believe can be most useful in getting persons with dementia where they need to go? *(please check all that apply)*

- Persons driving selves
- Family members, friends, neighbors
- Fixed route public transit (e.g. bus)
- A senior center vehicle
- Church shuttle
- Information & referral service
- Don’t know

12. AVAILABLE TRANSPORTATION ALTERNATIVES: Which of the following transportation alternatives in your community adequately meet the transportation needs of people with dementia? *(check only top three)*

- Family members
- Friends and neighbors
- Fixed route public transit (e.g. bus)
- ADA paratransit service
- Human service
- A senior center vehicle
- Church shuttle
- A private service
- Don’t know

13. TRANSPORTATION ASSISTANCE: What types of transportation assistance do you believe are needed to help people with dementia access transportation? *(please check all that apply)*

- Curb-to-curb service
- Door-to-door service
- Door-through-door service
- Don’t know

14. TRANSPORTATION ASSISTANCE: What types of transportation assistance are available in your community to help people with dementia access transportation? *(please check all that apply)*

- Curb-to-curb service
- Door-to-door service
- Door-through-door service
- Don’t know

15. TRANSPORTATION TRAINING: What types of transportation training do you believe should be made available to caregivers, drivers, and transportation services to enable them to help people with dementia utilize transportation alternatives? *(check all that apply)*

- Transportation staff assistance training
- Driver assistance training
- Training for mobility managers
- Specialized travel training for using transportation services
- Travel buddy training
- Mobility management training for staff
- Don’t know

12. AVAILABLE TRANSPORTATION ALTERNATIVES: Which of the following transportation alternatives in your community adequately meet the transportation needs of people with dementia? *(please specify)*
16. **Silver Alert:** Are you aware of the Silver Alert program?  
☐ yes  ☐ no  
If yes, where did you hear about it? ________

17. **Silver Alert Awareness:** How would you rate the level of awareness of Floridians about Silver Alert?  
(check the one rating that applies)  

1. very low  2  3  4  5. very high
Caregiver Survey

Transportation and Dementia

This survey is being conducted with family members and caregivers of people with memory disorders and should take you about 10 minutes to complete.

**PART I – YOUR PROFILE**

(Please Check (✓) or Complete Response)

1. **YOUR GENDER:**
   - [ ] Male
   - [ ] Female

2. **YOUR AGE:**
   - [ ] Under Age 50
   - [ ] Age 65 – 74
   - [ ] Age 50 – 64
   - [ ] Age 75+

3. **YOUR EMPLOYMENT:** Do you work outside the home for pay?
   - [ ] yes
   - [ ] no

4. **YOUR CAREGIVER STATUS:** Do you help or care for someone with dementia?
   - [ ] yes
   - [ ] no

5. **YOUR INVOLVEMENT:** Are you a member of a caregiver support group?
   - [ ] yes
   - [ ] no

6. **YOUR HEALTH STATUS:** How would you define your current health status?
   - [ ] excellent
   - [ ] good
   - [ ] fair
   - [ ] poor

**PART II – CARE RECEIVER (FAMILY MEMBER OR FRIEND) INFORMATION**

(Please complete information if you are a full, part time, or periodic caregiver of a family member, friend, or neighbor with a memory disorder. If you help several people, think of one person you help when responding to the questions).

7. **AGE:** Age of person with dementia for whom you help or support __________

8. **RELATIONSHIP:** How is person for whom you care related to you?
   - [ ] Spouse
   - [ ] Sibling
   - [ ] Parent
   - [ ] Friend/Neighbor
   - [ ] Grandparent
   - [ ] Other __________________________ (please specify)

9. **LIVING ARRANGEMENT:** Does person for whom you care live in same household as you?
   - [ ] yes
   - [ ] no

10. **DURATION:** How long has the person for whom you help or care had a memory disorder?
11. **Warning Signs**: Does the person for whom you care exhibit any of the following characteristics? *(please check all that apply)*

- [ ] Memory loss
- [ ] Difficulty performing familiar tasks
- [ ] Problems with language
- [ ] Disorientation to time and place
- [ ] Poor or decreased judgment
- [ ] Problems with abstract thinking
- [ ] Misplacing things
- [ ] Changes in mood or behavior
- [ ] Changes in personality
- [ ] Loss of initiative

12. **Difficult Situation**: Has the person for whom you care ever gotten lost?
   - [ ] yes
   - [ ] no

13. **Driving**: Does the person for whom you care still drive?
   - [ ] yes
   - [ ] no

**Part III – Service and Support Information**

(Please complete information if you are a full, part time, or periodic caregiver of a family member or friend with a memory disorder)

14. **Service & Support Needs**: How would you rank the following needs of the family member or friend for whom you help or care. *(start with the most important)*

    Please rank from 1 *(most important)* to 7 *(least important)*

    - [ ] Health Care
    - [ ] Housing
    - [ ] Home Care
    - [ ] Nutrition Services
    - [ ] Transportation Services
    - [ ] Social Services
    - [ ] Life Enriching Activities
15. Driving Decline: Does the person for whom you care exhibit any of the following indicators of driving decline (or if they no longer drive, did they before they stopped driving?) (please check all that apply)

- Easily distracted while driving
- Other drivers often honk horns
- Incorrect signaling
- Scraps or dents on car, mailbox, or garage
- Riding the brake
- Driving at inappropriate speeds
- Not anticipating potential dangerous situations
- Bad judgment on making left hand turns
- Delayed response to unexpected situations
- Confusing the gas and brake pedals
- Other ____________________________
  (please specify)
- Don’t know

16. Destinations: What are the primary travel destinations of the person for whom you care? (please check only three destinations)

- the doctor
- a specialized health center
- adult day center
- social services
- senior center
- grocery shopping
- beauty shop
- visit family/friends
- other ______ (please specify)

17. Transportation Services: What types of transportation do you rely on to get the person for whom you care to activities and/or services? (please check all that apply)

- they drive their own car
- a taxi service
- I drive them
- ADA paratransit service
- fixed route public transit (e.g. bus)
- a volunteer driver service
- a senior center vehicle
- a private service
- church shuttle
- other ______ (please specify)

18. Transportation Options: Are the community-based transportation options adequate to meet the needs of the person with dementia for whom you care?

- yes
- no
- don’t know

If yes, why? If no, why not? __________________________

19. Transportation Support: Are the transportation services that are available to your care receiver adequate to meet their transportation access needs?

- yes
- no
- don’t know

If yes, why? If no, why not? __________________________

20. Silver Alert: Are you aware of the Silver Alert program? yes no

If yes, where did you hear about it? _______