

ALZHEIMER'S DISEASE ADVISORY COMMITTEE

2007 – 2008

Summary of Accomplishments



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Table of Contents

Message From the Committee	3
Alzheimer's Disease Advisory Committee	4
Alzheimer's Disease Initiative Program Summary	4
Fact Sheet: Florida and Alzheimer's Disease	5
Introduction and Background	6
Activities and Accomplishments for 2007-2008	7

Message From the Committee

It has been my pleasure to Chair the Alzheimer's Disease Advisory Committee for the past two years. As a caregiver for my wife for the past 15 years, I am extremely grateful for the dedicated members of the Committee and the dozens of other resource providers from throughout our state who gather with the Committee each quarter to bring their expertise to serve on our subcommittees. These are people who work with Alzheimer's patients and caregivers at the most critical level every day.

Our goal is to continue improvements in the level of care for Alzheimer's patients and guidance to the dedicated caregivers throughout the state of Florida.

I ask that you review this summary of accomplishments and Goals and join us in our goal of improving care for Alzheimer's patients and their caregivers until the day a cure is found for this dread disease.

Larry E. Butcher
Committee Chair

Alzheimer's Disease Advisory Committee

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Alzheimer's Disease Initiative Program Summary 2006-2007

Probable cases of Alzheimer's in Florida *	465,305
Number of persons with severe dementia	86,057
Number of clients receiving ADI Respite Care	2,569
<i>Memory Disorder Clinic services:</i>	
Evaluations of clients	4,872
Free memory screenings	2,656
Referrals for assistance	3,153
Number of diagnoses of postmortem brains (Brain Bank)	56
Number of clients receiving Model Day Care	107
(57,443 hours statewide)	

*Estimated cases of AD involve all stages, including the early stages, with little to no dementia. This is relevant because of the tremendous strain on caregivers and other community resources. The source of the estimates was the Department of Elder Affairs based on population data by the University of Florida Bureau of Business and Economic Research and prevalence estimates published in the following study: Manton KG, Gu X, and Ukraintseva SV. 2005. "Declining Prevalence of Dementia in the U.S. Elderly Population. Adv Gerontol 16:30-7."

Fact Sheet: Florida and Alzheimer's Disease

Florida has the ***highest*** percentage of older adults.

Age is the greatest risk factor for **Alzheimer's disease (AD) and related dementias (ARD)**.

Nearly **500,000** Florida residents suffer with ARD, and most are cared for at home.

First in the nation, Florida established the "Alzheimer's Disease Initiative" in 1985 (Florida Statute 430.501 – 430.504) to provide a continuum of care to patients and families.

The **Alzheimer's Disease Advisory Committee (ADAC)**, under gubernatorial appointment, provides direction for legislative, administrative and programmatic issues relating to ARD.

Since inception, the committee and its subcommittees (i.e., Cultural Diversity, Respite and Support Services, Ethics, Legislative, Brain Bank, Research and Education) have accomplished via collaboration with the DOEA the following:

- Expanded state funded memory disorder clinics (15 centers)
- Implemented state mandated training requirements for care providers
- Facilitated driving safety parameters for AD
- Summarized the best practice models for behavioral challenges
- Identified the need for legislation, similar to the Baker Act, but specific to dementia
- Established several vehicles for caregiver training and respite
- Supported numerous research endeavors involving the neurological, neuropsychological, psychosocial, and neuropathological aspects of Alzheimer's disease

The committee works closely with ARD organizations and care providers located throughout the state including the following:

- State-funded memory disorder clinics and State of Florida Brain Bank
- State universities and medical centers
- AD research facilities located in Florida
- Community-based day care, retirement communities, assisted living and nursing home facilities.

I. Introduction and Background

The Florida Legislature created the Alzheimer's Disease Initiative (ADI) in 1985 to provide a continuum of services to meet the needs of individuals and families affected by Alzheimer's disease and related memory disorders. The initiative includes a 10-member advisory committee appointed by the Governor and four program components: 1) supportive services including counseling, consumable medical supplies and respite for caregiver relief; 2) Memory Disorder Clinics to provide diagnosis, research, treatment, education, training and referral; 3) Model Day Care programs to test new care alternatives; and 4) a research database and brain bank to support research.

