

2019 – 2020
**ALZHEIMER'S DISEASE
ADVISORY COMMITTEE**

 *Annual Report*



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Section 1: Introduction

Alzheimer's disease and related dementias (ADRD) represent a category of chronic illness characterized by progressive neurologic degeneration. They are currently incurable and the course of ADRD illness is characterized by years of declining ability and increasing dependency and co-morbidity. "Alzheimer's disease (AD) is the most common cause of dementia, accounting for an estimated 60% to 80% of cases. The characteristic symptoms of dementia are difficulties with memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. AD is thought to begin 20 years or more before symptoms arise, with changes in the brain that are unnoticeable to the person affected. Only after years of brain changes do individuals experience noticeable symptoms such as memory loss and language problems. Symptoms occur because nerve cells (neurons) in parts of the brain involved in thinking, learning, and memory (cognitive function) have been damaged or destroyed. As the disease progresses, neurons in other parts of the brain are damaged or destroyed. Eventually, nerve cells in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. Individuals become bed-bound and require around-the-clock care. AD is ultimately fatal."¹

Currently, Florida has approximately 580,000 individuals over the age of 65 who are estimated to have AD.² By the year 2025, 720,000 are projected to have this fatal disease.³ Since aging is a major risk factor for developing AD, Florida will likely continue to lead the nation with 19% of the population over the age of 65 and the second highest incidence of ADRD. A major factor in progressive loss of memory and other mental abilities in older adults, AD is the sixth-leading cause of death in the United States and is the fifth-leading cause of death among those age 65 and older. The prevalence of dementia varies among different populations in the U.S. and in Florida.

ACCORDING TO THE ALZHEIMER'S ASSOCIATION 2020 FACTS AND FIGURES:

- Almost **TWO-THIRDS** of Americans with AD **ARE WOMEN**.
- There are over **200,000 PEOPLE UNDER THE AGE OF 65** who are living with young-onset Alzheimer's.
- **AFRICAN AMERICANS ARE TWICE AS LIKELY TO HAVE ADRD** as older whites.
- **HISPANICS/LATINOS ARE ONE AND ONE-HALF TIMES AS LIKELY TO HAVE ADRD** as older whites.
- **INDIVIDUALS WITH DOWN SYNDROME ARE AT A HIGH RISK** for developing AD or a related dementia, and typically develop the disease in their 50s or earlier.⁴

Between 2020 and 2025, the State of Florida is predicted to have a 24.1% increase in AD rates.⁵ The economic impact of this disease will be overwhelming. Despite the current lack of disease modifying treatment, there is sufficient evidence that people with ADRD 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 taxpayer dollars.

In 1985, the Florida Legislature, recognizing the alarmingly high percentage of Floridians affected by ADRD, created the Alzheimer's Disease Initiative (ADI) within the Department of Elder Affairs (DOEA). ADI is a statewide program that provides services to individuals and families affected by ADRD. ADI includes three components:

- Supportive services such as counseling, consumable medical supplies, and respite for caregiver relief.
- Memory Disorder Clinics (MDCs) to provide diagnosis, education, training, research, treatment, and referral.
- The Florida Brain Bank to support research.

The Alzheimer’s Disease Advisory Committee (ADAC) was established by the Florida Legislature – under the umbrella of the ADI – to serve as a major resource to it regarding issues involving ADRD and advise DOEA regarding legislative, programmatic and administrative matters related to persons living with AD and their caregivers. Appreciating the importance of supporting those living with ADRD and their caregivers, during the 2019 legislative session the membership of ADAC was increased from ten to fifteen.

Per section 430.501, Florida Statutes, ADAC is required to submit an annual report which must include information and recommendations



on Alzheimer’s disease policy; all state-funded efforts in Alzheimer’s disease research, clinical care, institutional, home-based and community-based programs and the outcomes of such efforts; and any proposed updates to the Alzheimer’s disease state plan. The members of ADAC have compiled and written the information in this report based on feedback from Floridians through community listening sessions, surveys, and input from community partners across the state who are caring for people living with ADRD. ADAC has also prioritized 8 recommendation areas for DOEA to consider in the Alzheimer’s disease state plan. The content of this report was exclusively written by ADAC members with technical support from DOEA staff.

DOEA is responsible for administering human services and long-term care programs, including programs funded under the Federal Older Americans Act of 1965, as amended, and other programs that are assigned to it by law, 430.04, F.S. (2019). Regarding service provision and policy development as it relates to persons who are in the early stages of AD, who have younger-onset AD, or who have a related form of dementia, DOEA administers the ADI, Home Care for the Elderly (HCE), Respite for Elders Living in Everyday Families (RELIEF), and the federally funded Family Caregiver Support Program. All of these programs provide caregiver support; however, only the ADI is designed to provide dementia-specific services.

Each year, ADAC confers at quarterly meetings with many ADRD specialists and healthcare providers from around the state and continuously evaluates a wide range of issues that impact people with ADRD and their families. These issues include public safety, educational and training needs, providing services, addressing financial needs, resource shortfalls (especially long waiting lists for services), research, ethical and legal concerns, and legislative matters. Over the years, ADI has taken up new initiatives to be able to better serve the targeted population. The timeline below highlights the major milestones covered by ADI.



1965

The Older Americans Act was passed and created the Area Agency on Aging.

1985

Alzheimer's Disease Initiative (ADI) was legislatively created in 1985 to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer's Disease and Related Dementias.

The start of the ADI respite programs and model day care services.

The First Memory Disorder Clinics (MDCs) established at USF, UF, and UM.

1986

The Alzheimer's Disease Advocate Committee (ADAC) established and the first chairperson was appointed.

1987

The Florida Brain Bank was created at Mt. Sinai Medical Center in Miami by Dr. Ranjan Duara.

1992

Department of Elder Affairs (DOEA) established.

1999

ADRD training program established.

2008

Florida Silver Alert Plan was established through Executive Order 08-211 by Governor Charlie Crist.

2010

Silver Alert coordination and support project started.

2011

Florida Silver Alert became state law under Florida Statute sections 937.021 and 937.0201*.

2012

HB 473 passed that created the Purple Ribbon Task Force (PRTF) housed within DOEA.

2013

Submitted Florida Alzheimer's Disease State Plan to the Governor and Legislature. The PRTF adjourned following the submission.

2015

DOEA announced the Dementia Care and Cure Initiative (DCCI).

2016

Tallahassee announced as the first DCCI pilot task force

2019

Florida became the 4th designated Age-Friendly State.

ADRD placed into the State Health Improvement Plan and Priority Area 9 created.

14th DCCI task force created.

*Florida Statute

Section 2: ADI Overview & History

As the ADI expands, Florida has the infrastructure in place to provide clinical services, diagnosis, support services, education, research, and most importantly committees to identify gaps in services and make recommendations for change to better serve our ADRD population. The ADI has four funded program components listed in Florida statute: ADAC, ADI respite and support services, Memory Disorder Clinics, and the Florida Brain Bank. Program advancements now include four supporting components: Florida Silver Alert, a priority area in the State Health Improvement Plan (SHIP) devoted to ADRD (PA9), Dementia Care and Cure Initiative (DCCI), and ADRD training program. DOEA developed a brochure to share information regarding ADAC with community and agency partners. (See Appendix: Table 1)

Alzheimer's Disease Advisory Committee (ADAC)

- ADAC was established by the Florida Legislature in 1986 and the size and scope of ADAC were increased in 2019.
- Other duties include:
 - » Preparing and submitting an annual report to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the Secretary of DOEA.
 - » Proposing updates to the Alzheimer's Disease State Plan.
 - » Making recommendations on AD policy and research, clinical care, institutional, home-based and community-based programs.
 - » Providing input and support for the state implementation of the federal BOLD Act law.
- There are 15 members of the ADAC, 11 of whom are appointed by the Governor, two by the President of the Senate, and

two by the Speaker of the House of Representatives. Currently ADAC has 11 appointed members and 4 pending openings. The ADAC recommends representation from: law enforcement, Area Agencies on Aging, a person living with dementia, and Department of Health.

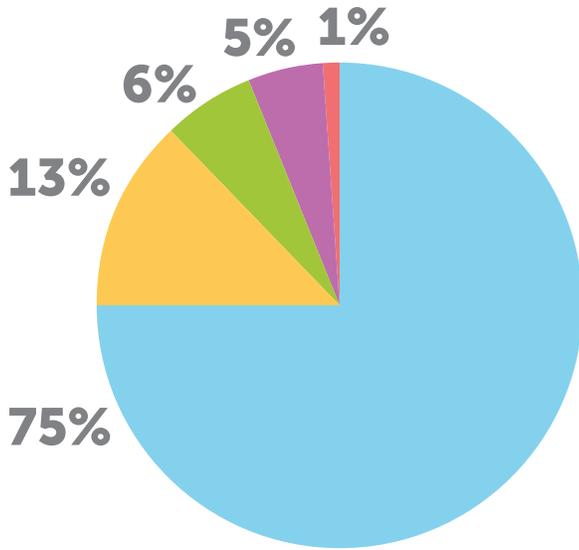
- Committee Members:
 - » **Rosemary Laird** (Committee Chair); Medical Director Advent Health Maturing Minds Memory Disorder Clinic
 - » **Michelle Branham**; VP of Public Policy, Alzheimer's Association
 - » **Peggy Connelly**; National Director of Memory Care
 - » **Donna Flanagan**; Speech and Language Pathologist
 - » **Minority Leader Senator Audrey Gibson**
 - » **Robert Glueckauf**; Professor Department of Behavioral Sciences and Social Medicine
 - » **Representative Michael Grant**; State Legislator
 - » **María de los Ángeles Ordóñez**; Director Louis and Anne Green Memory and Wellness Center
 - » **Fátima Perez**; Regional Manager, State Government Affairs Koch Co Public Sector
 - » **Representative Scott Plakon**; State Legislator
 - » **Aileen Ruess**; Owner of Ace Senior Care Management

ADAC Committee members meet quarterly to discuss the progress made by the committee and future action plans. In 2019-2020, ADAC met on following dates:

- July 25, 2019
- November 14, 2019
- February 4, 2020
- June 26, 2020

At its first meeting following the expansion of ADAC, members focused on providing an

