January 17, 2006

Ms. Fran Carlin-Rogers
Chairperson
Alzheimer’s Disease Advisory Committee

Dear Ms. Carlin-Rogers:

Thank you for submitting the Alzheimer’s Disease Advisory Committee’s report, “Ethics-Based Policy on Driving Safety & Progressive Dementia,” to the department. Secretary Green and I have reviewed and discussed the report, and we are pleased to support the recommendations contained therein.

We would like to commend the Alzheimer’s Disease Advisory Committee and the Ethics Subcommittee for providing strong leadership and advocacy on driver safety issues. Though the ethical issues surrounding driving and dementia have only begun to garner national attention over the past few years, we realize that the ADI Committee has been promoting public safety, individual rights, family and community responsibility, transportation alternatives, and, above all, compassion and caring for people dealing with dementia and driving, for well over ten years. We are pleased that your efforts have culminated in such a thorough and informative report.

As you may be aware, the department is expanding the Communities for Lifetime (CFAL) initiative in 2006. This program provides the department with a mechanism to reach out to more elders who may not require state human services assistance, as well as to help communities plan for the future needs of all its citizens, throughout the lifespan. The department will focus on three vital issues in 2006: transportation, housing and employment. The recommendations contained in the Alzheimer’s Disease Advisory Committee’s report will form a strong foundation as the department develops a broader transportation policy for elders and caregivers.

Though we will need some time to develop and validate a set of screening questions to assess driver safety, we can begin to implement the other recommendations on page 19 of the report immediately. We look forward to working with the committee and the Alzheimer’s Disease Initiative network to incorporate information, referral and education initiatives on driver safety into the department’s elder service delivery system.

Once again, thank you for your leadership on this critical issue.

Sincerely,

Tom Reimers
Director
Division of Volunteer & Community Services

CC: Secretary Carole Green
WHITE PAPER: FINAL REPORT to

FLORIDA DEPARTMENT OF ELDER AFFAIRS (DOEA)

ALZHEIMER’S DISEASE INITIATIVE (ADI)

ETHICS-BASED POLICY on

DRIVING SAFETY &

PROGRESSIVE DEMENTIA

Prepared by: Leilani Doty, PhD & Kathleen Houseweart, MBA
ADI Ethics Subcommittee

Presented to and adopted by the Alzheimer’s Disease Initiative (ADI) Advisory Committee on September 16, 2005 in Tampa, Florida, pursuant to an ADI Strategy Session on Driving and Dementia held June 16, 2005, in Orlando, Florida.

The greatest appreciation is extended to the gracious, visionary leadership of Fran Carlin-Rogers, Chair of the Alzheimer’s Disease Initiative (ADI) Advisory Committee and a Certified DriveWell Trainer, for her undaunted commitment to serve people in Florida dealing with Alzheimer’s disease and related dementias, safe transportation over a lifetime, and, particularly, for her assistance on this ADI Driving and Dementia Project. In addition, it is important to recognize the invaluable support of the Department of Elder Affairs (DOEA), the administrative skills of Tom Reimers, Director, DOEA Division of Volunteer & Community Services, and numerous DOEA staff who helped strategize, implement, and participate in the ADI Driving and Dementia Project.
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PREFACE

Nation-wide and Florida-wide increasing attention has focused on driver safety. Leaders in the Alzheimer’s Disease Initiative (ADI) program of the Florida Department of Elder Affairs pioneered an effort to develop an ethics-based policy on driving safety related to people dealing with Alzheimer’s disease and related dementias and other members of the community. (NOTE: Dementia is, while a person is alert and awake, a decline in memory and at least one other thinking function such as difficulty: understanding or expressing words, making decisions, doing arithmetic, coordinating hand movement to use utensils or to do tasks, or doing math/counting change. Alzheimer’s disease (sometimes called in simpler words, a memory disorder) is one of more than 50 types of progressive dementias.

Concerns about progressive dementia and driving safety as a major public safety issue germinated in the ADI Ethics Subcommittee a decade ago. In February 2005 an initiative was launched to develop an ADI Policy Statement reflecting the highest level of integrity to address families dealing with progressive dementia, motor vehicle privileges and safety, and supportive, competent alternative transportation. The initiative encompassed a thorough literature and web site review, telephone conferences with national experts on driving, a day-long think tank session in June 2005 with experts on driving and progressive dementia, rounds of drafting and revising (with input from experts) an ADI Policy Statement document, and the adoption of the ethics-based policy statement and full report on September 16, 2005.

This White Paper is a Final Report: it encapsulates the process of the project which culminated in the ADI Ethics-Based Policy Statement on Driving Safety and Progressive Dementia and contains recommendations for action steps to move people in Florida toward better driver fitness and safer mobility.

**Leilani Doty, PhD.** Chair Emeritus and Founder of the ADI Ethics Subcommittee; Administrator of the University of Florida, Department of Neurology, ADI Memory Disorder Clinic

**Kathleen Houseweart, MBA.** Chair, ADI Ethics Subcommittee; Program Coordinator of the Sarasota Memorial Health Care System, Sarasota Memorial Hospital, ADI Memory Disorder Clinic

*September 16, 2005*

*For additional copies or further information about this White Paper (Final Report), please contact the Florida Department of Elder Affairs, Division of Volunteer and Community Services, 4040 Esplanade Way, Tallahassee, FL 32399-700; phone (850)414-2000.*
EXECUTIVE SUMMARY
Alzheimer’s Disease Initiative (ADI) ETHICS-BASED POLICY STATEMENT on Driving Safety and Progressive Dementia

The Alzheimer’s Disease Initiative (ADI) Ethics-Based Policy Statement on Driving Safety relates to people in Florida dealing with Alzheimer’s disease and related dementias and others members of the community.

Research
Research has shown that drivers with a cognitive or memory dysfunction have 7.6 times the number of crashes as do unimpaired elders. People with Alzheimer’s disease or a related dementia experience changes in memory, naming, decision making, sustained focus, predicting consequences, praxis, judgment especially judging distances and handling multiple stimuli (such as simultaneous road or detour signs, flashing arrows, and road debris), and other cognitive functions over time which result in decreased capacity and roles. Thus, people with Alzheimer’s disease or a related dementia are at higher risk for cognitive overload which may explain why crashes result more often during complex driving situations. In Florida, of the 14.8 million drivers, almost 250,000 of them are over age 85, which may translate (if 47.3% are at risk for progressive dementia) to almost 115,000 elder drivers with dementia. And these numbers are growing.

Most older adults (90%) drive their own or the family car to destinations, 85% of people 75 to 79 years of age, 78% of people 80 to 84 years of age, and 60% of people 85 and older. Eighty-two percent of family caregivers provide transportation for loved ones with Alzheimer’s disease. Ultimately all people diagnosed with Alzheimer’s disease or a related dementia must stop driving.

Ethical Issues
During the protracted course and progressive changes of Alzheimer’s disease and related dementias, the ethical values of autonomy, informed consent, and individualism evolve into setting limits on autonomy for safety, limiting or replacing informed consent with beneficence, and shared or partnered activities to maintain quality of life. The struggle to honor confidentiality and to protect civil liberties must be balanced carefully with public safety. As changing capacity limits driver privileges, it is critical that the expanding numbers of people dealing with Alzheimer’s disease or a related dementia not be marginalized, but continue meaningful, integrated lives in communities that provide support systems for lifelong driver fitness and safe mobility with compassion and caring.

