

ALZHEIMER'S DISEASE ADVISORY COMMITTEE

2009-2016

Summary of Accomplishments



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Alzheimer's Disease Advisory Committee Member
Document reviewed and approved by Advisory Committee April 28, 2017



August 14, 2017

An essential program of the Florida Department of Elder Affairs, the Alzheimer's Disease Initiative was created in 1985 by the Florida Legislature to address Alzheimer's Disease and related dementias. As a component of that initiative, three Memory Disorder Clinics were initially designated to provide diagnostic services and education to those living with these disease processes and their caregivers. By 2017, an additional 13 Memory Disorder Clinics had been designated to meet the growing population needs statewide.

The Alzheimer's Disease Advisory Committee 2009-2016 *Summary of Accomplishments* reviews Florida's Aging Network accomplishments. The 11 Aging and Disability Resource Centers, 16 Memory Disorder Clinics, Brain Bank, and supportive lead agencies have provided referrals for other medical/social services, comprehensive clinical evaluations, educational opportunities, and other vital means of assistance for caregivers.

The Alzheimer's Disease Advisory Committee has been a directional entity for the Department of Elder Affairs and continues to provide supportive guidance as Florida faces an increasing aging population. We express our appreciation to the Committee for the development of the report and deep commitment to fellow Floridians.

Sincerely,

A handwritten signature in blue ink that reads "Jeffrey S. Bragg".

Jeffrey S. Bragg
Secretary

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Fact Sheet: Florida and Alzheimer's Disease

In the United States, Florida has the **highest** percentage of adults over 65 years of age. (United States Census Bureau. Table Age and Sex) (www.census.gov/quickfacts/table/AGe135215/12)

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

More than **500,000** Florida residents suffer with ARD¹, and most receive care from family members 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 people with Alzheimer's disease and their families/significant others.

The **Alzheimer's Disease Advisory Committee**, under gubernatorial appointment, advises the DOEA regarding legislative, programmatic, and administrative matters relating to Alzheimer's victims and their caregivers.

Since inception, the Alzheimer's Disease Initiative (ADI) program has accomplished the following:

- Expanded to 15, partially funded, State-designated Memory Disorder Clinics/Centers
- Implemented Statewide mandated education and training requirements for paid care providers
- Facilitated ethics-based driving safety parameters for people with ARD
- Summarized the best practice models for behavioral challenges
- Identified the need for legislation, similar to the Baker Act, but specific to people with progressive dementia
- Established several ways to provide caregiver training and respite
- Supported numerous research endeavors involving the neurological, psychosocial, and neuropathological aspects of ARD
- Supported and approved the 1st edition (2012) and 2nd edition (2016) of Florida's *Alzheimer's Disease Initiative EDUCATION MANUAL: Understanding & Dealing with Alzheimer's Disease & Related Disorders*
Accessible free 24/7 at DOEA website:
elderaffairs.state.fl.us/doea/docs/adi_manual_2016.pdf
- Developed the Alzheimer's Disease Initiative Guidelines into Standards of care for the Memory Disorder Clinics

- Helped develop the “Silver Alert” program of Florida and actively collaborated with providers such as law enforcement officers to assist, consult with and actively work with the Memory Disorder Clinics and the Aging and Disability Resource Center to help family/significant other caregivers and people with a diagnosis of Alzheimer’s disease or related dementia
- Referred families to the State of Florida Brain Bank, a program that provides a neuropathological evaluation of brain tissue for an accurate post-mortem diagnosis and serves as a repository of brain tissue for scientific study
- Supported and assisted in the work of the Purple Ribbon Task Force
- Produced the White Paper: Alzheimer’s Disease & Related Dementias: Optimizing Health, Lives, & Costs in Florida (CoAuthors: J.Miller, LCSW & L. Doty, PhD, 2016)
- Supported and collaborated with the DOEA Dementia Care & Cure Initiative
- Supported and linked to the Florida Department of Health ED and Ethel Moore Alzheimer’s Disease Research Program Grant
- Awarded grant for Persons with Disabilities and Alzheimer’s for two pilot projects to develop crisis intervention training

The services, education, training, and research information provided by the ADI, help people with Alzheimer’s disease and related dementias and their caregivers manage more effectively the challenges of the illness. Education about caregiving, links to community services and support groups assist in keeping the person with Alzheimer’s disease in community based services longer, resulting in a tremendous cost savings for the State of Florida.