Total State ADI Funding 2019-2020



Total ADI Funding	\$28,484,25
 Brain Bank	\$117,535
 Non-Recurring Projects	\$1,454,290
 Recurring Projects	\$1,805,019
 MDCs	\$3,686,484
 Respite & Special Projects	\$21,420,926

overview of State-funded efforts in AD research, clinical care, institutional, home-based and community-based programs and the outcomes of such efforts. Matrixes were developed to look at resources by each Planning and Service Area (PSA) (a PSA is a geographic area, that is either a city, a single county, or a multi-county district). A sub-committee was formed in July 2019 to conduct surveys and community listening sessions that would serve as needs assessments for this report. An overview of existing resources in the State of Florida is included and a detailed description of the existing services in Florida and the gaps in services is covered in sections 4-8. (See Appendix: Table 2 and 3)

ADI Respite Care and Special Projects

- ADI is a general revenue-funded program. Each year the level of funding is determined by the Florida Legislature during its budget process. The allocation for ADI respite funding is based on each county's population aged 70 and older and the probable number of Alzheimer's cases. Additional ADI funds are administered to the MDCs and the Florida Brain Bank, and remaining funds are allocated to special projects per proviso language and legislative intent in the General Appropriations Act. ADI respite care is available for caregivers of adults age 18 and older who have been diagnosed as having probable ADRD.
- Services include:
 - » In-home/In-facility respite
 - » Adult day care
 - » Emergency and extended care for caregivers
 - » Training

Memory Disorder Clinics (MDC)

- MDCs fall within the ADI and they are statutorily established for the purpose of conducting research and training in a diagnostic and therapeutic setting for persons living with ADRD. A full report outlining the MDC accomplishments for 2018-2019 is included. (See Appendix: Table 4)
- There are 17 MDCs in Florida and they provide the following services for persons living with ADRD:
 - » Diagnostic evaluations
 - » Education
 - » Referral services
 - » Service-related research
 - » Develop caregiver training materials

Florida Brain Bank

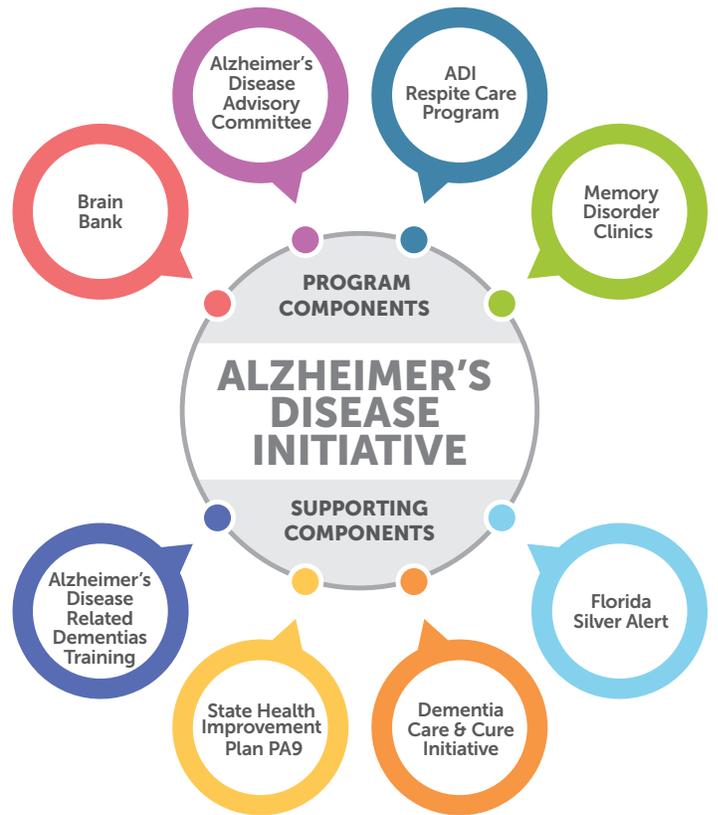
The Florida Brain Bank was created and funded by the Florida Legislature in 1986. The purpose of the Florida Brain Bank is to study the brains of individuals with progressive dementia by collecting and studying the brains of deceased individuals who were clinically diagnosed with ADRD, provide families with a definitive diagnosis, and to acquire brain tissue for research. Through a network of researchers, the Florida Brain Bank shares common goals of finding a cure, improving diagnostic tools, treatment options, and providing education. A full report outlining the Brain Bank accomplishments for 2018-2019 is included. (See Appendix: Table 5)

ADI Supporting Components

Florida Silver Alert: MDCs collaborate with Florida law enforcement to facilitate the fast and safe return of persons with ADRD who have gone missing. A full report on 2019 Silver Alerts is included. (See Appendix: Table 6)

Alzheimer's Disease and Related Disorders (ADRD) Training: In 1999, the ADRD Training program was established to ensure that employees of licensed facilities receive specialized training on ADRD. DOEA contracts this program out to USF's Training Academy on Aging. All trainers must be approved training providers with an approved curriculum through USF's Training Academy on Aging. A full report of 2018-2019 ADRD activities is included. (See Appendix: Table 7)

State Health Improvement Plan (SHIP) ADRD Priority Area: In 2019, a priority area was created in the SHIP to work on specific goals, strategies and objectives related to ADRD. Florida is the only state in the nation to have a SHIP priority area devoted exclusively to those living with ADRD and their caregivers. A full report of the 2020-2021 SHIP goals is included. (See Appendix: Table 8)



The ADI Respite Care Program is a collaborative effort with the Area Agencies on Aging. SHIP and PA9 are a collaborative effort with Florida Department of Health and Alzheimer's Association.

Dementia Care and Cure Initiative (DCCI): In 2015, DOEA announced DCCI to engage local communities throughout the state to be more dementia caring, promote better care for Floridians affected by dementia, and support research efforts to find a cure. A full report for the 2019 DCCI year in review is included. (See Appendix: Table 9)

Section 3: Overview of Key Legislation

The Florida Legislature recognizes the increasing number of Floridians living with ADRD and the ongoing need to implement strategies to support Floridians with ADRD and their caregivers. Recent legislative updates include:

- On June 19, 2020, House Bill 835 was signed into law establishing the position of a dementia director within the DOEA. The director position will assist ADAC with the development of the annual report and development of the Alzheimer's Disease State Plan, support the ADI, MDC, Florida Brain Bank, facilitate public education on AD, coordinate dementia research programs, and collect data on the impact of AD on the state. The bill also makes a minor change to the funding formula for respite care. Under the bill, DOEA must consider the number of persons 70 or older, rather than 75 or older, in each county when distributing funding for respite care.
- On June 22, 2020, House Bill 767 was signed into law. This bill amends various statutes related to the regulations of Assisted Living Facilities (ALF). A few that will have impact on those living with ADRD include: Allows the use of certain physical restraints in ALFs, including any device the resident chooses to use and is able to remove or avoid independently. Allows ALFs to admit residents that require 24-hour nursing care, residents that are receiving hospice services, or residents who are bedridden that meet specific criteria. Requires an ALF to notify a resident's representative or designee of the need for health care services and assist in making appointments if an underlying condition of dementia or cognitive impairment is determined to exist. If the resident does not have a representative or designee or the ALF cannot



reach their representative or designee, the ALF must arrange for the necessary care and services to treat the condition with an appropriate health care provider.

Important legislation that was passed in 2019 included:

- On June 27, 2019, House Bill 449 was signed into law, revising the membership and duties of ADAC and requiring the DOEA to collect and report pertinent information on the impact of Alzheimer's disease in Florida. The ADAC was increased from 10 to 15 members. Additionally, this bill provided the establishment of a 17th Memory Disorder Clinic at Miami Jewish Health.
- On June 27, 2019, House Bill 1045 Closing the gap grant proposals was signed into law. The bill amends 381.7355, F.S., to expand the priority areas eligible for a Closing the Gap grant award to include ADRD. The bill also amends 381.7354, F.S., to eliminate the requirement that up to 20% of any grants awarded under the program be set aside for projects related to Front Porch Florida Communities. The bill also prohibits the Department of Health (DOH) from establishing a minimum or maximum award amount, requires the DOH to determine grant award amounts based on the merit of the application, and requires the DOH to award grants in various regions of the state.

Section 4: Statewide Research

The primary objectives of the research section of the ADAC annual report include: (1) describing the history, structure, aims and recent activities of state-funded research programs; and (2) identifying important gaps in dementia care research that merit consideration for future funding.

Ed and Ethel Moore Grant Program

In 2014, the Florida Legislature created the Ed and Ethel Moore Alzheimer's Disease Research Program to support the development of innovative research in the prevention, assessment and treatment of progressive dementia. The program is located in and managed by the DOH. The long-term objectives of the program include:

- Improving the health of Floridians through research on prevention, treatments, diagnostic tools, and cures for ADRD.
- Expanding the foundation of knowledge related to the prevention, diagnosis, treatment, and cure of this syndrome of disorders.
- Stimulating economic activity in areas related to research on ADRD.

Florida's Surgeon General and Secretary of the DOH is responsible for appointing 11 members to the Alzheimer's Disease Research Grant Advisory Board (Advisory Board). The Advisory Board, authorized in section 381.82, F.S., consists of two gerontologists, two geriatric psychiatrists, two geriatricians, two neuroscientists, and three neurologists.

The major responsibilities of the Advisory Board are to provide advice to the State Surgeon General on program priorities and

area emphasis; assist in the development of appropriate linkages to nonacademic entities, such as voluntary organizations, health care delivery institutions, industry, government agencies, and public officials; and develop and provide oversight regarding mechanisms for the dissemination of research results. The Advisory Board submits recommendations for proposals to be funded to the State Surgeon General by December 15th of each year. Grants and fellowships are awarded by the State Surgeon General, after consultation with the Advisory Board, based on scientific merit.