Policy of Alzheimer’s Disease Initiative
The Alzheimer’s Disease Initiative (ADI) integrates the worlds of policy and practice. The policy of the ADI on driver safety relevant to those dealing with Alzheimer’s disease and related dementias is to focus through a prism of the highest ethics and to work proactively to enhance the quality of daily, meaningful life, to balance individual and public safety with individual rights, and to promote consumer-friendly transportation over the lifetime which entails driver/transportation research, education, comprehensive assessment, mobility counseling,
mobility resources, and funding. Essentially, the ADI policy is to adhere to the most worthy values of the public conscience, more specifically, to:

1. **Support and link to the policy and activities** of the Florida At-Risk Driver Council (February 2004) report\(^{13}\) that relate to the specific issues of people dealing with Alzheimer’s disease and related disorders. Support the education and training of credentialed mobility resource people to assist in a continuum of transportation specific to helping people dealing with Alzheimer’s disease and related dementias to maintain a community-based, self-sufficient quality of life.

2. **Assist in the research and ethical translation of findings** to identify and develop robust screening tools, comprehensive assessment programs, and a continuum of services ranging from referral, assessment, habilitation and rehabilitation to follow-up and identifying supportive, consumer-friendly transportation alternatives for families dealing with Alzheimer’s disease and related disorders. Driver fitness provides functioning, for as long as possible, as fit and safe drivers; planning ahead provides for resources when driving is no longer appropriate.

3. **Educate Legislators and other Florida leaders** to be ethically tuned and responsive to the needs of people dealing with Alzheimer’s disease and related disorders regarding policy, Florida Statutes and funding that enhance for these people driver safety programs and consumer-friendly transportation services statewide. Educate health providers, social service providers, law enforcement officers, transit providers, other local and state level providers and the general public on issues pertinent to the spectrum of transportation issues specifically related to Alzheimer’s disease and related disorders.

4. **Foster communities-for-a-lifetime** with consumer-friendly, supportive, reliable, transportation resources that address with integrity the specific issues of people dealing with Alzheimer’s disease and related disorders.

5. **Work with Florida policy makers to identify funding and work with industries**, such as makers of car products and driver insurance companies, to access funding for research, education, services, scholarships for comprehensive driver skill assessment, and community resources for driver safety and ethical, consumer-friendly transportation specific to the issues of people dealing with Alzheimer’s disease and related disorders.

**Recommendations for Ethical Action Steps Regarding Driving Safety and Progressive Dementia**

On September 16, 2005, the ADI Advisory Committee, in pursuit of integrity, recommended that the following ethics-based action steps should be implemented as soon as possible in all ADI, ADI-related and relevant Department of Elder Affairs (DOEA) programs throughout Florida:

1. **Assessment**: It is recommended that each program includes a screening question or two regarding driving safety as part of the initial intake and/or medical evaluation of a patient/client
coming in for a new evaluation or a return/follow-up visit. The person who does the intake screening or reviews the intake information should be alert to signs that driver safety may be at risk. Possible questions to revise as fits each program: Any changes in driving skill? Any car accidents or near misses? A “yes” to either question (or both) merits a referral for a comprehensive driver evaluation.

2. **Habilitation, Remediation, and Rehabilitation**: It is recommended that each program identify appropriate patients/clients for driving assessment referrals to assessors trained to complete comprehensive driving evaluations with appropriate follow-up.

3. **Mobility Counseling**: It is recommended that each program provide information regarding transportation alternatives in the local area for people who give up driving privileges.

4. **Education**: It is recommended that each ADI and DOEA training program include information about the ethics of driving safety and the impact of progressive dementia in the annual mandated hours of training to service providers and in other educational sessions.

5. **Networking**: It is recommended that the ADI Advisory Committee link with efforts of other local and national groups such as the Florida At-Risk Driver Council and the National Highway Traffic Safety Administration to address ethics and other issues specific to people dealing with progressive dementia. Networking with Florida leaders and policy makers should include requests for funding for the 2006-07 year for driver skill assessment scholarships for people referred for comprehensive driver evaluations.

Succinct versions of the preceding Executive Summary with briefly stated recommendations were developed as a Fact Sheet and as a Slide Presentation, which are available on the following two pages.
FACT SHEET

Alzheimer’s Disease Initiative (ADI) Ethics-Based Policy on Driving Relevant to Alzheimer’s Disease and Related Dementias

RESEARCH FACTS
- drivers with a cognitive or memory dysfunction crash 7.6 times as often as unimpaired elders.  
- Alzheimer’s disease and related disorders result in decreased capacity and roles  
- most (90%) elders drive their own vehicle  
- 82% of family caregivers transport loved ones with Alzheimer’s disease  
- Florida has 14.8 million drivers, almost 250,000 of them are over age 85  
  - 115,000 elder drivers have a progressive dementia such as Alzheimer’s disease  
  - baby boomer retirees are increasing these numbers  

Ultimately everyone diagnosed with Alzheimer’s disease or a related dementia must stop driving. As changing capacity limits driver privileges, these expanding numbers of people dealing with progressive dementia must not be marginalized, but continue meaningful, integrated lives in communities that balance public safety with systems for lifelong driver fitness and safe mobility.

ADI Policy
The Alzheimer’s Disease Initiative (ADI) integrates the worlds of policy and practice. The ADI policy on driving relevant to those dealing with Alzheimer’s disease and related dementias has an ethics focus, a focus to enhance the highest quality of daily, meaningful life, to balance individual and public safety with individual rights, and to promote consumer-friendly transportation over the lifetime which entails driver/transportation research, education, comprehensive assessment, mobility counseling, mobility resources, and funding. Essentially, the ADI policy is to adhere to the highest integrity of the public conscience, more specifically, to:
1. Support and link to activities of the Florida At-Risk Driver Council (2/04) report  
2. Assist in research and translate findings with an ethics perspective on assessment programs, a continuum of mobility resource people, and services,  
3. Educate with an ethics perspective Florida Legislators and other leaders, health/safety/social service providers and the general public,  
4. Foster ethics-based communities-for-a-lifetime, and  
5. Work with Florida policy makers, industries and others to identify funding.

CALL for ACTION
All ADI, ADI-related and relevant DOEA programs, should implement as soon as possible pertinent, ethics-based: assessment; habilitation, remediation, and rehabilitation; mobility counseling, education, and networking (especially to identify funding).

Prepared by: Leilani Doty, PhD, 9/16/05 (References in Whitepaper (Final Report), Florida Department of Elder Affairs, Alzheimer’s Disease Initiative, Ethics-Based Policy on Driving Safety & Progressive Dementia)
Slide Summary of Ethics-Based Policy Recommendations and Action Steps

Slide 1  Driving & Dementia
Session: June 16, 2005
• Convened by the ADI Ethics SubCommittee – Kathleen Houseweart,MBA, Leilani Doty, PhD
• DriveWell presentation by Fran Carlin-Rogers
• Lunch presentation by Nina M. Silverstein, PhD
• Roundtable discussions to develop policy recommendations
• Expert Guests: Nina M. Silverstein, PhD, Ken Brummel-Smith, MD, Ira J. Goodman, MD, Tom Reimers, Selma Sauls, Denise Sparks, PhD, Wendy Stav, PhD, OTR/L, CDRS

Slide 2  General Recommendations
from June 16, 2005
• Support Recommendations of At-Risk Drivers Council February 2004 report
• Facilitate development of robust screening and assessment tools & a continuum of services to promote driving safety and appropriate alternatives
• Educate legislators and support funding for programs that support driving safety and consumer friendly transportation alternatives

Slide 3  Ethical Considerations
• Autonomy vs. setting limits
• Informed consent vs. beneficence
• Individualism vs. shared activity
• Individual rights vs. public safety

Slide 4  General Recommendations
• Foster communities-for-a-lifetime which offer consumer friendly, supportive, reliable transportation resources for individuals with cognitive impairment
• Work with policy makers to identify funding sources and opportunities for partnership with private industry to pay for research, education and scholarships for comprehensive driver evaluations, and community resources for transportation alternatives