The Advisory Committee collaborates closely with the Memory Disorder Clinics and ADRD organizations and care providers located throughout the State including the following:

- Alzheimer’s Disease Initiative state-funded Memory Disorder Clinics/Centers and State of Florida Brain Bank
- State-funded respite providers for caregivers of persons with ADRD
- State universities and medical centers
- ADRD research facilities located in Florida
- Community-based support groups; education at local and statewide meetings and conferences; adult day (health) care programs; retirement communities, assisted living facilities; rehabilitation centers; and skilled nursing care facilities.

I. Introduction and Background

According to the Alzheimer's Association Facts and Figures 2016, "Alzheimer's disease is a degenerative brain disease and the most common cause of dementia. Dementia is characterized by a decline in memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities. This decline occurs because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed. In Alzheimer's disease, the damage and destruction of neurons eventually affect other parts of the brain, including those that enable a person to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease are bed-bound and require around-the-clock care. Alzheimer's disease is ultimately fatal."¹

In the State of Florida, in 2016, over 510,000 individuals over the age of 65 were estimated to have Alzheimer's disease. By the year 2025, 720,000 are projected to have this fatal disease.¹ Of great concern to this population is maintaining intellectual and memory functions. Decreases in these abilities often precede loss of independence, which consequently places greater economic demands on our limited resources. Alzheimer's disease (AD) is a major factor in progressive loss of memory and other mental abilities in older adults and is one of the top 6 causes of death in individuals age 65 or older. In fact, advancing age is the greatest risk factor for AD and AD rates are predicted to rise from 5 million to 16 million by 2050¹ if effective treatment is not found. Between 2016 and 2025, the State of Florida, which has a high percentage of older adult residents, is predicted to have a 41% increase in AD rates³. The economic impact of this disease will be overwhelming. Despite the current lack of disease modifying treatment, there is sufficient evidence that people with AD who receive active (and early) medical care and caregivers who receive appropriate supportive services have a higher quality of life than those who do not. Furthermore, appropriate care reduces premature institutionalization and saves tax dollars.

Nursing home care costs Florida over \$50,000 per year per person, annually a median rate of \$87,600 (semi-private room) according to Genworth Financial, Inc.² and the Florida Health Care Association.³ The average annual cost of assisted living in Florida in 2016 is about \$37,000 with an additional annual average of more than \$13,000 added for people with Alzheimer's disease according to Paying for Assisted Living & Home Care in Florida.⁴ Home/community based care is far less (about \$10,000 per year).

In 1985, Florida Legislators, realizing the continued growth of our older population and their increasing rates of AD and related disorders, created the Alzheimer's Disease Initiative (ADI) and the Alzheimer's Disease Advisory Committee housed in the Department of Elder Affairs. The ADI was developed to meet the needs of individuals and families with AD and related disorders.

II. Alzheimer's Disease Advisory Committee

The Florida Statute assigns the role of the Advisory Committee to “advise the Department of Elder Affairs (DOEA) regarding legislative, programmatic, and administrative matters relating to AD victims and their caregivers”. Each year, the Advisory Committee and four Standing Subcommittees confer at quarterly meetings with many AD specialists and healthcare providers from around the State. They regularly evaluate a wide range of issues that impact families dealing with AD and bring these concerns and recommendations to the Advisory Committee to forward to the Secretary of the DOEA. These issues include public safety, educational and training needs, providing services, addressing financial needs, resource short falls (especially long waiting lists for services), research, ethical and legal concerns, legislative matters, addressing the underserved, etc. This Report, *Summary of Accomplishments, 2009-2016*, will be followed by a summary of related needs identified in Florida that will include items of “High Priority” in order to provide recommendations for DOEA action.

The Alzheimer's Disease Initiative and Alzheimer's Disease Advisory Committee were created under Chapter 430 (430.501 – 430.504), Florida State Statutes. The 10-member Advisory Committee advises the Department of Elder Affairs regarding legislative, programmatic, and administrative matters that relate to victims of Alzheimer's disease and their caregivers. All members of the Advisory Committee must be residents of the State. The Advisory 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 Advisory Committee elects one of its members to serve as Chair for a term of one year. Advisory Committee meetings are held quarterly or as frequently as needed.

The Advisory Committee also serves as the major resource to our Florida Legislators regarding issues involving Alzheimer's disease and related disorders.

As previously stated, the purpose of this 2009-2016 Report is to summarize accomplishments and then identify needs including items of “High Priority” and provide recommendations for DOEA action.