During the 2018-19 fiscal year, the Advisory Board designated five research priority areas outlined in the Funding Opportunity Announcement:

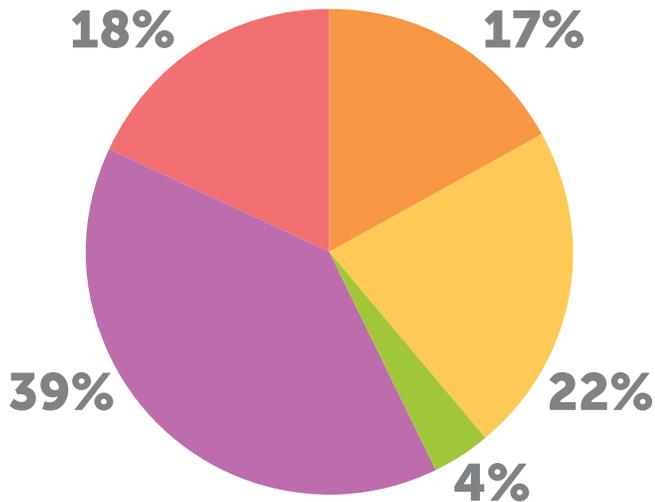
- The social/behavioral aspects of care, as well as palliative and end-of-life care for people with ADRD.
- Elucidation of the basic science relating to progressive dementia.
- Development of consortium grants between Florida-based institutions to augment established research networks and promote novel networks.
- Epidemiological studies examining the prevalence, incidence, and risk factors of the disease with priority given to studies examining health disparities.
- Fellowships aimed at enhancing the workforce of Florida's researchers working on AD.

During the 2018-2019 fiscal year, the Florida Legislature allocated \$5,000,000 for research grants sponsored by the Ed and Ethel Moore Alzheimer's Disease Research Program. Table 10 details all newly awarded grants and Table 11 details all active grants in 2018-2019. Information regarding progress reports, funding, publications and patents of each active grant is included. (See Appendix: Table 10 and 11)

For the 2019-2020 fiscal year, Ed and Ethel Moore Alzheimer’s Disease Research Program established the following five priority areas:

**Overall Program Applications and Funded Projects
Fiscal Year 19/20 by Priority Area**

Grant Applications Funded



Grant Priority Areas	PERCENT FUNDED
Priority Area 1 Therapeutic strategies <i>(this category was expanded this year to address palliative care, advanced care planning, and end-of-life care)</i>	18%
Priority Area 2 Therapeutic targets, identification of novel biomedical markers and pathophysiology	39%
Priority Area 3 Consortium grants with the potential of including new partners (Memory Disorder Clinics)	4%
Priority Area 4 Epidemiology research studies	22%
Priority Area 5 Post-doctoral research fellowships	17%

Additional information about the Ed and Ethel Moore Grant Program can be retrieved on this website: floridahealth.gov/provider-and-partner-resources/research/funding-opportunity-announcements/alzheimersfoa.html

State of Florida Brain Bank: Research Contributions

The goals of the Florida Brain Bank are:

- Provide a final pathological diagnosis of the cause of dementia to families and the patients’ physicians.
- Provide education and feedback to health care professionals and the public about the relationship between the clinical diagnosis during life and the final pathological diagnosis.
- Provide opportunities for clinical researchers to study the frequencies of various dementias in Florida, accuracy of clinical diagnoses and the associations between risk factors for dementia, such as a family history of dementia, medical conditions (e.g., head injury, diabetes, and hypertension) and the presence and severity of various forms of dementia.
- Conduct basic research on the biology, pathology and genetics of ADRD.

Over the last 30 years, over 3,000 brains have been studied by the Florida Brain Bank. Referrals to the Brain Bank are obtained primarily by the MDCs and other ADI entities, health care professionals and organizations all over the State who have knowledge of the activities of the Brain Bank, and by word of mouth from those who have had previous experience with the Brain Bank.

Enrollment in the Florida Brain Bank is initiated by:

- Signing a consent form by family members or others who are authorized to provide consent for autopsy of their loved one.
- Filling out a standardized form documenting the clinical history of the patient.
- Obtaining medical records (including CDs of brain scans and other tests over the course of the condition), beginning ideally at the first evaluation of the illness.

Those family members or other individual authorized to provide consent for autopsy are given detailed written instructions about how to inform the autopsy site regarding the impending death of the donor and the procedures to be undertaken at the time of death, including the 24-hour phone number to call. The Florida Brain Bank arranges and pays for transportation of the donor's body to the autopsy site and autopsies are conducted on the same day or the day after death. Immediately subsequent to the autopsy, the donor's body is transported to a funeral home selected by the family of the deceased. No evidence of the autopsy procedure is visible, allowing an open casket funeral.

Currently, there are only two fixed sites that are registering donors and conducting the autopsies: Mount Sinai Medical Center in Miami Beach (which is contracted by the State of Florida to coordinate the Brain Bank) and Orlando Regional Medical Center in Orlando. Those donors living outside the catchment area of these two sites may have autopsies conducted in local funeral homes, using a contracted autopsy service (1-800-AUTOPSY). Frozen and formalin preserved brain components of autopsied sections are then shipped to a contracted neuropathologist. Following the completion of the pathological diagnosis, reports are sent to Mount Sinai Medical Center, from which the reports are forwarded (along with a cover letter explaining the findings in lay terms) to the family member of the donor or other person authorized to receive the reports.

Florida has a strong research team; the Florida Brain Bank has conducted over 3,000 autopsies to date and is fortunate to have the team of neuropathologists at Mayo Clinic in Jacksonville, led by Dr. Dennis Dickson, who is an international authority in the field of pathological diagnosis of dementia and leads a highly talented team researchers who have provided invaluable service to the Florida Brain Bank over the last 25 years. Dr. Melissa Murray has joined the team of researchers at Mayo Clinic, resulting in a large increase in research collaboration between

the Pathology team at Mayo Clinic, the Clinical team at Mount Sinai Medical Center, and other institutions around the state.

This increase in collaboration has resulted in several important discoveries about the pathology of ADRD and how it relates to the clinical presentation of the disease and the treatment of the condition. A full report on these discoveries is included. (See Appendix: Table 12)

State-Funded Memory Disorder Clinics: Research Activities

Currently, all 17 state-funded MDCs participate in funded research projects. As part of their contractual agreement, they are required to partner with research programs focusing on dementia and dementia care. However, the scope and intensity of research activities varies considerably across the 17 sites. MDCs with strong ties to academic health centers are likely to have a broader research portfolio than those who do not have such affiliations.

MDCs meet quarterly to discuss opportunities for collaborating on research initiatives across different state planning and service areas (PSAs). All MDCs are encouraged to refer patients with dementia and their family caregivers to the Institutional Review Boards approved research studies and the Florida Brain Bank. MDC coordinators also liaise with Florida Area Agencies on Aging and their lead agencies to provide information about ongoing research opportunities for their constituencies.

During the 2018-2019 fiscal year, MDCs referred patients with dementia and their caregivers to 4,480 different research opportunities. (See Appendix: Table 13)

Examples of types of research studies in which MDC clients participated during fiscal year 2018-2019 include:

- Pharmaceutical Clinical Trials to Prevent Onset of Dementia in Persons with Mild Cognitive Impairment.
- Behavioral and Neuropsychological Interventions to Prevent or Attenuate Cognitive Decline in Adults with Mild Cognitive Impairment.
- Culturally Tailored Behavioral Interventions to Enhance Caregiving Skills and Self-Care in Minority Caregivers.
- Treatments of Psychosis and Agitation in Persons with AD.
- Assessing Predictive Power of MRI, Amyloid PET, Spinal Fluid, Blood Proteins, Neurocognitive and Daily Functioning in the Identification of AD.
- Effects of Traumatic Brain Injury and Post-Traumatic Stress Disorder on AD.
- Longitudinal Evaluation of Amyloid Risk and Neurodegeneration.
- Role of Type 2 Diabetes and Metformin Use in Cognitive Decline.
- Delirium Prevention Intervention for Community-Dwelling Older Adults with Dementia.

Alzheimer's Disease Research Centers

The 2013 DOEA Purple Ribbon Task Force Report recommended that ADAC support the scientific, teaching, and service objectives of Alzheimer's Disease Research Centers (ADRCs) in Florida. Researchers affiliated with ADRCs are leaders in dementia-related research, diagnosis, and education.

ADRCs serve as hubs of translational science that focus on preventing and treating AD. They play a pivotal role in fostering enrollment for industry-sponsored clinical trials and for ensuring advances in evidence-based care for AD are efficiently and rapidly disseminated to community-based medical practices.

For patients and families affected by dementia, ADRCs offer:

- Help with obtaining diagnosis and medical management.
- Information about the dementias, community services, and local resources.
- Opportunities for volunteers to participate in clinical trials and studies as well as patient registries.
- Support groups and other special programs for volunteers and their families.

The National Institute on Aging (NIA) funds 32 ADRCs located at medical institutions across the U.S. Florida currently has two NIA-funded ADRCs:

Mayo Clinic Jacksonville ADRC

The Mayo Clinic Alzheimer's Disease Research Center has two branches, one in Jacksonville, Florida and one in Rochester, Minnesota. The Mayo Clinic Jacksonville's early work focused on understanding and characterizing healthy brain aging, mild cognitive impairment (MCI), and the transition from MCI to AD. More recently, Mayo Clinic Jacksonville has centered its efforts on promoting individual and community awareness about AD within the African-American community. African-Americans are two times more likely to develop AD than non-Hispanic Whites. Outreach/discovery programs offered through the Mayo Clinic ADRC in Jacksonville seek to educate, empower, and enlist African-American community members in the fight against AD.

For additional information about Mayo Clinic Jacksonville ADRC's activities, contact:

Neill Graff-Radford, M.D., Medical Director

Memory Disorder Clinic
Mayo Clinic Jacksonville
4500 San Pablo Road
Jacksonville, FL 32224

mayo.edu/research/centers-programs/alzheimers-disease-research-center

1Florida Alzheimer's ADRC

The 1Florida Alzheimer's ADRC is a consortium of universities and health science centers,

including University of Florida, Mt. Sinai Medical Center, University of Miami, Florida International University, and Florida Atlantic University. The 1Florida ADRC conducts research on the effectiveness of new medications in slowing down, stopping, or preventing ADRC. The center also provides assessment of people who have memory disorders and problems with thinking functions.