Slide 5  Action Steps for ADI
1. ADI Memory Disorder Clinics include screening questions about driving safety
2. ADI Memory Disorder Clinics provide referral information to comprehensive driving evaluation programs
3. ADI Memory Disorder Clinics provide information about driving alternatives

Slide 6  Action Steps for ADI (Cont’d)
4. ADI Memory Disorder Clinics include Driving & Dementia as a topic in the 4 hour annual training required by contract
5. ADI Advisory Committee maintain links to local and national groups that address driving and advocate for innovative funding options for scholarships for driver assessment programs

Prepared by: by Kathleen Houseweart, MBA, 9/16/05 (Further information in “White Paper(Final Report), Florida Department of Elder Affairs, Alzheimer’s Disease Initiative, Ethics-Based Policy on Driving Safety & Progressive Dementia”)


BACKGROUND TO DEVELOPMENT OF ETHICS-BASED POLICY STATEMENT

Introduction
One of the major programs of the Florida Department of Elder Affairs, the Alzheimer’s Disease Initiative (ADI) is a statewide network of memory disorder clinics, model adult day (health) care programs, respite workers, and other services to address the needs of people in Florida who are struggling with the challenges of Alzheimer’s disease and related memory disorders (dementias). The ADI Advisory Committee, comprised of medical, social service, family and other experts in the areas of progressive dementia make recommendations to the Secretary of the Department of Elder Affairs and to the Governor of Florida to strengthen programs to help families.

After many years of discussion and concerns in the ADI Ethics Subcommittee about driving safety, respecting and assisting families dealing with progressive dementia, acceptable risks in the operation of motor vehicles, and the need for comprehensive driver evaluation and follow-up programs, several driver accidents in Florida and nationwide in 2004 alerted the network of the Alzheimer’s Disease Initiative that a policy and action were imperative for the communities of Florida.

Charge to the Ethics Subcommittee
In February 2005, the Alzheimer’s Disease Initiative Advisory Committee charged the ADI Ethics Subcommittee under the leadership of its Chairperson Kathleen Houseweart, MBA (Sarasota Memorial Health Care System Memory Disorder Clinic) and Past Chairperson Leilani Doty, PhD (University of Florida Memory Disorder Clinic) to draft a policy statement. The charge included the request to convene a special, strategy session to address the ethical issues relating to driver privileges of those dealing with Alzheimer’s disease or a related progressive dementia, and to develop recommendations for an Alzheimer’s Disease Initiative (ADI) policy statement.

With the operational assistance of the staff of the Department of Elder Affairs, a day long session convened June 16, 2005 in Orlando, Florida. The purpose of the session was to identify critical driver safety issues for people in Florida who deal with changes related to Alzheimer’s disease and related disorders and to draft ethics-based recommendations for an ADI policy. Leilani Doty was tasked with developing a white paper on the recommendations.

Role of the ADI Advisory Committee
The ADI Advisory Committee is appointed by the Governor of Florida to guide the development of policy pertinent to dealing with Alzheimer’s disease and related dementias. Essentially, the ADI links the worlds of policy and practice. The recommendations from the June 16th, 2005 strategy session provided considerations from an ethics perspective regarding ADI Policy on driving safety relevant to Alzheimer’s disease and related dementias and to the Florida community at large.
Importance of an ADI Policy Statement on Driving Safety in Florida
A policy is a plan, a value, or a course of action that may be useful or prudent for a government, political party or business to impact and guide plans, decisions and actions. A great deal of controversy exists about driving privilege and safety risks associated with the health changes that result in decreased memory and cognitive dysfunction in Alzheimer’s disease and related progressive dementias. It is ethically imperative that experts in the area of progressive dementia such as those comprising the ADI Advisory Committee and Florida policymakers address this dire transportation issue in the State of Florida. Florida should lead the nation in the legislation, support and implementation of statutes that will maintain the highest, safest and wisest standards and guidelines for driving privileges. Florida should offer the most creative solutions for supportive alternative transportation resources for Floridians who no longer have driver privileges.

Some of the ethical concerns regarding driver safety and the transportation needs of people dealing with Alzheimer’s disease and progressive dementia include:

1. **Lifelong and intergenerational mobility and safety issues** for individuals, family members and the community.

2. **Privacy issues** relating to physician referrals for driver evaluations: should the health provider compel a driver-safety evaluation, perhaps breeching patient confidentiality? What about breeching confidentiality in the case of Mild Cognitive Impairment (MCI) (Amnestic MCI with only decreased short-term memory versus Cognitive MCI, having evidence of a single cognitive deficit)?

3. **Policy issues** relating to the development of legislation and that may impact individual freedom, safety and the ability of individuals to meet their basic daily needs such as grocery shopping or getting to appointments.

4. **Planning** issues for families including access to driving alternatives.

5. **Determining acceptable risk**, including attention to early evaluation, diagnosis, and intervention regarding people with symptoms of Mild Cognitive Disorder of the Amnestic Type or Cognitive Type and people with early stages of a progressive dementia.

Ethical versus Legal or Constitutional Issues
Supreme Court Justice John Paul Stevens who has served on the Supreme Court for 30 years revisited the important role of policymakers, particularly Legislators, in a discussion of some of his recent opinions. Justice Stevens stressed that some recent opinions were compelled by a duty to the federal law or the Constitution rather than his preferences for a possibly wiser, more ethical decision. The decision of Justice Stevens in a New London, Connecticut eminent domain decision was compelled by the government’s right to take over private property for a commercial development, a decision he made against his own better personal judgment. The sense of duty to uphold the federal statute directed his decisions. Thus, policy makers must be alert to the pragmatics of policy and statutes and how their translation into rules and systems impacts the daily lives of citizenry.
Purpose and Method of Developing the ADI Policy Statement

The purpose of developing an ADI policy statement is to channel the wisdom of experts in the area of driver safety and Alzheimer’s disease and related dementias into recommendations for a policy statement that may provide some guidance for the Governor of Florida and the Florida Legislators. Following a model described by Peter V. Rabins, MD16, the proposed policy statement evolved from a complex series of meetings, literature and web site reviews, multiple draftings of text, and revisions from experts. A day long working meeting (June 16, 2005) with direct input from experts in geriatrics, progressive dementia and driver safety evinced the complex issues in Florida. Added to these Florida issues were important points from a review of the existing published research literature to form a draft-document of a proposed ethical policy statement. The draft was sent out to several Florida experts in driving and progressive dementia for revisions, and then the revised document was presented to the ADI Advisory Committee for consideration, further revisions and adoption. The adoption of the ethics-based policy statement (and full report) occurred September 16, 2005.

ADI Strategy Session on Driving Safety Issues (June 16, 2005)

The day long strategy session, Alzheimer’s Disease Initiative (ADI) Strategy Session on Driving and Dementia, convened June 16, 2005, in Orlando, Florida, for the purposes of developing recommendations for an ADI ethics-based policy on driving and progressive dementia (see appendaged Agenda). Kathleen Houseweart, MBA, Chair of the ADI Ethics Subcommittee, and Leilani Doty, PhD, Past Chair of the Ethics Subcommittee convened the meeting.

Fran Carlin-Rogers, Chair of ADI Advisory Committee and a Certified DriveWell Trainer, educated participants using the DriveWell curriculum and materials to train potential trainers. DriveWell is a public information campaign developed by the American Society on Aging and the National Highway Traffic Safety Administration to promote safety among the growing number of drivers 65 and older (see the DriveWell web site appended in the listed Resources). The additional goal of DriveWell is to broaden public awareness of older driver safety and mobility needs among family members, professionals serving older adults and local public policymakers. The DriveWell training program includes four complete curricula, training videos, handouts, etc.; one of the training modules focuses on driving and dementia.