III. Activities and Accomplishments for 2009-2016

Standing Subcommittees and Workgroups

The four Standing Subcommittees supporting the Alzheimer's Disease Advisory Committee are:

1. Clinical Services,
2. Home and Community Based Services,
3. Education and Research and
4. Legislative Advocacy

Clinical Services Subcommittee:

Overview: The coordinators, administrators and directors as well as the general public bring issues regarding the need for increased support of the Memory Disorder Clinics in order to reduce the waiting time for a comprehensive evaluation as well as other issues that may arise, such as driver fitness and safety issues that surface during the medical evaluation or refusal of health insurance companies to provide pre-approval for a necessary test or for a clinic evaluation.

Accomplishments:

- *Developed the Alzheimer's Disease Initiative Guidelines into Standards of care for the 15 Memory Disorder Clinics which were approved by the Advisory Committee in April 2015 as: Criteria for Standards for ADI Memory Disorder Clinics/Centers (MDC)*
- *Produced a White Paper; Alzheimer's Disease & Related Dementias; Optimizing Health, Lives & Costs in Florida (CoArthurs; J. Miller, LCSW & L. Doty, PhD, 2016)*
- *Helped develop the "Silver Alert" Program of Florida and actively collaborated with providers such as law enforcement officers to assist, consult with and actively work with Memory Disorder Clinics and other resource programs to help families/significant other caregivers and people with a diagnosis of Alzheimer's disease or related dementias.*

Goal for 2016-2020

1. *Identify issues, barriers and challenges that interfere with careful clinical evaluations, treatments, caregiver management, caregiver stress, caregiver respite, etc.*

State of Florida Brain Bank Overview: The State of Florida Brain Bank was established by DOEA Rule 58D-1.002(4) Florida Administrative Code, in 1987 and covered the 67 counties in the State. Due to budget constraints, the initial five offices of the State of Florida Brain Bank have been reduced to two offices. The main office is at Mt. Sinai Medical Center, Miami Beach, FL. The satellite office is located in Central Florida and is coordinated through the Alzheimer's and Dementia Resource Center, Inc. in Orlando. The 15 Alzheimer's Disease Initiative Memory Disorder Clinics (MDC) invite people who receive an evaluation at a MDC to consider signing up for the State of Florida Brain Bank program.

Accomplishments 2016:

Number of new brain donors enrolled: 61

Number of autopsies performed: 59

Number of diagnoses completed: 39

Number of families counselled: 160

Goals for 2016-2020

- 1. Continue providing brains of individuals with dementing illnesses*
- 2. Educate the community about progressive dementia and the role of the Brain Bank to provide an accurate post-mortem diagnosis for the diagnosing primary care physician and for the designated family*
- 3. Have available tissue for scientific researchers*

Home and Community Based Services Subcommittee:

Accomplishments: Supported the Purple Ribbon Task Force. Supported the Dementia Care & Cure Initiative. Supported the Silver Alert Program enacted in 2011. Worked with the Legislative Advocacy Subcommittee to obtain funding for two active Memory Disorder Clinics: 1) the Madonna Ptak Center for Memory Disorders at Morton Plant Mease (Clearwater, FL) and 2) the Florida Atlantic University Louis and Anne Green Memory Wellness Center; Memory Disorder Clinic; Adult Day Center (Boca Raton, FL).

Goals for 2016-2020

- 1. Establish standards for Specialized Adult Day Care and Model Day Care*
- 2. Work with Silver Alert to create policy and protocol for the Lost on Foot program*
- 3. Work towards 2018 Alzheimer's Summit as recommended by the Purple Ribbon Task Force*
- 4. Continue to review Medicaid funding for Assisted Living Facilities, related programs and waitlists*
- 5. Increase Elder Abuse Awareness*

Education and Research Subcommittee:

Accomplishments: The 18 Chapter (1st edition, 2012) 2nd edition (2016) of the *Florida Alzheimer's Disease Initiative Education Manual: Understanding & Dealing with Alzheimer's Disease & Related Disorders*. Accessible free, 24/7 at DOEA website. The online *Education Manual* is used by professional caregivers, families and the general public from within Florida and beyond its borders. The Education and Training Ad Hoc Subcommittee became a Standing Subcommittee of the Alzheimer's Disease Advisory Committee with the charge to address the ongoing education and training issues of importance to the mission of the Alzheimer's Disease Initiative. Later the Education and Training Subcommittee merged with the Research Subcommittee.

Goals for 2016-2020:

1. Develop an ongoing link between the Training Academy on Aging at USF and the Alzheimer's Disease Initiative
2. Establish requirement of the Memory Disorder Clinics for certification for ADRD specialized training
3. Strengthen research activities of the 15 MDCs and the three model adult day health care centers (in Gainesville, Tampa, and Miami)
4. Link to Florida universities and other Florida research institutes to participate in research studies, as appropriate

Legislative Advocacy 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. Supported the work of the Purple Ribbon Task force. Supported the increased ADI funding for community-based services especially to eliminate waiting-lists.