For additional information about 1Florida Alzheimer's ADRC's activities, contact:

Todd E. Golde, M.D., Ph.D., Director

University of Florida
Center for Translational Research
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1275 Center Drive, BMS J-497
P.O. Box 100159
Gainesville, FL 32610-0159
1floridaadrc.org/index.html?pgid=index&lang=en

Important Gaps and Future Directions for Research

In reviewing dementia-related studies funded by the State of Florida over the past five years, ADAC has identified key research gaps that need to be addressed. The gaps identified are listed below. Subsequent discussion will determine a priority ranking.

1. Assessing the effectiveness of community-based models of care for persons with dementia, including those from underrepresented populations. For example, only a small number of studies have compared the effects of different models of adult day care on the health, emotional, and psychological functioning of older adults with ADRC. In addition, limited research has been conducted on the impact of community-based programs, such as culturally diverse education and awareness, and preventing and delaying long-term care placement.
2. Evaluating the effects of tailoring lifestyle interventions (e.g., exercise and diet) to the socio-cultural characteristics and delivery

preferences (e.g., telecommunication-based or in-person) on cognitive decline and health quality of life for adults with mild cognitive impairment. Only a limited number of dementia prevention studies have assessed the benefits of matching intervention to the socio-cultural characteristics of persons with MCI and their preferences for mode of treatment delivery and types of health providers.

3. Identifying and testing best methods for promoting the completion of advance directives across Florida. Despite the high proportion of older adults residing in Florida who have not completed advance directives, statewide intervention research to bolster this important element of advance care planning has received little attention.
4. Developing and evaluating the impact of a tiered program of intervention (i.e., providing information and support, care planning, brief problem-solving intervention to intensive skills training) for family caregivers of older adults with dementia across Florida. Only a modicum of studies have evaluated the impact of a tiered model of intervention to enhance the skills and self-care management of family caregivers of older adults with dementia.
5. Comparing the effects of different models in delivering services for assessment and treatment of cognitive decline (e.g., clinic-based versus community-based) on utilization, costs, and consumer appraisals of benefits. Limited research has been conducted for establishing best practices for delivering cognitive assessment and treatment services across the State of Florida, particularly programs that facilitate ease-of-access, optimal treatment benefits, generalizability of effects, and cost-effectiveness.



- 6.** Assessing the impact of culturally responsive, skills-building and support programs on the emotional functioning, health status, and self-identified caregiving and self-care problems of distressed minority caregivers of older adults with dementia. Most skills-training and support programs (e.g., cognitive-behavioral intervention) have not taken into account the specific preferences of minority caregivers for type of provider (e.g., trained faith community worker versus mental health professional), inclusion of spiritual beliefs and values, and method of delivery (e.g., home-based telehealth versus facility-based in-person training). These shortcomings have led to low uptake of currently offered skills-building and support services and substantial opportunity costs in terms of preventable emotional and physical health conditions (e.g., depression and cardiovascular disorders).
- 7.** Examining the impact of disseminating dementia awareness and prevention programs within the framework of minority faith communities (e.g., churches and mosques) using trained, same-culture facilitators on changes in lifestyle (e.g., exercise and diet) and in turn, cognitive functioning and health quality-of-life. Only limited research has been conducted on the impact of dementia awareness and prevention programs using trained faith community workers both in terms of expanding outreach to minority communities and improvement in lifestyle, cognitive functioning, and health quality-of-life.
- 8.** Establishing a Florida statewide ADRD registry to collect data on the number of people being diagnosed with specific types of dementia, improve the quality of care, determine funding areas, and allow Florida to take a proactive approach to link people to national studies, clinical trials, and trial matches.

Section 5: Clinical Services

ADRD diminishes a person's ability to manage their health care and drains the wellness out of their caregivers. Early diagnosis, treatment, and coordination of care for dementia, starting at the primary care point of entry, can mitigate the growing social and financial burdens on health care systems, Medicaid, Medicare, and caregivers.

The lack of management of ADRD is partly due to diagnosis late in the disease, denial on behalf of caregivers/patients, ageism, cultural barriers, stigmas associated with the disease, and a lack of knowledge on how to be diagnosed.

Families and professionals often face challenges in finding medical care and resources for people with dementia. Having a single-entry access point in Florida would help connect families and primary care providers to resources. Florida has invested in the diagnosis and treatment of ADRD with the establishment of MDCs throughout the state and we need to highlight the clinics and the services they offer.

Memory Disorder Clinics (MDCs)

The location of many of the 17 MDCs does not allow easy access for seniors who are unable to drive or travel long distances. Also, rural communities face additional barriers to services, including the finding and accessibility of providers with the appropriate expertise. The use of technology could bridge that gap by allowing health care providers, their patients, and even community leaders to consult with medical directors at Florida's designated MDCs.

The clinics, all of which receive funding from the State, also conduct service-related research and develop caregiver training materials and educational opportunities. The MDCs are required to:

- Provide services to persons who are suspected of being afflicted with ADRD. Services include accepting referrals from all respite and service providers and conducting subsequent diagnostic evaluations for all referred consumers and the public within the MDCs designated service area.
- Provide four hours of in-service training during the contract year to ADI respite service providers in the designated service area and develop and disseminate training models to service providers and the DOEA. A staff member of the MDC is to be designated to act as a training liaison for service providers.
- Develop training materials and educational opportunities for lay and professional caregivers who serve individuals with ADRD and provide specialized training for caregivers, caregiver groups, and organizations in the designated service area.
- Conduct service-related applied research that may address, but is not limited to, therapeutic interventions and support services for persons living with ADRD.
- Establish a minimum of one annual contact with each respite care and service provider to discuss, plan, develop, and conduct service-related research projects.

Many primary care practitioners are not prepared to screen and diagnose ADRD. Some of these issues may stem from a lack of understanding the impact of ADRD on patients and families, ageism attitudes, and not valuing the importance of AD and treatment options. The consequence is that larger numbers of individuals go without a proper diagnosis of ADRD at the earliest stage possible, which is when the patient is most likely to benefit from treatment.

Recommendations to Close Care Gaps:

There is a need to adopt a Comprehensive and Specialized Care, Life Course, Person and Family Centered Care, Holistic Approach while providing clinical care

and supportive services for persons living with ADRD and their family caregivers.

- Establish a subcommittee to research the clinical care needs and establish goals, objectives and strategies to improve access to care, screening tools, care planning, and brain health registry.
- Promote the use of CPT code 99483 for care planning within our MDC network.
- Establish standardized protocols for diagnosis of ADRD for primary care providers, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.
- Consider recommendations for a comprehensive aspect of care throughout the trajectory of the disease.
- Assess and make recommendations on the process of connecting people to services and treatment.
- Assess and address modifiable risk factors.
- Assess for the potential for primary prevention.
- Make recommendations to streamline the MDC quarterly data collection process.

Baker Act

The Florida Mental Health Act, also known as the “Baker Act,” went into effect on July 1, 1972. This law provides individuals with emergency mental health services and temporary detention, should their mental illness render them unable to make competent decisions about their care. The process can be either voluntary or involuntary; the latter is initiated by law enforcement officers, a qualified professional (i.e., medical doctor, psychologist, or advanced registered nurse practitioner), or via court, based on the review of provided testimonies. Once initiated, the individual is committed to a facility for up to 72 hours, during which the mental health professional provides an evaluation to ensure the individual will not harm himself/herself or others. Should the person require intervention,

the treating professional can petition the court to hold the patient beyond the 72 hours.

There are currently 134 Baker Act Receiving Facilities, which are designated by the Department of Children and Families and licensed by the Agency for Health Care Administration (55 of these facilities are licensed Crisis Stabilization Units (CSUs), which provide brief psychiatric care (average 3 to 14 days) primarily for low-income persons with acute psychiatric conditions). They lead to the patient’s return to his/her own residence, placement in a long-term mental health facility, or other living arrangements. Short Term Residential Treatment Facilities (SRTs) offer an alternative route for residents of CSUs who require additional but less intensive psychiatric treatment. SRTs were developed as an intermediate to CSUs and residential treatment facilities.⁶

Behavioral health settings such as CSUs and SRTs have demonstrated positive health outcomes for those in crisis, allowing individuals to receive services within their communities and promoting community-based resources for assistance. This system must be expanded to ensure that the psychiatric and psychological needs of older adults are being met and that care is sustained.

Recommendations to Close Care Gaps:

The MDC system has consistently provided psychiatric evaluations and treatments for those with psychiatric conditions, along with supportive structures to assist affected families. Further integration of the MDCs with the Baker Act Receiving Facility network and government entities may serve as an initial stepping point to resolve the presented issues, via the creation of a Baker Act subcommittee. This action will help to identify undiscovered gaps in services and plan for potential future scenarios.

- Create a subcommittee to access the root cause of statewide concerns related to Baker Act and recommendations for alternative care options for people living with ADRD.



- Establish training guidelines for law enforcement, hospitals, ERs, CSUs, and Baker Act receiving facilities to properly identify someone living with ADRD and best practice standards.
- Assess the current issues with underfunding of CSUs and SRTs (more and consistent funding must be allocated, as sources of income generally rely on grants and narrow insurance requirements, which often reduce applicability).
- Assess the need for additional qualified mental health personnel to provide services in CSUs and SRTs.
- Consider the lack of access to behavioral health services under the Baker Act to unserved and underserved elderly populations.
- Assess the current lack of varied community-based options integrating aspects of the CSU/SRT model of care. Make recommendations to better address mental health needs in multiple situations and prevent instances of institutionalized care through the Baker Act.
- Establish standards for communication in multidisciplinary/institutional teams

involved in an individual's care, which greatly impact the sustainability of outcomes, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.

- Establish procedures that address the needs of the family caregivers of admitted individuals, who often experience significant distress from the severity in seeing their loved ones Baker Acted and require psychotherapeutic services and guidance on resources to accommodate their loved ones upon return.