II. Alzheimer's Disease Advisory Committee

The Alzheimer's Disease Initiative and Alzheimer's Disease Advisory Council were created under Chapter 430 (430.501 – 430.504), Florida State Statutes. The 10-member committee advises the Department of Elder Affairs regarding legislative, programmatic, and administrative matters that related to Alzheimer's disease victims and their caretakers. All members must be residents of the state. The committee membership reflects the following representation:

1. At least four of the 10 members must be licensed pursuant to Chapter 458 or 459 or hold a Ph.D. degree and be currently involved in research of Alzheimer's disease;
2. The 10 members must include a least four persons who have been caregivers of victims of Alzheimer's disease;
3. Whenever possible, there should be one individual from each of the following professions: a gerontologist, a geriatric psychiatrist, a geriatrician, a neurologist, a social worker and a registered nurse.

Members are appointed to four-year staggered terms. The committee elects one of its members to serve as chair for a term of one year. Committee meetings are held quarterly or as frequently as needed.

The ADI Committee has six subcommittees and task forces that meet and report quarterly on issues related to Alzheimer's disease: Brain Bank, Diversity and Inclusion, Education, Ethics, Legislative, Research and Clinical, Ethics, Respite Care and Memory Disorder Clinic. In addition, the Memory Disorder Coordinators meet quarterly to discuss ways to improve services. These meetings are held in conjunction with the ADI Committee meetings.

III. Activities and Accomplishments for 2007-2008

Subcommittees and Workgroups

Brain Bank Workgroup

Overview: The State of Florida Brain Bank was established by rule 58D-1.002(4), Florida Administrative Code, in 1987. There are five brain banks that cover the 67 counties in the state. All but the Central Florida Brain Bank (which is coordinated through the Alzheimer Resource Center) are a part of a Memory Disorder Clinic (MDC), of which there are 15 Alzheimer Disease Initiative MDCs in the state.

Goals for 2008-2009:

1. Continue providing brains of individuals with dementing illnesses,
2. Continue providing brains of healthy individuals,
3. Educate the community about dementia and the brain bank, and
4. Educate the diagnosing physician and the family of the accurate diagnosis.

Diversity and Inclusion Subcommittee

Accomplishments: In May 2006, in recognition of the importance of the Alzheimer's Disease Initiative (ADI) in the continuum of services for individuals and families affected by Alzheimer's disease, the department pledged its support to the memory disorder clinic coordinators and the Alzheimer's Disease Advisory Committee for their efforts to ensure the availability of services to under-served areas and populations. The department and the Diversity and Inclusion Subcommittee announced a diversity training session for memory disorder clinic coordinators. The training session entitled "Improving the Quality of Life in the African American Community of Alzheimer's Disease Patients and Families" was held on Thursday, October 19, 2006, in conjunction with the October 2006 ADI/MDC quarterly meeting. The presenter was Floyd Willis, MD, Mayo Clinic Jacksonville.

The goal of the session was to help each clinic develop a strategic plan for addressing diversity outreach over the next one-to-five years. In preparation for the memory disorder clinic coordinators' diversity training session, the Diversity and Inclusion Subcommittee of the Alzheimer's Disease Advisory Committee developed a strategic plan template to assist each clinic coordinator in developing a strategic plan to increase diversity outreach. The coordinators reviewed historical performance data and planned for the future.

August 30, 2007, marked the first due date that the department required an annual electronic submission of the clinics' strategic plans indicating the contract year projected percentage increase and the memory disorder clinics' lists of planned

actions/activities to increase outreach and services to diverse patients. The clinic coordinators have reported satisfaction with the use of the form and indicated it will help them to plan, monitor and track their outreach efforts.

Goals for 2008-2009: Continue working with memory disorder clinic coordinators to increase outreach efforts to diverse patient populations.