The Legislative Advocacy Subcommittee worked to obtain funding for the Madonna Ptak Center for Memory Disorders at Morton Plant Mease (Clearwater, FL) and the Florida Atlantic University Louis and Anne Green Memory Wellness Center; Memory Disorder Clinic: Adult Day Center (Boca Raton, FL).

Achieved keeping the ADI funding as a recurring DOEA budget line item.

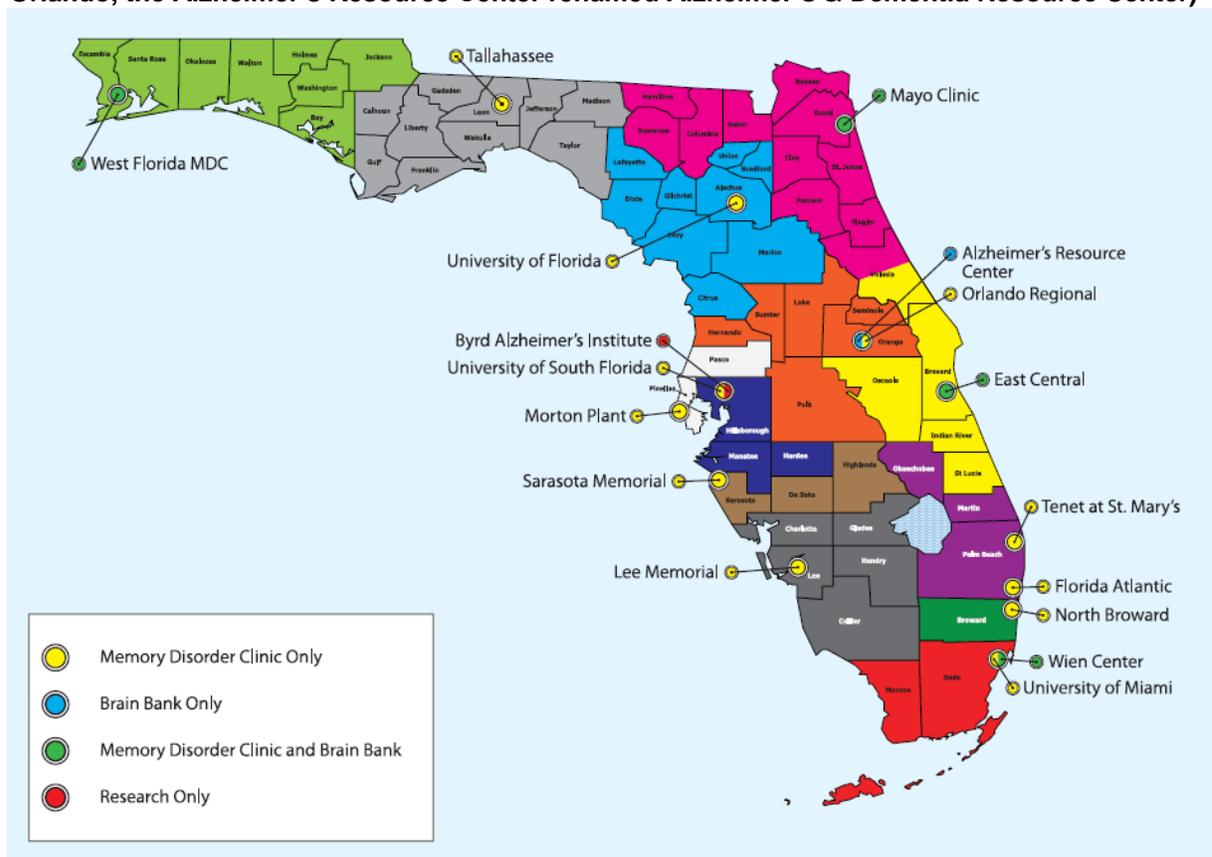
Goal for 2016-2020:

To ensure that Alzheimer's disease and related dementia services and programs are a primary focus of Florida Legislators for future advocacy.