ADI Respite Care

The ADI respite program provides specialized services to meet the needs of caregivers and individuals with ADRD. Supporting caregivers is an essential part of AD. In Florida, there are approximately 1.1 million caregivers with over 1.3 billion hours of unpaid care to loved ones valued at \$16.4 billion.⁷ According to the AARP 2020 Caregiver Report, caregivers are facing longer and more complicated care situations. On average, caregivers spend 4.5 years caring for their loved ones and provide 23.7 hours per week providing care. One in five, or 21% of caregivers, provide 40+ hours each week, which is like having an additional job. In the report, 32% of the people reported they are providing care due to memory or dementia problems; this is up 6% from the 2015 report.⁸

Under ADI, caregivers of eligible consumers can receive training and other supportive services in addition to respite care. "Also offered is a unique program known as Extended Respite that allows for up to 30 consecutive days of respite care in which a loved one goes into a residential memory care community."⁹ A complete list of people living with AD per county is included. (See Appendix: Table 14). Also, a list of ADI funding per county and the number of clients served is included. (See Appendix: Table 15)

The ADI program provides the following services:

- Caregiver Training/Support

- Case Aide
- Case Management
- Counseling (Gerontological)
- Counseling (Mental Health/Screening)
- Education/Training
- Intake
- Specialized Adult Day Care Programs
- Respite (Facility-Based)
- Respite (In-Home)
- Respite (In-Facility, Specialized Alzheimer’s services)
- Specialized Medical Equipment, Services, and Supplies
- Transportation
- Shopping Assistance – COVID-19
- Telephone Reassurance – COVID-19

Though respite care is an invaluable resource for caregivers of persons with ADRD, there are gaps in the system that act as a barrier to those resources. Respite programming is one in a number of systems in place to counterbalance the depletion of resources when caring for a family member with dementia at home, and this study demonstrates that respite programming has the potential to help caregivers emotionally and physically reset through the transitions resulting from their family member’s dementia. This focus on respite programming for caregiver resilience is appropriate and timely, in light of current fiscal challenges and potential funding cuts at the state and national levels.”¹⁰

Recommendations to Close Care Gaps:

- Develop a plan to promote awareness and understanding of what respite is, and what the benefits of such services are.
- Assess the gaps in accessing services and allocating culturally and linguistically appropriate respite care, especially as “respite care” may be defined, understood, and appreciated differently by persons of different racial, ethnic, socioeconomic, and geographic backgrounds.

- Assess the barriers that prevent caregivers from accessing services. Consider the confusion about how to navigate a system and network of resources that is not caregiver friendly.
- Establish evidence-based guidelines for AD-specialized day care centers, including gaps in research in benefits of such programs, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.
- Determine the need or potential shortage of emergency respite services and an understanding of such services.

Adult Day Care Centers

Adult Day Care Centers (ADCCs) are non-residential facilities that offer social, therapeutic, health, and nutritional services in a supervised and professional group setting. ADCCs provide caregivers respite and peace of mind. According to the National Center for Health Statistics, 4,600 ADCCs are serving 486,000 participants throughout the United States. More than half of the older adults who attend an ADCC have a cognitive impairment. As reported by the Agency for Health Care Administration (AHCA), there are currently 351 licensed active ADCCs in the State of Florida (47.3% of the ADCCs in Florida are in Miami-Dade County). (See Appendix: Table 16) Most ADCCs are regulated and require licensing by state standards. In Florida, ADCCs are licensed by AHCA’s assisted living unit. AHCA monitors and inspects ADCCs biennially.

Types of Adult Day Care Centers

There are three main types of adult day care centers:

- Adult Social Day Services: provide socialization and meals to older adults.
- Adult Day Healthcare Center (ADHC): provide health and therapeutic services such as physical, occupational, and speech therapy as well as social activities for older adults.

- Specialized Services for Adults: provide social and health services specifically for individuals with developmental disabilities and dementia.

Services

ADCCs provide the following services in a supervised setting:

- Social activities
- Meals and snacks
- Respite care
- Exercise
- Counseling
- Personal Care
- Health Services
- Transportation (to and from the ADCC)
- Services for caregivers such as support groups
- Therapy (occupational, speech, and physical)
- Day trips

Specialized Adult Day Care Centers

In 2012, the Florida Legislature passed the "Specialized Alzheimer's Services Adult Day Care Act." An ADCC may not claim to be licensed or designated to provide specialized Alzheimer's services unless the ADCC's license has been designated as such pursuant to section 429.918, F.S. "Specialized Alzheimer's Services" means therapeutic, behavioral, health, safety, and security interventions, clinical care, support services, and educational services that are customized for the specialized needs of a participant's caregiver and the participant who is affected by AD or an irreversible, degenerative condition resulting in dementia. Florida has approximately 40 Specialized Alzheimer's ADCCs licensed with AHCA.

Gap in Research on Adult Day Care Centers

Although some articles and studies exist on ADCCs, many of the authors conclude there is a gap in research related to ADCCs and its benefits to participants. One author concluded

there is little information about the importance of ADCCs in assisting families with loved ones to age in place.¹¹ The author also noted a lack of research on the "inherent cost-effectiveness of adult day services in a nation of increasing and complicated health care costs."¹² In another literature review, which focused on the influence of ADCCs for individuals with dementia on family caregivers, it concluded that ADCCs reduce stress and burdens as well as help caregivers to feel secured. However, the authors determined that there is a need for researchers to focus on qualitative information and take a broader look at how day centers provide respite to family caregivers.¹³

Benefits of Adult Day Care Centers

There are several benefits of ADCCs. ADCCs provide a safe environment for day care center participants. ADCCs decrease isolation and offer the participants a sense of belonging. It is a growing sector within long-term care. The cost to attend a day center is quite less than a residential facility such as an Assisted Living Facility or nursing home. In addition to this, ADCCs provide respite and support to caregivers as well as add quality of life for the caregiver.

Facts on Adult Day Care Centers

- The average annual cost for adult day services is \$17,904 as opposed to "homemaker" home care at \$44,616 and a home health aide at \$45,760. Assisted living is \$43,200, with semiprivate nursing home care at \$80,300 and private nursing home care at \$91,250.¹⁴
- Approximately 35% of seniors who visit an ADCC live with an adult child, while 20% live with a spouse, 18% in an institutional setting, 13% with parents or other relatives, and 11% live alone.¹⁵
- Adult day services participants have increasingly higher levels of chronic conditions and disease, such as hypertension (46%), physical disability (42%), cardiovascular disease (34%), diabetes (31%), mental illness (25%), and developmental disability (20%).¹⁶

- 52% of ADCCs participants using adult day services centers nationwide have some cognitive impairment.¹⁷
- Over 80% of participants attend full days and 46% attend five days per week, enabling family caregivers to remain in the workforce.¹⁸

Recommendations to Close Care Gaps:

- Assess the need for additional centers that provide care to early memory loss or mild cognitive impairment programs.
- Assess the demand for extended weekday and weekend hours.
- Work with DCCI task forces to provide training to transportation drivers on dementia. We need more trained drivers to provide door-to-door service for day center participants.
- Assess the demand for additional ADCCs that provide specialized programming for persons with young-onset Alzheimer's or individuals who are under the age of 65 years old.
- Assess the barriers and need for ADCC's in rural communities and increased funding to provide increased care to low-income participants, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.
- Expand Florida ADRD training requirements for ADCCs to include four hours of training upon hire and another four hours within 90 days. Also include four hours of continuing education requirement.

Program of All-Inclusive Care for the Elderly (PACE)

The Program of All-Inclusive Care for the Elderly (PACE) model targets individuals who would otherwise qualify for Medicaid nursing home placement and provides a comprehensive array of home and community-based services at a cost less than nursing home care. Individuals who choose to enroll in PACE

have both their medical and long-term care needs managed through a single provider.

In addition to services covered under Medicaid, PACE includes all services covered by Medicare. PACE is unique in several respects. PACE providers receive both Medicare and Medicaid capitated payments and are responsible for providing the full continuum of medical and long-term care services. In addition, PACE organizations receive an enhanced capitation payment from Medicare beyond that of a traditional Medicare health maintenance organization. PACE also has a unique service delivery system, with many services being delivered through adult day care centers and case management provided by interdisciplinary teams.

PACE is administered by DOEA, in partnership with AHCA and the Federal Centers for Medicare & Medicaid Services (CMS). To be eligible for PACE, an individual must be age 55 or older, be eligible for Medicare or Medicaid with income and assets up to the Institutional Care Program (ICP) level, meet medical eligibility, and live in proximity to a PACE Center. (See Appendix: Table 17 and 18). There are five PACE providers covering parts of Florida that provided services to over 2,150 people during 2018-2019 fiscal year.

Recommendations to Close Care Gaps:

- Develop a plan to increase education and awareness on the availability of PACE.
- Assess current training and determine need for updated training standards for PACE staff consistent with other agencies providing care to people living with ADRD, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.
- Establish a subcommittee to assess the need to expand PACE services across the state.
- Identify the ability to incorporate PACE services into current senior centers and ALFs to share costs.

Section 6: Institutional Care

There are different types of Long-Term Care (LTC) Facilities in our state. Currently, there are 694 skilled nursing facilities with over 70,000 residents in them. Some are able to accommodate patients experiencing ADRD and others are not. The goal of care in a skilled nursing facility is to help individuals maintain their quality of life by meeting their daily physical, social, medical and psychological needs. AHCA has created and manages floridahealthfinder.gov; this site provides Floridians with access to healthcare information where consumers can easily locate and compare facilities, review recent inspection reports, and payer sources.¹⁹ According to the Alzheimer's Association, AD is the most expensive disease in the U.S. costing \$290 billion.²⁰ In Florida, Medicaid costs of caring for people with AD is \$2.6 billion with an expected increase of 28.4% by 2025.²¹

Before a patient can be admitted to a facility a nurse liaison is responsible for screening the patient, either in the hospital, their home, or an ALF. This screening process allows the facility to determine if these patients would be safe in their LTC environment.

The Comprehensive Assessment and Review for Long-Term Care Services (CARES) Program is Florida's federally mandated pre-admission screening program for nursing home applicants. A registered nurse or assessor performs face-to-face client assessments. A physician or registered nurse reviews each application to determine the medical level of care needed by the applicant. By identifying long-term care needs and establishing appropriate levels of care, the program makes it possible for individuals to remain safely in their homes using home and community-based services or in alternative community settings such as ALFs.