Education Subcommittee

Accomplishments: Education & Training was set up as an ad hoc subcommittee, formed to address concerns being raised around the approval process of the state mandated Alzheimer's Disease and Related Disorder initiative and the education and training of the staff at the ADI Memory Disorder Clinics (MDC). The ad hoc subcommittee began the year by conducting an informal survey to learn what the concerns were related to the education, training and the application-approval process of the Training Academy on Aging, University of South Florida. The query focused on issues in Florida relevant to Alzheimer's disease and related dementias regarding training, certification of curricula and certification of educators.

A summary of the responses with three recommended action steps were reported in January to the ADI Legislative Subcommittee meeting and the ADI Advisory Committee. The survey results identified examples of inconsistent training requirements for curricula to be approved by the University of South Florida Training Academy on Aging. Sometimes requests for revisions and resubmission of applications for certification were clear; often they were unclear, frustrating and time- and labor-intensive. Three Recommendations for Action were:

1. **Request that the ADI Education and Training Ad Hoc Subcommittee become a standing subcommittee of the ADI** with the charge to address the ongoing education and training issues of importance to the mission of the Alzheimer's Disease Initiative.
2. **Workshops: Request that workshops take place during the next contract year** to gather information and to learn more about the issues related to Education and Training.
3. **Develop an ongoing link between the Training Academy on Aging at USF and the Alzheimer's Disease Initiative.**

The ADI Advisory Committee passed a motion to make the ADI Education and Training Ad Hoc Subcommittee a standing subcommittee of the ADI.

Goals for 2008-2009: The following goals were established:

1. Develop an ongoing link between the Training Academy on Aging at USF and the Alzheimer's Disease Initiative.

2. Create a gold standard curriculum that will update the *Alzheimer's Disease Training Manual*, published in 1996, and be used to meet the training requirement of the Memory Disorder Clinics.

Ethics Subcommittee

Accomplishments: The Ethics Subcommittee continues discussion regarding the issue of driving safety and liability. Extensive efforts to contact several insurance providers led to a review of information obtained from The Hartford Insurance Company relating to automobile insurance coverage & liability for patients with dementia. Several Memory Disorder Clinics were awarded grant funding to complete at risk driving screenings during the contract year.

The issue of firearm safety and dementia was also addressed. Each clinic shared its procedures in dealing with questions relating to firearms in the home.

The Ethics Subcommittee continued to be a place for collaboration and discussion of best practices pertaining to ethical issues faced by ADI providers. The committee never lacked for lively discourse and allowed for brainstorming among experts on difficult issues pertaining to the care and treatment of families affected by Alzheimer's disease and related disorders.

Goals for 2008-2009:

1. Work with DOEA staff to update the rules pertaining to AD training for the state.
2. Committee members will work to update the DOEA AD training manual – last updated in 1996.
3. Committee members will work with DOEA staff to revise the current "*Strategic Plan to Increase Diverse Patient Outreach*" form to better reflect the outreach activities completed by ADI providers contracting with DOEA.
4. The committee will continue to facilitate discussion, brainstorming and review of best practices of complex ethical issues for ADI providers.

Legislative Subcommittee

Accomplishments: The Legislative Advocacy Subcommittee worked on several initiatives including increasing awareness of the ADI to state lawmakers and enhancing advocacy efforts among ADI participants throughout Florida. Advocacy training was provided by a representative from AARP in July 2007. The subcommittee chair subsequently developed and disseminated a fact sheet for distribution to legislators at fall delegation meetings. In addition, the subcommittee submitted a Legislative Budget Request (LBR) for funding for Morton Plant Mease and FAU Wellness Center, which received MDC status in 2004 and 2005 respectively. LBRs were also submitted to effectuate language changes in Florida Statute including a name change for the East Central Florida MDC and the inclusion of the word "adult" in Florida Statute 430.502 relating to day care programs. The name change was later adopted. The subcommittee

also tracked and supported the Medicaid Waiver extension bill, which was passed, and made recommendations for alternations in the proposed Memory Screening Bill and Electronic Monitoring Bill.