Experts invited to serve as educators and facilitators at the strategy session roundtable discussions of issues included Nina M. Silverstein, PhD, Ira J. Goodman, MD, Selma Sauls, Ken Brummel-Smith, MD, Wendy Stav, PhD, OTR/L, CDRS, Tom Reimers, and Denise Sparks, PhD (see descriptors of the experts in the following Table 1). During the Working Lunch, the Keynote Speaker, Nina M. Silverstein, PhD, a professor at the University of Massachusetts, Boston, and Fellow to the National Highway Traffic Safety Administration, addressed the national scene regarding driving safety issues and transportation support programs in her talk, “It’s not just about the keys: Reframing Research and Policy Issues about Driving and Dementia” (see Table 2. Major Points of Dr. Nina Silverstein’s Presentation. See Appendix for handout of Dr. Silverstein’s slides). Then roundtable discussions with the invited experts facilitating participants from throughout Florida (see appended list of facilitators and participants) ensued. Summaries of their discussions follow in the next section.
Table 1

The Seven Invited Expert Facilitators

1. **Nina M. Silverstein, PhD**, University of Massachusetts, Boston, Fellow to the National Highway Traffic Safety Administration, Nina.Silverstein@umb.edu;

2. **Ken Brummel-Smith, MD**, Chair of the Florida At-Risk Driver Council (FADC); Professor and Chair, Department of Geriatrics, College of Medicine, Florida State University, Tallahassee, FL; phone (850)644-2291; fax (850)645-2824; Ken.Brummel-Smith@med.fsu.edu;

3. **Ira J. Goodman, MD**, Director, Orlando Regional Memory Disorder Clinic (Orlando Regional Lucerne Hospital), (407)244-3281; (321)841-2452; ijgmd@aol.com;

4. **Tom Reimers**, Director, Division of Volunteer & Community Services Florida Department of Elder Affairs, 4040 Esplanade Way, Tallahassee, FL 32399-7000 phone (850)414-2000; reimerst@elderaffairs.org

5. **Selma Sauls**, Management Analyst III, Department of Highway Safety and Motor Vehicles, Division of Driver Licenses- Division of Driver Licenses, Director's Staff, 2900 Appalachie Parkway, MS 80, Room C314A, Tallahassee, Florida 32399-0570; Phone (850)487-0867; Fax (850)488-4091; Sauls.Selma@hsmv.state.fl.us

6. **Denise Sparks, PhD**, psychologist, specializes in dementia and driving, runs the Florida Atlantic University driving program, phone (561)297-0506; general office Connie (secretary) (561)297-0502; msparks@fau.edu

7. **Wendy Stav, PhD, OTR/L, CDRS**, Research Assistant Professor - Department of Occupational Therapy; Research Coordinator - National Older Driver Research and Training Center, University of Florida, College of Public Health & Health Professions, P. O. Box 100164, Gainesville, FL 32610; phone (352)273-6022; fax (352)273-6042; wstaw@phhp.ufl.edu
Table 2

Major Points of Dr. Nina M. Silverstein’s Presentation

“It's not just about the keys: Reframing Research and Policy Issues about Driving and Dementia”

1. Need full range of community mobility options.

2. Driver ability expectancy is much less than life expectancy.

3. Drivers with dementia less likely to restrict or cease driving.


5. Beverly Foundation: 5 “A’s” of transportation: Available, Acceptable, Accessible, Affordable; Adaptable

6. Skills for driving: memory, vision & visual processing, attention, decision-making, praxis, etc.

7. Address warning signs of decreased driving skills.


9. Recommendations: Strengthen Medical Advisory Boards
   Improve reporting
   Reassess at intervals
   Funding
   Mobility counseling
   Supportive, dementia-friendly transportation resources

Summary of Roundtable Discussion Issues

To precipitate discussion, several issues such as controversies regarding assessment, legal issues, education and transportation alternatives were introduced. Some of the discussion led to recommendations for an ADI ethics-based policy statement; several points of controversy merit further think tank sessions for future ADI projects. The following questions, also, primed the roundtable discussions:

1. Based on your expertise, what are important points to include in developing a policy statement for the Alzheimer’s Disease Initiative of Florida?

2. What are the driver safety issues for Florida when progressive dementia is an issue?
The Roundtable Discussion handouts are appended at the Agenda. The roundtable discussions are condensed in the next section of ten issues.

**Issue 1: Support for the Florida At-Risk Driver Council Report, Dated February 2004**

In particular, the discussions at the roundtables reached consensus about emphasizing support for the February 2004 recommendations of the Florida At-Risk Driver Council Report (Florida Senior Safety Resource Centers, www.fssrc.phhp.ufl.edu) summarized below:

1. Continued research and development of assessment, mobility counseling, remediation, rehabilitation, and supportive transportation alternatives.
2. Widespread education and training on strategies for driver safety, transportation for a lifetime, and communities for a lifetime, for the general public, transportation staff and administrators, health providers and social service providers.
3. Focused training for public helpers, such as law enforcement officers.
4. Funding support for education, development of resource programs and resource people such as certified mobility counselors.
5. Expansion of culturally competent services and people to support and assist people dealing with progressive dementia.
6. Creation of a strong, staged action plan for Florida to deal with the driver safety issue for all its citizens.

**Issue 2: Reporting**

The roundtable discussions posed the following questions regarding reporting. What are the criteria for identifying at-risk people? What are the criteria for reporting a person with a possible progressive dementia and who may be or definitely is an unsafe driver? Who should be responsible for reporting; should any health or social service provider or staff of the Florida-wide Departments of Motor Vehicles (where licenses and registration tags are obtained and renewed) be responsible for reporting? How should reporting occur? Who should be tested regarding driver safety? When reporting results in revocation of a license, what are the barriers or supports to promote not driving? Overall, the discussions revealed a great deal of controversy about mandated reporting to the Florida Department of Highway Safety and Motor Vehicles. Nationwide, mandated reporting is fraught with controversy, such as privacy issues, informed consent, self-reliance, and community safety. There was not enough support in this session to promote the idea of mandated reporting at the present time.

**Issue 3: Assessment**

When should the first driver-safety evaluation occur? What are the criteria for referral? What specific trigger should compel a health provider to refer the patient for a driver-safety evaluation? Which criteria and which diagnosis compel a referral for a driver-safety evaluation? The roundtable discussions had consensus about the importance of addressing the issue of driving in each case of a diagnosis of progressive dementia. They concurred that physicians, dentists and other health providers as well as social service providers should include a simple driving safety screening test as part of an assessment. The screening test could be as simple as one or two questions that address any changes or concerns about driving.

Discussants postulated that a memory and cognitive test and a computer check of crash-history should precede license and car registration renewals. The person who does the intake screening
Reviews or reviews the intake information should be alert to signs that driver safety may be at risk. Discussants addressed the pros and cons of basing referrals for assessment only on chronological age (research indicates that almost 50% of people, age 85 or more, may have a progressive dementia6).

Questions arose about the valid and reliable components of a comprehensive driver evaluation program. Working memory and short-term memory should be assessed. Praxis (learned skilled movements such as using machines, for example the manual skills to operate a car) and executive function (such as considering options before making an appropriate choice and completing all the steps of a task to achieve a goal, for example appropriately preparing for and attending an appointment) are also critical functions to assess. Is it useful or pragmatic to establish a baseline? For example, if a neuropsychologist finds a deficit in short-term memory and language, but normal function in visual spatial skills and attention and concludes that there is no need for driver-safety evaluation, is that acceptable? Psychiatric conditions such as depression or high caregiver stress may indicate a need for a driver evaluation.