Federal law mandates that the CARES Program perform an assessment or review of each individual who requests Medicaid

reimbursement for nursing facility placement or home and community-based services. Any person or family member can initiate a CARES assessment by applying for the Medicaid Institutional Care Program (ICP). Assessments are completed at no cost to the clients.

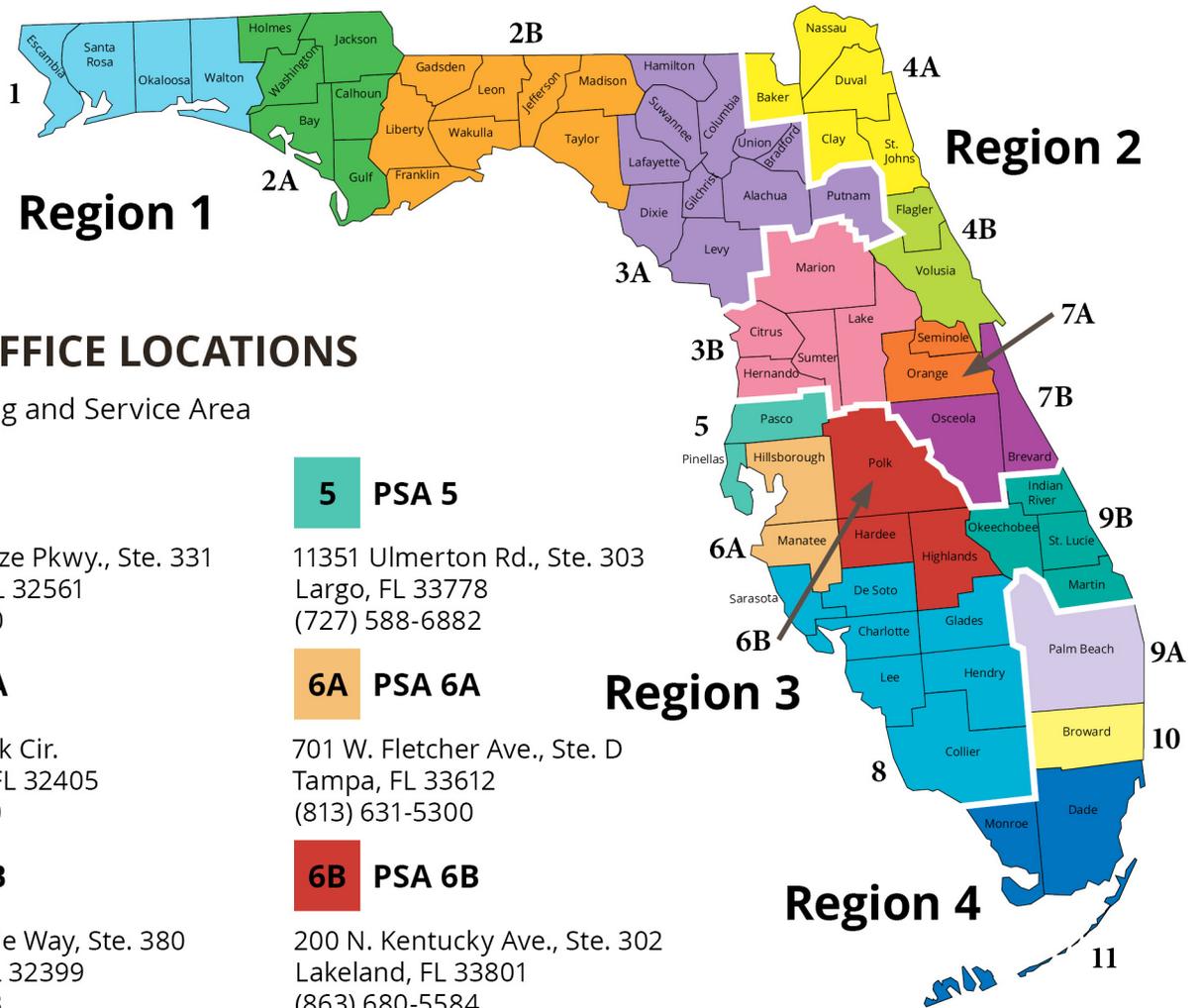
If a patient with ADRD is exit seeking, this will usually limit them to a facility that has the resources needed to keep the patient safe. Another consideration prior to a patient being admitted into a memory unit is the behaviors the person is exhibiting. There may be some behaviors that would prohibit the patient from integrating safely into certain Skilled Nursing Facilities (SNFs). Some patients with ADRD may be placed into an unlocked unit if they are not exit seeking or perhaps non-ambulatory.

Additional screening/assessment tools used during this initial assessment are the Brief Interview for Mental Status (BIMS), which scores a patient as being cognitively intact, moderately impaired, or severely impaired.

Another tool frequently used is the (Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS). The GDS is broken down into seven different stages. Stages one through three are the pre-dementia stages. Stages four through seven are the dementia stages. Beginning at stage five, a person can no longer survive without assistance. By observing an individual's behavior, caregivers can get a rough idea of where an individual is at in the disease process, based on the characteristics of each stage.

The Montreal Cognitive Assessment (MoCA) test is a ten to fifteen-minute test that includes memorizing a short list of words, identifying a picture of an animal, and copying a drawing of a shape or an object. The MoCA is a straightforward tool for diagnosing cognition of patients and gauging an appropriate follow-up and treatment plan.

Before a patient is accepted into an LTC facility, a payor source has to be determined. An individual will be transferred into an



CARES OFFICE LOCATIONS

PSA - Planning and Service Area

- 1**

PSA 1

1101 Gulf Breeze Pkwy., Ste. 331
Gulf Breeze, FL 32561
(850) 916-6700
- 2A**

PSA 2A

278 Forest Park Cir.
Panama City, FL 32405
(850) 747-5840
- 2B**

PSA 2B

4040 Esplanade Way, Ste. 380
Tallahassee, FL 32399
(850) 414-9803
- 3A**

PSA 3A

14101 US Hwy. 441, Ste. 400
Alachua, FL 32615
(386) 418-6430
- 3B**

PSA 3B

1515 E. Silver Springs Blvd., Ste. 203
Ocala, FL 34470
(352) 620-3457
- 4A**

PSA 4A

4161 Carmichael Ave., Ste. 101
Jacksonville, FL 32207
(904) 391-3920
- 4B**

PSA 4B

210 N. Palmetto Ave., Ste. 408
Daytona Beach, FL 32114
(386) 238-4946

- 5**

PSA 5

11351 Ulmerton Rd., Ste. 303
Largo, FL 33778
(727) 588-6882
- 6A**

PSA 6A

701 W. Fletcher Ave., Ste. D
Tampa, FL 33612
(813) 631-5300
- 6B**

PSA 6B

200 N. Kentucky Ave., Ste. 302
Lakeland, FL 33801
(863) 680-5584
- 7A**

PSA 7A

400 W. Robinson St., Ste. 709
Orlando, FL 32801
(407) 540-3865
- 7B**

PSA 7B

1970 Michigan Ave., Bldg. C-2
Cocoa, FL 32922
(321) 690-6445
- 8**

PSA 8

2295 Victoria Ave., Ste. 153
Fort Myers, FL 33901
(239) 338-2571
- 9A**

PSA 9A

4400 N. Congress Ave., Ste. 102
West Palm Beach, FL 33407
(561) 840-3150

- 9B**

PSA 9B

337 N. 4th St., Ste. E
Fort Pierce, FL 34950
(772) 460-3692
- 10**

PSA 10

8333 W. McNab Rd., Ste. 235
Tamarac, FL 33321
(954) 597-2240
- 11**

PSA 11

9495 Sunset Dr., Ste. B-100
Miami, FL 33173
(305) 270-6535

LTC facility under Medicare A, Private Pay, and Medical/Medicaid pending status.

The patient's physician writes an order for the patient to be admitted to an LTC facility (Form 3008) and at that time the screening is initiated.

Medicaid Managed Care Program

The Statewide Medicaid Managed Care Long-term Care Program (SMMC LTC) was authorized by the 2011 Florida Legislature, which created Part IV of Chapter 409, F.S., to establish the Florida Medicaid program as an integrated Statewide Managed Care Program for all covered services, including long-term care services.

Medicaid recipients who qualify and become enrolled in SMMC LTC receive long-term care services from a managed care plan. The program uses a managed care delivery system to provide long-term care services and acute care services, including case management and coordination, to individuals who are dually eligible for Medicare and Medicaid or to Medicaid-eligible adults with a disability. The State Medicaid program, through a monthly capitated rate, funds all home and community-based services and nursing home care. Clients are able to receive an array of acute and long-term services, such as home-delivered meals, coordination of health services, and intensive case management.

Recommendations to Close Care Gaps:

- Access current training for Medicare Managed Care Program staff and set standardized training requirements.
- Access the current process for placement into LTC from home, access current wait time, and possible recommendations for improvement.
- Create a systemized, streamlined process for more individuals with ADRD to integrate into appropriate LTC facilities with less wait time for them and their families.

State Policy Requirements for ADRD Training

In accordance with statutes governing ALFs licensed under 429.178 F.S.; Nursing Facilities licensed under 400.1755 F.S.; Hospices licensed under 400.6045 F.S.; ADCCs licensed under 429.917 F.S.; Home Health Agencies licensed under 400.4785 F.S.; and Specialized Alzheimer's ADCCs licensed under 429.918 F.S., the approval of ADRD-specific training is the responsibility of DOEA. The ADRD Training Approval Program provides for review and approval of training providers and training curricula for health service providers that provide dementia-specific care. DOEA contracts with University of South Florida's Training Academy on Aging within the Florida Policy Exchange Center on Aging to administer the program and to ensure that qualified clinical professionals review and approve the training providers and curricula. Please visit trainingonaging.usf.edu/products/atc to view the current list of approved trainers and approved curricula.

The requirements are as follows:

ALF employees who have regular contact with residents who have ADRD must complete up to four hours of initial AD training approved by DOEA within three months of employment. Any ALF employee who provides direct care to residents who have ADRD must complete four additional hours of approved training. The additional four-hour training for a direct caregiver employee must be completed within nine months of employment. ALF employees who provide direct care are required to complete four hours of continuing education annually.