Goals for 2008-2009: Continue tracking of Alzheimer's-related legislation, increased advocacy efforts, support of suitable alternatives to Baker Act bill for Alzheimer's patients, appropriate legislation for wandering and elopement issues, and funding for Morton Plant Mease and the FAU Wellness Center.

Research and Clinical Subcommittee

Accomplishments: The Research and Clinical Subcommittee continues to improve the ADI research database. The database is used by the Memory Disorder Clinics as the basis for analysis of services and for research purposes. In keeping with Chapter 430.502, "such research may address, but is not limited to, diagnostic technique, therapeutic interventions, and supportive services for persons suffering from Alzheimer's disease and related disorders and their caregivers. This year the Research and Clinical Subcommittee also hosted a series of educational meetings with top researchers around the world. These meeting included the following:

1. Dr. Ranjan Duara, Medical Director, Wein Center at Mt. Sinai Medical Center, Presenting on Memory Screening for the Minority
2. Dr John Lucas, Mayo Clinic Jacksonville, Presenting on Older African American Studies in patients with Alzheimer's
3. Dr Rivka Ravid, Executive Director Brain Bank in Amsterdam Netherlands, Presenting on the National Brian Bank Donor Program in the Netherlands
4. Dr. Gary Small, Director of UCLA Center on Aging, Presenting on Strategies for Keeping Your Mind Sharp and Body Young.

Goals for 2008-2009: Continue to offer research quarterly update meetings with prominent clinicians involved in dementia research.

Respite Care and Services Subcommittee

Accomplishments for 2007-2008: The subcommittee established the formation of a two-year examination process for evaluating the effectiveness of adult day care programs in delaying institutionalization for those who suffer with Alzheimer's disease and related disorders. The subcommittee enlisted the expertise of Dr. Brent Small from the Johnnie B. Byrd Sr. Alzheimer's Center and Research Institute, who developed the survey with the approval of a peer review board. We continued updating the latest developments of the Special Needs Shelter Interagency Committee on accepting persons suffering with dementia and their caregivers with recommendations on what their needs are. We are advocating for the Alzheimer's Medicaid Waiver authorization for another two years and continuing to monitor the progress of that program. We researched the Silver Alert Program in four states and are making recommendation to

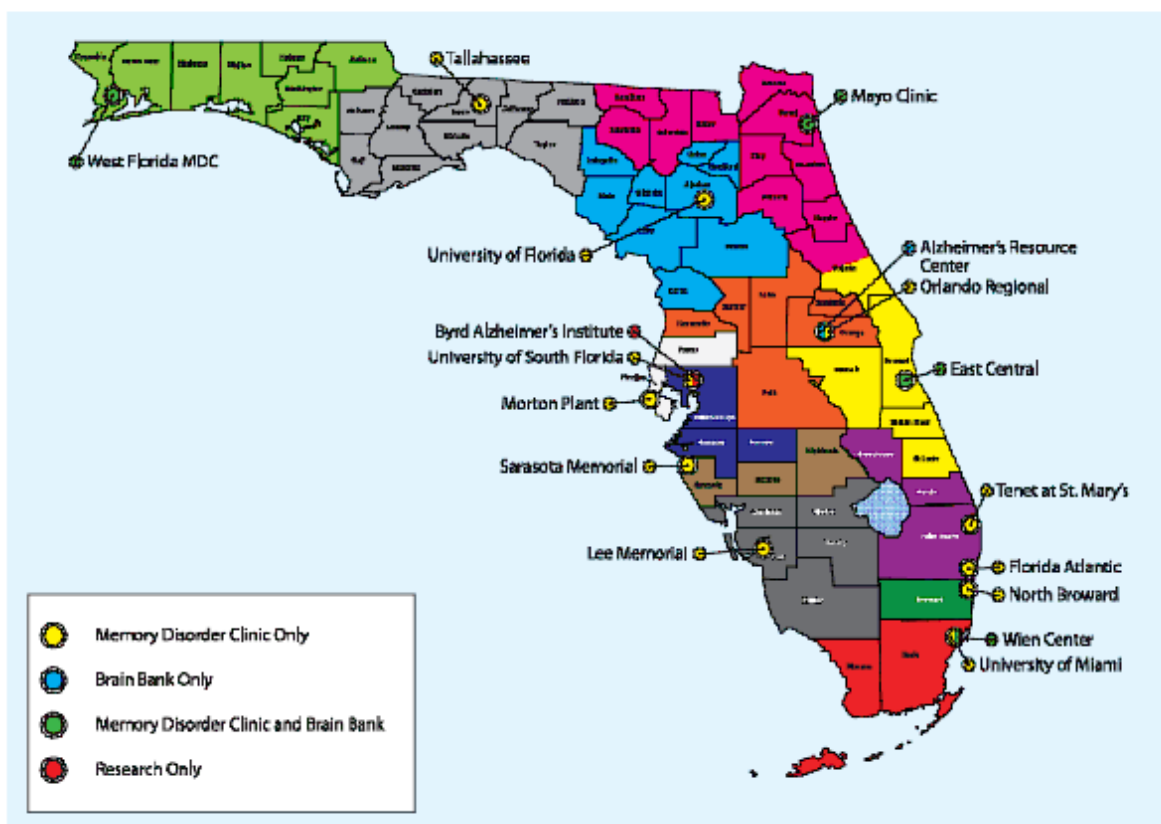
the ADI Advisory Committee on what their position should be for legislative recommendations.