Some discussants felt that any diagnosis of Alzheimer’s disease or related dementia should result in revocation of the driver’s license and no conditional license while others thought such action was inappropriate, and that comprehensive assessment and follow-up assessment were essential. Since symptoms are now being identified at earlier stages of memory and cognitive dysfunction, it is unclear that diagnosis alone should be a trigger for evaluation and that individual assessment is more appropriate. The American Medical Association urges physicians to take responsibility for identifying and dealing with at-risk drivers.4 Occupational therapists feel strongly that the driver assessment team should be a rehabilitation team, that the testing should be termed “driver rehab testing”. For example, the testing should look more at the cognitive AND motor skills in people, especially those recovering from a stroke. Psychologists (and neuropsychologists) develop, standardize and apply tools to assess memory and cognitive function, translate results and apply therapies; their role in driver assessment is critical.

It was clear that in most communities there are still inconsistencies in the diagnosis of progressive dementia. Even among professionals differences exist. For example, psychiatrists use the criteria from the DSM IV and DSM IV-R for diagnosis, Neurologists use different criteria. Some participants proposed using the American Medical Association (AMA) Council on Ethics proposal to apply the CDR (Clinical Dementia Rating Scale) (www.adrc.wustl.edu/adrc/cdrScale.html; www.adrc.wustl.edu/cdrGrid.html) with resulting scores at CDR1 or CDR2 indicating risk and possible revocation of driver privilege. The AMA Council on Ethics suggests three referral levels: 1) unsafe patients merit a letter to the Department of Highway Safety and Motor Vehicles, 2) unsafe suspects merit a referral for appropriate testing, and 3) unsafe history (accidents or near misses) merit revoked license. Once referred, the individual can either retain or lose driving privileges; there is no middle ground. These scales are not widely used yet in the medical community.

Much discussion centered on specific criteria to discontinue driver privileges. What if a person barely passes the comprehensive driver test, should limits be imposed on driving privileges (such as: drive only during the day/no night driving, drive only with a co-pilot, drive only in familiar areas, etc.)? When the person has driver privileges removed, who drives the person home from
the test site? When a person has driver privileges removed by one physician, the person often just goes to a different physician for their ongoing medical needs.

Another intense discussion centered on the criteria for the assessors. Currently, few certified assessment facilities (the list of 22 sites are appended) and few trained assessors exist in Florida. Certification programs for comprehensive driver assessment are restricted to licensed occupational therapists who have undergone 1600 hours of supervised training. Such requirements may provide barriers to certification, availability and accessibility to comprehensive assessment throughout Florida. Some discussants supported referrals for driver assessment, rehabilitation, and mobility counseling as the responsibility of occupational therapy and other discussants felt that these professional activities should be available to people in other health and social service career paths. Barriers to certification for assessors were identified but there was no consensus regarding recommendations for change. It may be appropriate to consider the education, training and certification of driver assessors under an inclusive, continuum format. The inclusive format of the Association for Driver Rehabilitation Specialists (web site listed in Resources at the end of this report) supports different “professionals” working in the field of driver education and driver training. The continuum format would include the perspectives of habilitation, remediation and rehabilitation as well as other comprehensive perspectives in assessment and follow-up.

**Issue 4: Referrals**

The roundtable participants discussed referrals. The primary care health provider, typically a physician, should refer the person, based on a comprehensive medical evaluation and findings of memory and/or cognitive dysfunction. There was not consensus on making this mandatory for physicians though people agreed that the topic warranted more education for physicians who evaluate older patients.

The Department of Highway Safety and Motor Vehicles (DMV) requires vision checks at the DMV offices for driver license renewals; it may be appropriate to strengthen the DMV process by adding a risk inventory which screens for medicines, chronic conditions such as diabetes, history of unstable walking or falls, or other health conditions in addition to the vision checks. Such a risk inventory may be useful to law enforcement officers who respond to requests for help or stop unsafe motorists. These assessments could be simple, standardized inventories to identify potential driver-risk. Referrals should go to a mobility counselor and/or a rehabilitation specialist for education, counseling, informed consent, comprehensive driver-safety evaluation and long-term mobility planning.

If the person passes the driver evaluation, the testing establishes a baseline and retesting may occur every 6 months. A follow-up system after the initial referral for driver-safety evaluation is critical.

**Issue 5: Implementation**

The roundtable discussions recommended that the letter reporting the comprehensive driver assessment results should go, based on informed consent, to the referral physician, to the person undergoing testing and to the primary family caregiver or identified companion. If the evaluation results in continued driver privileges, there should be a follow-up testing schedule, for example, retesting every 3 months or 6 months. People who do not return for retesting may need to be
reported to the Department of Highway Safety and Motor Vehicles to ensure community safety. Test results should be discussed in a family meeting with guidelines provided to help the family plan ahead for their needs. The patient, the family, and the legal guardian of the patient, not health or social service providers, are responsible for the challenging task of enforcing “No Driving” directives.

Some of the participants suggested that Safe Return (program of the Alzheimer’s Association) or Medic Alert bracelets or necklaces may offer a way to identify “no driving” along with terms regarding health conditions and contact phone numbers.

**Issue 6: Education**

The roundtable discussions reached consensus about the merit of education and the importance of a positive approach, for example using phrases like “staying safe and driving well” or “driving fitness”. Physicians, other health/social service providers, transit providers, law enforcement officials/staff, and other providers need education about driver safety screening, communication strategies to address the removal of driver privileges and alternate transportation resources. For example, Florida physicians need 40 hours of Continuing Medical Education (CME) every 2 years (HIV, domestic violence, medical malpractice, etc. are mandated). Several attendees suggested working with the Florida Medical Association and the professional associations of other providers to mandate CME/CEU (Continuing Education Units) training regarding driver safety screening and referral for comprehensive testing. The education should also include liability issues for physicians, other health/social service professionals, law enforcement officers, transit providers, and other providers with examples of case law. Another suggestion was to include a more general requirement of dementia training that included information on driving.

**Community and Family Workshops:** Community workshops open to all (for the general public, especially anyone middle-age or older) should include training that hones in on driver safety relevant to changing function that may be age-related such as vision changes or related to progressive dementia such as decline in memory and visual-spatial function. Elected officials, leaders and administrators of the community infrastructure should receive education about the needs of citizens with progressive dementia. Para-transit drivers should receive training in communication and relationship skills relevant to people with progressive dementia. Training should address strategies to facilitate travel for families and other caregivers and to facilitate the family in preventing the unsafe driver from operating any motor vehicles. Community education may involve classes at places of employment such as corporations or classes necessary for driver license renewals. Several educational formats exist through the internet and in community programs such as DriveWell or the AARP 55 Alive/Mature Driving Program.

**Media Messages:** There should be dementia-friendly options in programs throughout the state. Public education should include media messages. The general public needs to learn to think with integrity and plan ahead regarding the high probability that people will outlive their ability to drive; **“driver life-expectancy” is shorter than actual life expectancy**. People need to learn more about the many available, educational internet resources, such as GrandDriver and CarFit (see some web sites listed in the Appendix).

**Liability:** Family members, professionals, and the general public need information about individual liability when an impaired driver is allowed on the road. Many families are unaware
of the legal and financial implications if a driver, who has been identified by a physician as being at risk, continues to drive. Physicians also need education regarding their options when a patient may be an at-risk driver. Many physicians still have questions regarding confidentiality and liability issues when referring for driving evaluations. The Department of Highway Safety and Motor Vehicles (DMV) protects the identity of the referral source and assumes liability when they receive a referral regarding an at-risk driver.

**Issue 7: Supportive Transportation System**
The roundtable discussions emphasized the importance of supportive transportation systems that provide competent, safe, elder-friendly (elder-friendly cab companies), dementia-competent, “arm-in-arm” transportation. Options that exist to help the disabled should be adapted to help those with progressive dementia. Dementia-competent (dementia-friendly) translates to: drivers trained in the special needs of and strategies to deal with people who have Alzheimer’s disease or a related dementia, wheelchair accessible vans, kneeling buses, secured (seat-belt), door-to-door transportation, and reimbursements for a travel-buddy, escort or volunteer rider. Independent Transportation Network (web site: [http://www.itninc.org/](http://www.itninc.org/)) (ITN), a model from Portland, Maine, is now being piloted in Orlando, Florida.