Nursing facility, hospice, and adult day care center employees who have direct contact with residents who have ADRD must complete one hour of AD approved training within the first three months of employment. Any employee who provides direct care must complete an additional three hours of approved training within nine months of employment.

The SMMC program has five types of plans:

MANAGED MEDICAL ASSISTANCE (MMA)

- Coverage: Preventive, Acute, Behavioral, Therapeutics, Pharmacy, Transportation Services
- Enrollment: Most Medicaid Recipients must enroll in an MMA plan.
- This plan cannot provide services to recipients who are eligible for LTC services.

LONG-TERM CARE (LTC)

- Coverage: Nursing Facility, Assisted Living and Home-based Services
- Enrollment: 65 Years of age and older or age 18 or older and eligible for Medicaid by reason of a disability. Require Nursing Facility level of care or Hospital level of care, for individuals diagnosed with Cystic Fibrosis.
- Provides MMA services and LTC services to recipients enrolled in the LTC program. Cannot provide services to recipients who are only eligible for MMA services.

DENTAL

- Coverage: Preventive and Therapeutic dental services
- Enrollment: All Medicaid recipients in managed care and all and fully Medicaid eligible fee-for-service individuals.

COMPREHENSIVE

- Coverage: Provides MMA services and LTC services to eligible recipients.

SPECIALTY

- Coverage: Provides MMA services to eligible recipients who are defined as a specialty population.

Home health agencies must have employees who provide direct care to patients with ADRD complete two hours of AD approved training within nine months of beginning employment.

Specialized Alzheimer's ADCC employees must receive and review basic written information about interacting with ADRD participants. Employees who have direct contact with residents who have ADRD must complete four hours of training within three months of employment. Any employee who provides direct care must complete an additional four hours of training within six months of employment.

This training must include an overview of dementia and some basic skills for communicating with persons with dementia. An individual providing direct care must complete training that includes managing problem behaviors, promoting the resident's independence in activities of daily living, and skills in working with families and caregivers.

Many ADRD educators utilize the Hand-in-Hand tool kit, a training that focuses on caring for residents with dementia and on preventing abuse. Centers for Medicare and Medicaid Services created this training to address the need for nurse aides' in-service training on these important topics.

When speaking with training educators at LTC facilities, the consensus is there needs to be additional training in more ways to connect with the ADRD patient. One suggestion was to have an in-house 'mentor' for a new employee to work closely with during the first few shifts at the facility to watch how that employee interacts with the patient with ADRD. That employee can also be a person to go to with questions the new employee may have regarding appropriate ways to connect with the patients assigned to him/her throughout the first 90 days of employment.

Recommendations to Close Care Gaps:

- Expand continuing education requirement for ADRD Training in all licensed facilities to include four hours of training upon hire and another four hours within 90 days. Also include four hours of annual continuing education requirement.
- Establish standardized templates for each four-hour training to be specific to the type of licensed facility the providers are working in. Standardized templates would ensure consistency in the training message across the state. Additionally, this would eliminate numerous amounts of hours that are currently being put into reviewing every curriculum in the state of Florida.
- Establish mentor training programs within facilities to train new staff on procedures and best practices.
- Promote awareness of person-centered care model.

Long-Term Care Ombudsman Program

An LTC ombudsman is a trained volunteer who helps to improve the quality of care/life of residents of LTC facilities. These volunteers are passionate about improving the life of residents in LTC.

Volunteer ombudsmen work to identify, investigate, and resolve the concerns of residents and their loved ones. They work with residents and their family members to communicate concerns and resolve problems by providing support, education, advocacy, and empowerment. They advocate for residents' rights and respond to residents' concerns.

Ombudsmen perform annual assessments of every facility in Florida. They also investigate complaints on behalf of the LTC residents and their families and ensure that facilities meet mandated legal standards for any person receiving long term care services. Common issues in nursing homes include discharges and evictions, medication administration,



and matters of personal hygiene. All services provided by Ombudsmen are provided at no cost, and all complaints are confidential.

Recommendations to Close Care Gaps:

- Assess current training and determine need for updated training standards for LTC ombudsman volunteers consistent with other agencies providing care to people living with ADRD, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.

Office of Public and Professional Guardians (OPPG)

In the state of Florida, local public guardians are appointed by OPPG to provide guardianship services to persons who do not have adequate income or assets to afford a private guardian and there is no willing family or friend to serve as guardian.

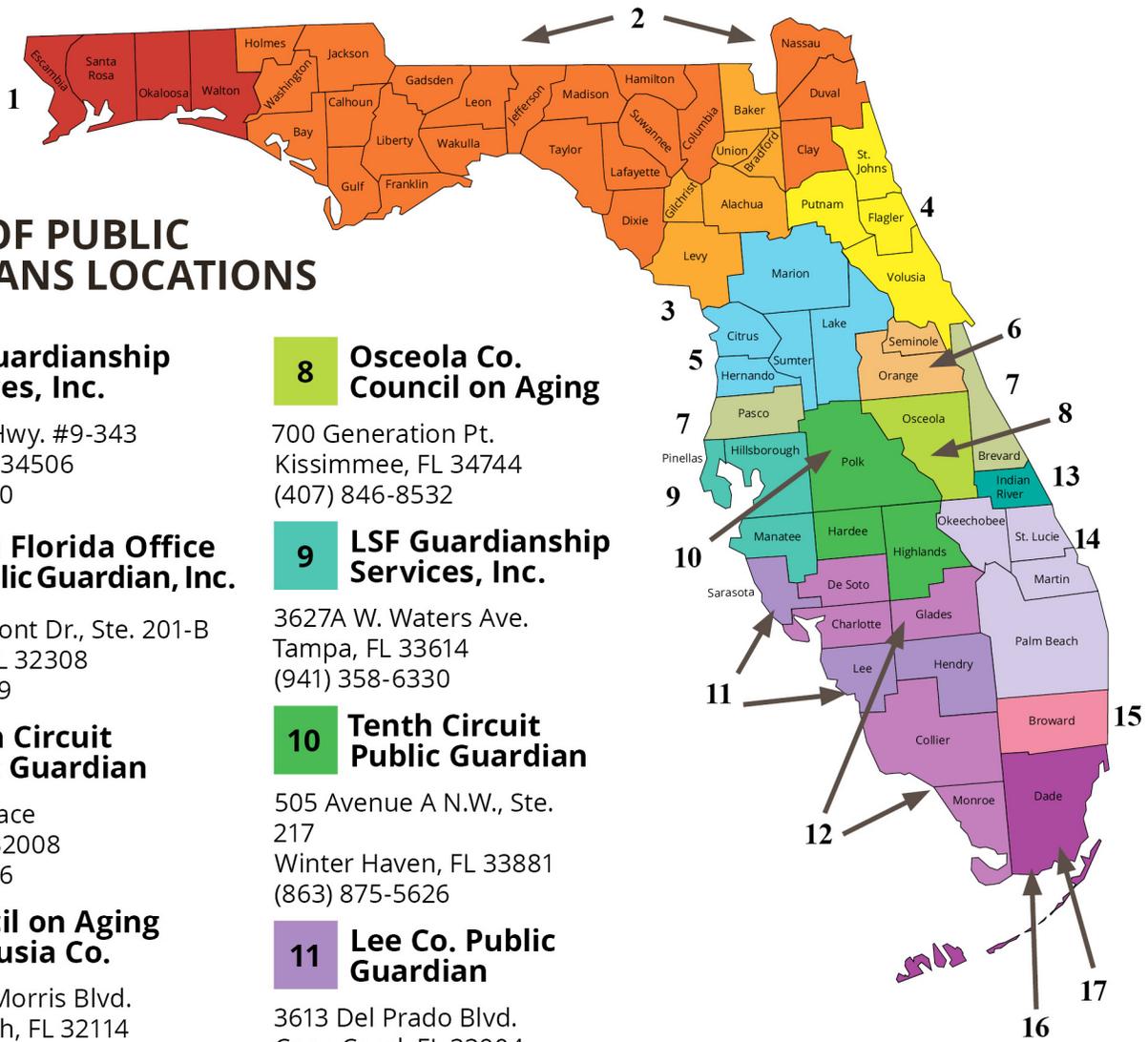
OPPG provides direction, coordination, and oversight of public and professional guardianship services in the state, develops performance measures, collects data on individuals served, and works to find ways to enhance funding to increase the availability of public guardians to serve individuals in need.

OPPG develops the curriculum and training of public and professional guardians, creates and administers the professional guardian competency exam, and registers professional guardians as mandated by Florida Statutes.

OPPG is also responsible for establishing standards of practice for public and professional guardians, receiving and investigating complaints against public and professional guardians, and taking disciplinary action pursuant to Chapter 120, F.S., when warranted. OPPG may impose penalties, up to and including the permanent revocation of a professional guardian's registration, for a violation of any administrative rule adopted by the office governing guardians or guardianship or for the violation of any offense enumerated in section 744.20041(1), F.S.

Recommendations to Close Care Gaps:

- Assess current training and determine need for updated training standards for public guardians consistent with other agencies providing care to people living with ADRD, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.