Goals for 2008-2009: To continue to advance the project on the effectiveness of adult day care programs for patients and caregivers: to identify and expand the dementia specific care network throughout Florida and remain involved in the ongoing needs of patients and caregivers who need to register with special needs shelters in case of a disaster; to increase funding for the specialized needs for the care of patients and caregivers; and to support research relating to the work and mission of the MDCs, the Brain Bank and the other projects within Florida.

Memory Disorder Clinics Workgroup

Accomplishments: The Alzheimer's Disease Initiative (ADI) program includes a Florida-wide network of 15 memory disorder clinics (MDCs). (See following map.) The goals of the expert medical teams at the memory disorder clinics are as follows: 1) provide full clinical evaluations, accurate diagnoses, and recommendations for treatment, referrals and long-term care management, 2) provide education and information to families, health students and providers, social service students and providers, and the general public, 3) through basic biomedical and applied research to identify the changes in the brain and behavioral changes related to Alzheimer's disease and the more than 100 other related disorders, and 4) community outreach.

Florida Memory Disorder Clinics and Brain Banks



Services: Clinical, Education and Community Outreach

The MDC teams, some of which are bilingual, evaluated 4,872 patients, accompanied by at least 3,123 caregivers. During the year, the MDCs conducted 2,656 community screenings, which were held at a variety of locations, such as health fairs, senior centers, retirement communities, assisted living and low income housing communities, public libraries, YMCAs and hospitals. Thousands of hours of MDC education and training included face-to-face visits or telephone conversations to educate and support the patient and family, invited lectures to various public meetings, support groups, senior center sites and religious gatherings; research seminars to Florida, national and international audiences; medical education of health and social service providers; education through the media including radio, television, and telehealth; and half-day or full-day workshops open to the general public.

Research: Basic and Applied

Some examples of the basic and applied research include:

1. Longitudinal and observational studies of the progression and genetics of dementia;
2. Link of changing olfactory function and Alzheimer's disease;
3. Tools to identify early symptoms of memory decline, language changes, Alzheimer's disease and various related dementias;
4. Understanding the brain-mediated areas of attention, arousal, neglecting one side of space in the environment (outside of the body) or one side of the actual body;
5. Research on "when," such as when to start a movement, how long to continue the movement and when to stop it;
6. Understanding and expressing emotion in faces and voices;
7. Remembering how and moving the body to use tools such as a key or pen;
8. Studies involving 30 (or more) medicines;
9. Retraining (rehabilitating) memory and thinking;
10. Studies of risks for falling, flexibility and balance;
11. Caregiver immunological response to stress;
12. Impact of adult day (health) care on community-based people with Alzheimer's disease and their caregivers;
13. Driving issues; and
14. Identifying various community needs such as the need for non-professional caregivers.