Memory Disorder Clinics Workgroup

Accomplishments: The Alzheimer’s Disease Initiative (ADI) program includes a Florida-wide network of 15 Memory Disorder Clinics (MDCs) and three model adult day health care centers (located in Gainesville, Tampa, and Miami). (See following map identifying the location of the 15 MDCs and adult day care centers.) The goals of the expert medical and social service teams at the Memory Disorder Clinics are as follows: 1) provide full clinical evaluations, accurate diagnoses, and recommendations for treatment, referrals, planning ahead such as for weather emergencies, Brain Bank enrollment, 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 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 (Note: In Orlando, the Alzheimer’s Resource Center renamed Alzheimer’s & Dementia Resource Center)



Services: Clinical, Education and Community Outreach

In 2016, the 15 MDC teams, evaluated 7,006 people with Alzheimer's disease or related dementia, accompanied by at least 2,977 family or significant other caregivers. Evaluations were provided in consideration of various languages and cultures. During the year, the MDCs conducted 1,529 community screenings, which were held at a variety of locations, such as health fairs, senior centers, retirement communities, assisted living facilities 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 person with the diagnosis and family caregiver(s), invited lectures to various public meetings, support groups, senior center sites and religious gatherings; research seminars throughout Florida and at national and international meetings; 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 progressive dementias;
2. Link of changing olfactory function and Alzheimer's disease;
3. Assessment tests and tools to identify early symptoms of memory decline, language changes, Alzheimer's disease and related dementias;
4. Understanding the brain-mediated areas of attention, arousal, awareness of self in relationship to space, neglecting one side of space in the environment (outside of the sense of self-exogenous) or one side of inner sense of self (endogenous);
5. Research on brain function controlling "when," such as when to start a movement, how long to continue the movement and when to stop it;
6. Critical for accurate communication research on understanding and expressing emotion in faces and voices;
7. Remembering how and moving the body (shoulder, elbow, wrist, hand and fingers) to do learned skilled movements to use a tool such as a key, toothbrush, fork or pen;
8. Studies involving 30 (or more) medicines;
9. Retraining (rehabilitating) memory and thinking;
10. Studies of balance, flexibility, walking and risks for falling
11. Caregiver immunological response to stress;
12. Impact of adult day (health) care on community-based people with Alzheimer's disease or related dementias and their caregivers;

13. Driving issues: driving fitness, driving safety, driving retirement, and transportation alternatives; and
14. Identifying various community needs such as the need for trustworthy and reliable non-professional caregivers.

References

1. Alzheimer's Association. *2016 Alzheimer's Disease Facts and Figures*. https://www.alz.org/documents_custom/2016-facts-and-figures.pdf. (accessed 1/12/17)
2. Genworth 2015 Cost of Care Survey, Florida. https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/cost-of-care/118928FL_040115_gnw.pdf. (accessed 1/12/17)
3. Florida Health Care Assoc. http://www.fhca.org/media_center/long_term_health_care_facts. (accessed 1/12/17)
4. Paying for Senior Care. <https://www.payingforseniorcare.com/financial-assistance/florida.html>. (accessed 1/12/17).

Alzheimer's Disease Advisory Committee, 2016-2017

Chair, Leilani Doty, PhD, 2016 to current, Gainesville, FL

Members:

- **Thomas Buckley, EdS, 2016-current, Hollywood, FL**
- **Peggy Connelly, 2016-current, Vero Beach, FL**
- **Jamie L. Glavich, CDP (Certified Dementia Practitioner) 2010-current, Jacksonville, FL**
- **David G. Morgan, PhD, 2013-current, Tampa, FL**
- **Christine Lecher Powers, BA, MS-HSA, 2014-current, Largo, FL**

Subcommittee Chairs:

- **Clinical Services, Chair: Joy Barbee, RN, BSN, CPAN**
- **Home and Community Based Services, Chair: Jamie Glavich , CDP**
- **Education and Research, Chair: David G. Morgan, PhD**
- **Legislative Advocacy, Chair: Christine Lecher Powers, BA, MS-HAS
Co-chair: Peggy Connelly**

Alzheimer's Disease Initiative, Advisory Committee Leadership History: Chairs and Dates of Service

**John "Malcom" Randall, AB, Honorary Doctorate of Public Service,
University of FL, 1986-2001**

Fran Carlin-Rogers, BA, NHA, 2001-2006

Larry E. Butcher, 2006-2008

Cheryl A. Luis, PhD, ABPP-CN, 2008-2010

Jamie L. Glavich, CDP, 2010-2012

Frank M. Webbe, PhD, 2012-2014

Christine Lecher-Powers, BA, MS-HSA, 2014-2016

Leilani Doty, PhD, 2016-current

Appendix

The following documents are available as additional information about the work of the Alzheimer's Disease Initiative and its Advisory Committee:

- Educational Manual (2016) flyer
- White Paper re: Insurance Issues
- MEMORY DISORDER CLINICS and FLORIDA BRAIN BANK, 2015-2016 Year End Summary
- ADI Brochure
- Memory Disorder Clinic Standards
- Purple Ribbon Task Force Recommendations (Summary)