**Issue 8: Supportive, Mobility-Friendly Communities**
The roundtable discussions emphasized that communities should value safe streets that are easy to walk across, that have smooth sidewalks and that have resting benches with protective roofs. Culturally competent urban planners and environment planners should be able to design sound Communities-for-a-Lifetime.

**Issue 9: Mobility Counseling**
During the roundtable discussions issues surfaced about the risks, obstacles and challenges when driver licenses are removed. Mobility resources including certified mobility counselors should exist and be well networked with the information and services networks locally in each of the 67 Florida counties as well as statewide. People already trained and working with persons who have Alzheimer’s disease or a related disorder should receive training in the principles and skills of mobility counseling. Training should include respect for individual and family values, identifying accommodations, linking to creative community options and informing families about ways to prevent driving, such as ignition locks which use thumbprint technology to screen drivers, removing the car, disabling the car, trading in the old car for a different model or style car which the patient cannot learn to operate, etc.

**Issue 10: Funding**
The roundtable discussants were in consensus regarding the need for funding. Suggestions included the policy of partnering with other health and social service providers and related industries to provide funding for educational training and support to reduce costs of assessment. Some examples of such partners include pharmaceutical industries, manufacturers of tires, motor vehicles, and motor vehicle-related products, insurance industries, etc. There should be a cost-effective way of screening the general public.

Assessment is too expensive, $125 to $150 per hour with 2 to 4 hours to complete the comprehensive testing. Suggestions on how to make assessments more affordable included:
adding a small fee to all Florida driver license renewals, adding a small fee to all Florida driver registration tags, support or partial support from health insurance policies, and funding from Florida general revenues to support sliding-scale fees and scholarships for comprehensive driver assessments.

Incentives for driver assessment may include discounts on driver insurance if the person with the onset of progressive dementia symptoms undergoes an appropriate evaluation of driver skills. Alternatives to driving should be more accessible. Current options are often unreliable or expensive. People with a medical diagnosis of Alzheimer’s disease or a related dementia should qualify automatically for para-transit vouchers, passes or discounts. Sarasota County offers the SCAT–Plus program for special-needs riders. A one-way fare is $1 (one dollar) and provides door to door pick-up. Necessary escorts are encouraged to ride as well. However, this program is very limited. Volunteer programs (FISH in Sarasota) should also be encouraged. In Dade County (Florida) seniors ride the public transportation for free due to a ½ penny sales tax. Other programs mentioned included United We Ride, which also receives limited funding.

Summary of Issues and Proposed Action Steps

The ten major issues just reviewed revealed consensus on some points and a great deal of controversy on others. Consensus occurred on the need to support the work of the Florida At-Risk Driver Council, on the need for simple screening questions as indicators for comprehensive driving evaluation, on the need for educating a broad spectrum of Florida audiences, on the need for mobility counseling, and on the dire need for funding. Controversy arose on the issues of mandatory reporting, the elements of valid, reliable, robust assessment and assessment environments, the training and credentialing of assessors, the basics of and who pays for a supportive transportation system, and the roles of health and driver insurance institutions. The participants embraced and wanted more education about the fledgling concept of Communities-for-a-Lifetime.

Attention to the consensus of the roundtable discussants and facilitators evokes some recommendations for initial action steps. The recommendations include, when appropriate and as soon as possible, at all ADI and DOEA programs:

1. Initiate simple screening questions to assess driver safety.

2. Provide referral information to comprehensive driver evaluation programs.

3. Distribute information about local alternative transportation resources.

4. Educate about driving safety and the relevance of Alzheimer’s disease and related disorders, such as warning signs pointing to a potential at-risk driver, and mobility counseling including planning ahead for the time when alternative transportation is necessary.

The areas of controversy need further work that is beyond the scope of the charge to recommend a Policy Statement on driving relevant to progressive dementia to the ADI Advisory Committee.
Meanwhile, however, the ADI Advisory Committee should maintain links to state and national groups that address driver safety, specially the areas of controversy, and work with policy makers to identify funding.

References


Some Resources

Alternative transportation:  http://www.eldercare.gov

American Occupational Therapy Association:  http://www.aota.org

Association of Driver Rehabilitation Specialists:  http://www.aded.net


Driver refresher courses:  http://www.aarp.org/drive;  www.aaapublicaffairs.com

DriveWell:  http://www.asaging.org/drivewell


GrandDriver information & references:  http://www.granddriver.info/

Independence Drive:  http://driving.phhp.ufl.edu/index.php (NODRTC website);  http://www.phhp.ufl.edu/ot/ (OT website);  http://www.IndependenceDrive.phhp.ufl.edu

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Alzheimer's Disease Initiative (ADI) Ethics Subcommittee

AGENDA: Strategy Session - Driving & Dementia
June 16, 2005, Orlando, FL

8:30 - 8:45 AM Welcome, Purpose, Agenda Review, Introductions
Kathleen Houseweart, MBA, Chair ADI Ethics Subcommittee;
Coordinator, Sarasota Memorial Hospital Memory Disorder Clinic

8:45 – 12 Noon Drive Well, Train-the-Trainer Session
Fran Carlin-Rogers, Certified Trainer, Chair of ADI Advisory Committee

12:00 - 1:00 PM Working Lunch: Keynote Speaker: Nina Silverstein, PhD;
Fellow, National Highway Traffic Safety Administration;
Professor, University of Massachusetts: "It's Not Just about
the Keys: Reframing Research & Policy Issues about
Driving and Dementia"

1:00 - 1:15 PM Welcome & Instructions for afternoon Strategy Session
Kathleen Houseweart, MBA; Leilani Doty, PhD,
Administrator, University of Florida Memory Disorder Clinic

1:00 - 2:30 PM Roundtables with Experts:
Nina Silverstein, PhD
Kenneth Brummel-Smith, MD, Chair At-Risk Driver Council;
Chair/Professor, Dept. of Geriatrics, Florida State University
Ira J. Goodman, MD, Director, Orlando Regional Healthcare
Memory Disorder Clinic
Selma Sauls, Management Analyst III, Florida Department
of Highway Safety and Motor Vehicles
Wendy Stav, PhD, OTR/L, CDRS, University of Florida
Denise Sparks, PhD, Florida Atlantic University
Tom Reimers, Division Director, Department of Elder Affairs

2:30 - 2:40 PM Break

2:40 - 3:20 PM Roundtable Reports

3:20 - 3:50 PM Summary to form recommendations for submission to ADI
Advisory Committee

3:50 - 4:00 PM Closing Remarks: Kathleen Houseweart, MBA
OVERVIEW: Driving & Dementia, Alzheimer’s Disease Initiative
Strategy Session, June 16, 2005, Orlando, FL

Introduction
Welcome to a special session of the Alzheimer's Disease Initiative (ADI) Ethics Subcommittee, dedicated to the topic of Driving & Dementia. As many of you know, a brainstorming session was held in February 2005 to begin work on recommendations from some experts involved with the ADI on how Florida may address this important safety issue. During that important meeting, several themes emerged.

First, we discussed the complicated and controversial issue of testing: Who should be tested? How do we identify those at risk? How do we encourage testing, or self-restraint of the at-risk driver? Is there (or should there be) a standard test for driving safety and who should administer that test? How can we make testing available and affordable to those in need? Are there creative ways to fund testing?

Second, issues of legal responsibility, liability and reporting surfaced: What are the ethical and legal responsibilities of physicians and/or professionals working with people who are at-risk drivers? What are the consequences of driving, even after being advised by a professional health or social services provider not to drive? What are the issues if an impaired driver is involved with an accident? Should driving privilege and driver license renewal be tied to one's ability to register a vehicle? Are there creative ways to insure compliance if driving privileges are revoked?

Finally, the group reviewed educational opportunities and alternative transportation availability: How may people receive education regarding the issues of driving risk early in their driving lives? What should such education cover? Who should provide the information? What support, including program, transportation alternatives and transportation-savvy helpers, is available to help families develop coping strategies to address at-risk driver issues and removal of driver privileges? What alternatives are available to Floridians who lose driving privileges?

These three topics and others will be the focus of discussion during the afternoon round table discussion. Our hope is that the expertise of the participants will provide clarification and direction in developing recommendations for the ADI Committee.

To prepare for these discussions, the day will begin with a presentation of the Drive Well program conducted by Fran Carlin-Rogers. This 3-hour train-the-trainer session will inform participants about older drivers and driver safety issues, which they may apply to educational programs in their communities. Please register in advance for this program at www.asaging.org/drivewell (http://www.asaging.org/drivewell).

Enclosed you will find an Agenda for June 16, 2005. This full day of activity is another step of Florida, once again, to lead other states in addressing an important issue in the field of aging.
It's Not Just About the Keys...

Reframing Research and Policy Issues About Driving and Dementia

Alzheimer's Disease Association Meeting, June 24, 2005, Orlando, Florida

Presenter

Nina M. Silverstein, Ph.D.
Associate Professor, Gerontology
University of Massachusetts Boston
Nina.silverstein@umb.edu

Session Overview

- Reframing the Discussion
- Overview Of Older Drivers
- Alzheimer's Disease and Driving
- Public Positions On Dementia & Driving
- Recommendations for Policy and Research
It is not just about giving up the keys...

It is about assuring the full range of community mobility options, including supportive transportation.

It is about living.

- More older people
- Driving more miles than ever before
- Driving at older ages than ever before
- More likely to suffer a fatality when in a crash
- Driving expectancy is sig. less than life expectancy
- Few alternatives to driving

Most older drivers cease or restrict their own driving when they experience changes in their ability to drive.

BUT SOME DON'T...
Drivers with dementia are less likely to cease or restrict their own driving.

- Many who experience cognitive changes and decline lack insight into their loss of function.
- Objective assessment by a professional is needed to determine if the driver's ability to operate a vehicle is impaired.

Most older adults do not use public transportation.
Safe navigation and use of public transportation is often difficult for individuals with significant cognitive impairments.

Thus, strategies are needed to help public transportation become more “elder-friendly” overall, and specifically, more “dementia-friendly.”

5A’s of the Beverly Foundation

- Available,
- Acceptable,
- Accessible,
- Affordable
- Adaptable

Family caregivers report transportation as the main area of assistance they provide.
82% of Alzheimer's caregivers reported providing assistance with transportation.


Alzheimer's Disease and Driving

Driving requires cognitive abilities such as memory, recognizing images (visual processing), attention, and decision-making.
Currently about 40% of fatal automobile crashes are alcohol-related... 

By 2025 more than 40% of all fatal crashes may be associated with age-related frailties, with visual and cognitive impairments as major contributing factors per the... 

Changes Associated With AD 
- Short-term memory loss 
- Problems with language 
- Disorientation to time and place 
- Poor or decreased judgment 
- Problems with abstract thinking 
- Decreased reaction time 
- Loss of balance/abnormal gait 
- Visual-spatial impairment 

Wandering and Driving 
- Prevalence rates for wandering of up to 69% have been reported among people with dementia. 
- Persons with dementia get lost while driving 
- Executive function is impaired (i.e., the ability to sequence tasks is compromised or limited in the person with dementia) 
- While the ability to operate a vehicle may not be impaired early on, the ability to get from point A to point B and back again is a concern.
Why Driving Is A Concern

- More crashes
- Getting lost
- Unaware of not being a "responsible driver"

There is no argument among researchers that at some point people with the disease will be unable to drive safely (the "argument" is when)

Driving and community mobility options are issues that need to be addressed sensitively, inclusively and early in the disease process.
What are the warning signs?

There are lots of warning signs...
- Gets lost on familiar streets
  - Needs a "co-pilot" to cue directions in familiar areas
- Others are concerned
  - Police warnings, tickets, or "near-misses"
  - Gets hounded at often
- Has difficulty understanding road signs
  - Confusion at exits
  - Increased agitation when driving

And still others...
- Incorrect signaling
  - Moves into a wrong lane
- Drives at inappropriate speeds
  - Stops inappropriately
  - Confuses brake and gas pedals
- Scratches or dents on car, garage or mailbox
  - Hits curbs
Existing Policy Statements

Alzheimer’s Association Position
- A diagnosis of AD is never itself a sufficient reason for loss of driving privileges
- If an Alzheimer’s patient’s driving is impaired, driving privileges must be limited
- Driving privileges must be withheld when the individual poses a serious risk to self or others
- The person with dementia, if competent, should participate in the decision-making regarding driving restrictions

Three Other Opinions
- American Psychiatric Association: APA guidelines urge physicians to encourage even mildly impaired dementia patients to stop driving
- American Academy of Neurology: Recognizes that people with early Alzheimer’s are at an increased risk of car crashes, and has issued guidelines to help doctors determine when patients should stop driving
- American Medical Association: AMA ethical guidelines make public safety a priority over patient confidentiality, allowing physicians to notify their state’s Department of Motor Vehicles when a patient’s diagnosis makes him or her unsafe to drive
Recommendations for Policy/research

- Strengthen Medical Advisory Boards
- Improve reporting practices
- Develop intervals for measurment based on evidence-based research
- Explore reimbursement mechanisms for driving assessment
- Provide care and counseling and L & R on community mobility options
- Promote supportive/dementia-friendly transportation options
Driving & Dementia: Alzheimer’s Disease Initiative Strategy Session
June 16, 2005, Orlando, FL

Tally of Evaluation Results of Meeting

Results of the Evaluations received from 26 (of the 35) participants showed an overall rating of the session, the roundtables and the communication as excellent. The rating breaks down to approximately 88% of people rating all areas as excellent and 12% of the people rating good.

Special comments addressed new information or a new understanding of the complexity of issues. People liked the positive phrase of a “supportive transportation system” that provides competent, elder-friendly, dementia-friendly, “arm-in-arm” transportation. They thought the ITN (Independent Transportation Network) program was a wonderful concept and are hopeful that ITN will work in Orlando, FL with the potential for practical application elsewhere in Florida.

The issues of mobility counseling and mobility screening in the pre-visit form of health and social service providers impressed participants. Participants felt they could take those two points and begin to address how to integrate them into their practices in their home communities.

The three questions of 1) who should refer a person for testing, 2) who should do the testing and 3) who should revoke driver privileges entered into the area of controversy. Physicians, occupational therapists and their teams were proposed as links to the Department of Motor Vehicles and Highway Safety to implement resources and programs to address the driver safety issues relevant to dealing with Alzheimer’s disease and related dementias.

Tallied by: Leilani Doty, PhD (6/16/05)
Roundtable Facilitators, Recorders, & Participants
Driving & Dementia: Alzheimer’s Disease Initiative Strategy Session
June 16, 2005, Orlando, FL

Moderators: Kathleen Houseweart, MBA & Leilani Doty, PhD

Facilitator: Kenneth Brummel-Smith, MD; Tom Reimers
Recorder: Nancy Squillacioti, Alzheimer Resource Center, Orlando
Participants: Farah Mirza, East Central FL MDC, Melbourne
Martha H. Purdy, Alzheimer Resource Center, Orlando
Barbara VanderHeyden, East Central FL MDC, Melbourne
Michael D. Justiss, Dept. of Occupational Therapy, University of Florida, Gainesville

Facilitators: Ira J. Goodman, MD; Denise Sparks, PhD
Participants: Ellen Brown, Alzheimer’s Association, Southeast Florida Chapter, West Palm Beach
Jeff Loomis, AlOnline.net, University of Florida, Gainesville
Desiree Lanford, Dept. of Occupational Therapy, University of Florida, Gainesville
Maggie Freytes, AlOnline.net, University of Florida, Gainesville
Sue Maxwell, Lee Memorial Health System Memory Disorder Clinic, Ft. Myers
Laura D’Arcy, Orlando Regional Lucerne Hospital Memory Disorder Clinic, Orlando

Facilitator: Selma Sauls
Participants: Terri Mishos, Sarasota Memorial Hospital, Sarasota
Karl M. Dhana, MD, Morse Geriatric Center, West Palm Beach
Connie Hall, Department of Elder Affairs, Tallahassee
Larry Butcher, ADI Advisory Council, Stuart

Facilitator: Nina M. Silverstein, PhD
Recorder: Dennis McCarthy, Dept. of Occupational Therapy, University of Florida, Gainesville
Participants: Joy Barbee, West Florida Hospital Memory Disorder Clinic, Pensacola
Francine Parfitt, Mayo Clinic Memory Disorder Clinic, Jacksonville
Terressa Franklin, Department of Elder Affairs, Tallahassee
Bobbie Lockhart, West Florida Hospital Memory Disorder Clinic, Pensacola
Fran Carlin-Rogers, Chair, Alzheimer’s Disease Initiative Advisory Committee, Orlando

Facilitator: Wendy B. Stav, PhD, OTR/L, CDRS
Recorder: Susan Dorries, Orlando Regional Lucerne Hospital Memory Disorder Clinic, Orlando
Participants: Mary Ann Theurer, RN, MHS, Tenet at St. Mary’s Medical Center Memory Disorder Clinic, West Palm Beach
Joan M. Kelly, Volusia Council on Aging, Daytona Beach
Larry Kelly, Volusia Council on Aging, Daytona Beach
Dorothy Myles, Alzheimer’s Association – Outreach Program, Tallahassee
Natalie Kelly, Alzheimer’s Association Chapter, Orlando
Ann Getman, Department of Elder Affairs, Tallahassee
COMPREHENSIVE DRIVER EVALUATION PROGRAMS
(Revised by Leilani Doty, PhD, UF, 1/10/05)

BOCA RATON:
Telephone: (561) 955-8832
Contact: Denise Sparks, PhD, email; msparks@fau.edu
Location: FSSRC Driver Safety Program (Funding from FL Senior Safety Resource Centers), Florida Atlantic University, 777 Glades Road, Social sciences Building, Room 117, Boca Raton, FL 33431

DELRAY BEACH: *Prescription Required
Telephone: (561) 495-3634
Contact: Bonnie Kasmere
Location: Pinecrest Rehabilitation Center, 5360 Linton Blvd, Delray Beach, Florida 33484

FORT MYERS: *Prescription Required for both programs
Telephone: (239) 334-5244
Contact: Mary Bradley
Location: Lee Memorial Hospital, Rehabilitation Hospital, 2776 Cleveland Avenue Fort Myers, FL 33551

GAINESVILLE:
Telephone: (352) 265-5487; Fax: (352) 265-5431
Contact: Susan Maroney
Location: Shands Driver Rehabilitation Program *Prescription Required
Shands Rehabilitation Hospital, 4101 NW 89th Blvd., Gainesville, FL 32606-5625

Telephone: (352)392-8850; 273-6022
Contact: Wendy Stav, PhD; email: wstav@phhp.ufl.edu
Location: Independence Drive (Part funding: FL Senior Safety Resource Centers), University of FL, 5000 NW 34th Street, Northwood Plaza, Gainesville, FL 32610

JACKSONVILLE: *Prescription Required
Telephone: (904) 858-7242
Contact: Peggy Gannon
Location: Brooks Rehabilitation Hospital, 3901 University Blvd, P.O. Box 16406 Jacksonville, FL 32216

Telephone: (904) 858-7210
Contact: Linda (appointment secretary)
Location: Brooks Rehabilitation Southside
**KISSIMMEE:**
**Telephone:**  (407) 846-8532  
**Contact:** Beverly Hougland  
**Location:** DriveABLE /FSSRC Driver Safety Program (Funding: FL Senior Safety Resource Centers), Osceola County Council on Aging, 1099 Shady Lane, Kissimmee, FL  34744

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**MELBOURNE:**
**Telephone:** (321) 984-4662; 984-4685  
**Contact:** Christie or Ananda  
**Location:** Health South (Sea Pines Rehabilitation Hospital)  
*Prescription Required*  
101 East Florida Avenue, Melbourne, FL 32901

---

**MIAMI:**  
*Prescription Required*  
**Telephone:** (305) 279-5188  
**Contact:** Isabelle Maestu  
**Location:** Baptist Hospital, 8950 North Kendall Drive, Miami, FL 33176

---

**Telephone:** (305) 355-8288;  Fax:  (305) 355-9076  
**Contact:** Adam L. Bank, PhD; email: abank@med.miami.edu  
**Location:** FSSRC Driver Safety Program (Funding from FL Senior Safety Resource Centers), Center on Aging, University of Miami School of Medicine, 1695 NW 9th Avenue, Suite 3204 (Room D-1001), Miami, FL 33136

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**NORTH MIAMI BEACH:**
**Telephone:** (305) 770-0747 office or page (305) 201-5834  
**Contact:** Judi Hamelburg  
**Location:** Advanced Driving Rehabilitation, 1031 Ives Dairy Road, Suite 228, North Miami Beach, FL 33179

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**Telephone:** Page (305) 201-5834  
**Contact:** Judi Hamelburg,  
**Location (Tuesday & Thursday only):** Jackson Memorial Hospital

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**OCALA:**
**Telephone:**  (352) 629-3015  
**Contact:** Wendy Stav, PhD; email: wstav@phhp.ufl.edu  
**Location:** Independence Drive (Partial funding from FL Senior Safety Resource Centers), University of FL,3304 SE Lake Weir Avenue, Suite 1, Ocala, FL 34471
ORLANDO:
Telephone: (407) 426-8020
Contact: Susan Pierce; Carol Blackburn
Location: Adaptive Mobility Services, Inc.  *Prescription Required
        4797 South Orange Avenue, Orlando, FL  32806-6965

Telephone: (407) 228-1819
Contact: Brenda Reff, email: reffb@elderaffairs.org
Location: DriveABLE /FSSRC Driver Safety Program (Funding: FL Senior Safety Resource Centers), Senior Resource Alliance, 988 Woodcock Road, Suite 200, Orlando, FL  32803

PENSACOLA:  *Prescription Required
Telephone: (850) 494-6167
Contact: Laura Posey
Location: West Florida Rehabilitation Institute, 8391 North Davis Hwy, Pensacola, FL 32514

ST. PETERSBURG:
Telephone: (727) 893-6747
Contact: Karen Kearney
Location: Bayfront Medical Center  *Prescription Required
        701  6th Street South, St. Petersburg, FL 33701

Telephone: (727) 570-9696 Ext. 293
Contact: Susan Samson
Location: FSSRC Driver Safety Program (Funding from FL Senior Safety Resource Centers), Area Agency on Aging of Pasco-Pinellas, Inc., 9887 4th Street North, Suite 100, St. Petersburg, FL 33702

SARASOTA:  *Prescription Required
Telephone: (941) 921-8702
Contact: Jennifer Anderson-Hall
Location: Health South Rehabilitation Center, 3251 Proctor Road, Sarasota, FL 34231