OFFICE OF PUBLIC GUARDIANS LOCATIONS

1 LSF Guardianship Services, Inc.

4600 Mobile Hwy. #9-343
Pensacola, FL 34506
(850) 469-4600

2 North Florida Office of Public Guardian, Inc.

1425 E. Piedmont Dr., Ste. 201-B
Tallahassee, FL 32308
(850) 487-4609

3 Eighth Circuit Public Guardian

27052 83rd Place
Branford, FL 32008
(386) 438-8236

4 Council on Aging of Volusia Co.

425 N. Clyde Morris Blvd.
Daytona Beach, FL 32114
(386) 253-4700

5 Fifth Circuit Public Guardian Corporation

110 N.W. 1st Ave., 4th Floor
Ocala, FL 34475
(352) 401-6753

6 Seniors First, Inc.

5395 L.B. McLeod Rd.
Orlando, FL 32811
(407) 297-9980

7 Aging Solutions

19001 Sunlake Blvd.
Lutz, FL 33558
Brevard: (866) 92-AGING
Hillsborough: (813) 949-1888
Pasco and Pinellas:
(727) 442-1188

8 Osceola Co. Council on Aging

700 Generation Pt.
Kissimmee, FL 34744
(407) 846-8532

9 LSF Guardianship Services, Inc.

3627A W. Waters Ave.
Tampa, FL 33614
(941) 358-6330

10 Tenth Circuit Public Guardian

505 Avenue A N.W., Ste. 217
Winter Haven, FL 33881
(863) 875-5626

11 Lee Co. Public Guardian

3613 Del Prado Blvd.
Cape Coral, FL 33904
(239) 549-2505

12 Charlotte & Collier Co. Public Guardians

4680 Cardinal Way, Ste. 203
Naples, FL 34112
(239) 417-1040 Ext. 203

13 Public Guardianship Program of Indian River, Inc.

2101 Indian River Blvd., Ste. 200
Vero Beach, FL 32960
(772) 538-7101

14 Legal Aid Society of Palm Beach Co., Inc.

423 Fern St., Ste. 200
West Palm Beach, FL 33401
(561) 655-8944

15 Barry University School of Social Work

12401 Orange Dr., Ste. 214
Davie, FL 33330
(954) 862-3655

16 Guardianship Care Group, Inc.

337 Alcazar Ave., Unit 101
Coral Gables, FL 33134
(305) 748-6111

17 Guardianship Program of Dade Co., Inc.

8300 N.W. 53rd St., Ste. 402
Miami, FL 33166
(305) 482-3101

Section 7: Home and Community Based Services (HCBS) and Community Partnerships

Client Assessment

DOEA contracts with Area Agencies on Aging (AAAs) to provide services to older Americans residing in the state of Florida. In order to make sure that clients are enrolled in a program that best serves their needs, there is an assessment process that evaluates their current needs and their physical and mental state. The assessment process starts when individuals call the elder helpline.

When individuals call the elder helpline a Medicaid benefit specialist or intake staff will conduct a screen over the telephone. All the information gathered on a screening form is uploaded in the Client Information and Registration Tracking System (CIRTS) and the client is placed on the Assessed Priority Consumer List (APCL).

Lead agencies contact the AAAs when there is an opening in their service area. AAAs log into CIRTS to access the APCL and provide the lead agency with a list of prioritized clients. The lead agency will then contact the client to conduct an assessment which is used to determine the client's eligibility and what services the client needs.

All the information is uploaded in CIRTS and once determined eligible, clients begin receiving services. All clients are re-screened annually, and that information is updated in CIRTS. If a client is on the waiting list and their status changes, they can call the AAAs and request a new screening. These screenings are used to decide which

program will best suit the needs of the client; the client can also request services. The client has the option to accept or reject these services.

Home and Community Based Services (HCBS)

Home and Community Based Services (HCBS) are provided by the state of Florida through the AAAs. The 11 Planning and Service Areas (PSAs) each have an AAA which also operates as an Aging and Disability Resource Center (ADRC). Each AAA contracts with one or more Community Care for the Elderly (CCE) lead agencies that provide and coordinate services for elders throughout the state.

Each AAA/ADRC assists clients to access publicly and non-publicly funded services. These HCBS are accessible through local Direct Service Providers, including senior centers, lead agencies, health care providers, and other community agencies.

Services offered through HCBS include the following:

- Abuse Education
- Adult Care Food Program
- Adult Day Care
- Alzheimer's Disease Initiative (ADI)
- Caregiver Training and Support
- Case Management
- Community Care for the Elderly (CCE)
- Companionship
- Comprehensive Assessment & Review for Long-Term Care Services (CARES)
- Congregate Dining Sites or Congregate Meal Sites
- Disease information
- Elder Farmers Market Nutrition Program
- Emergency Alert Response systems
- Emergency Home Energy Assistance for the Elderly Program (EHEAP)
- Gerontological Counseling

- Health and Wellness
- Home Care for the Elderly
- Home Delivered Meals
- Homemaker Services
- Information, Referral, and Assistance provided by the Elder Helpline
- Legal Service
- Medicaid Long-Term Care Services
- Memory Disorder Clinics (MDCs)
- National Family Caregiver Support Program
- Nutrition Education
- Older Americans Act (OAA)
- Personal Care
- Program of All-Inclusive Care for the Elderly (PACE)
- Respite Care
- Respite for Elders Living in Everyday Families (RELIEF)
- Senior Companion Program (SCP)
- Serving Health Insurance Needs of Elders (SHINE)
- Statewide Medicaid Managed Care Long-Term Care Program (SMMC LTC)
- Supplemental Nutrition Assistance Program
- Transportation
- Utility Discounts and Assistance

For a list of DOEA programs and services, see Appendix 19.

Recommendations to Close Care Gaps:

- Analyze of current wait list status and develop a plan to triage concerns.
- Collaborate with Livable Florida and evaluate need for low-income housing for seniors.
- Collaborate with Livable Florida and evaluate transportation options in each county to assist with medical appointments and access to services for daily living needs.

Assisted Living Facilities (ALF)

ALFs are designed to provide personal care services in the least restrictive home-like environment. According to the Agency for Health Care Administration, there are 3,101 ALFs in Florida with 99,042 beds.²² ALFs range in size from one resident to several hundred and may offer routine personal care services under a standard license. ALFs meeting the requirements for a standard license may also qualify for specialty licenses. The purpose of specialty licenses is to allow individuals to “age in place” in familiar surroundings that can adequately and safely meet their continuing health care needs. Specialty licenses include limited nursing services (LNS), extended congregate care (ECC), and limited mental health (LMH) services. To obtain a specialty license, facilities must meet additional requirements, including those related to staffing and staff training.

While there is no specialty license for ALFs that care for residents with ADRD, a facility that claims it provides special care for persons with ADRD must disclose those services in its advertisements or in a separate document. There are also statutory standards for training, staff, activities, and the physical environment. The statute also provides direction for individuals conducting Alzheimer’s training. Examples of the special care standards include; if a facility has 17 or more residents, the facility must have awake staff at all times; if a facility has fewer than 17 residents, the facility must have awake staff on duty at all hours or have mechanisms in place to monitor and ensure the safety of the facility’s residents; offering activities specifically designed for persons who are cognitively impaired; having a physical environment that provides for the safety and welfare of the resident (§429.178, F.S.).

With the growing numbers of individuals who are living with ADRD, there are a number of ALFs that do have memory care units and some that designate the entire facility as memory care. As more and more families are choosing ALFs as an alternative to long-term care facilities and with the rising numbers of people living

with ADRD it makes sense to establish a fourth specialty license for memory care in Florida. This would ensure ADRD residents are receiving the highest quality of care to meet their needs.

While ALFs generally cost less than nursing facilities, the cost of an ALF varies greatly depending on the location, residential unit size, amenities, and services provided by the facility. In Florida, the average cost of an ALF in 2019 was \$3,092, ranking fourth in the United States as the least expensive ALF care. Although the majority of residents living in ALFs pay privately, there are programs designed to assist with assisted living for those who qualify. Medicaid Managed care providers may want to consider exploring ALFs as an option for LTC. Residents who do not require 24-hour supervision would have the option of living in a less restrictive environment at a lower cost.

Recommendations to Close Care Gaps:

- Determine the need for a specific Memory Care License in ALFs.
- Expand Florida ADRD training requirements for ALF, to include four hours of training upon hire and another four hours within 90 days. Also, include four hours of continuing education requirement.

Adult Family Care Home (AFCH)

An AFCH is a licensed, full-time, family-type living arrangement in a private home, under which individuals who own or rent a home provide room, board, and personal care on a 24-hour basis to no more than five disabled adults or frail elders who are not relatives. Each AFCH must designate at least one licensed space for a resident receiving an Optional State Supplement (OSS). OSS provides financial assistance to low-income seniors who cannot live independently and require residential care; it is administered by DCF. AFCH operators must live in the home; if they do not, the home must be licensed as an ALF. If an AFCH provides room, board, and personal services

for only one to two adults who do not receive an OSS, it does not have to be licensed.

To reside in an AFCH, a person must meet the AFCH "residency criteria," which is defined by Florida regulations and by the provider's admission policy. In most cases, AFCHs provide general supervision, assistance with personal care services, and assistance with medications to elders and disabled adults who require such services.

AFCHs are intended to be a less costly alternative to more restrictive, institutional settings for individuals who do not need 24-hour nursing supervision. While AFCHs generally cost less than other residential care facilities, the cost of an AFCH can vary based on the location, residential unit size, amenities, and services provided by the AFCH. Although many residents living in AFCHs pay privately, there are programs designed to assist with AFCH residency for persons who qualify. Florida currently has 317 licensed AFCHs.²³

Recommendations to Close Care Gaps:

- Determine the need for additional Adult Family Care Homes and assess the average cost.
- Assess current training and determine need for updated training standards for AFCH's staff and owners consistent with other agencies providing care to people living with ADRD, including culturally and linguistically appropriate services standards to advance health equity at every point of contact.

Hospice

Hospice is a coordinated program of palliative and supportive care for those with a limited life expectancy. It can be provided in a nursing facility, assisted living facility, personal care home, the individual's home, or at a hospice facility.

All hospices in the State of Florida must be licensed with AHCA and there are currently 49 licensed hospice care providers.²⁴ Some

hospices choose to seek accreditation which is a voluntary process that requires a hospice organization to undergo an extensive on-site evaluation that covers several areas of patient care and patient safety. Accreditation is one tool for measuring the quality of an organization. Hospice care is provided through a team approach. Team members may include a registered nurse, certified nurse aide, social worker, chaplain, and a bereavement specialist.

There are four levels of hospice care defined by law and paid for by Medicare, Medicaid, and most other insurance plans. Hospice care is available regardless of the patient's geographical location and keeps patients in the setting that best meets their needs, wherever they may reside. Typically, a physician will determine what level of care is needed using standardized criteria. Not every hospice provides 24-hour care.

- **Routine Care:** The patient receives hospice services at home or in a home-like setting, such as a nursing home, assisted living facility or a hospice residential facility. The family provides the primary care to the patient with the assistance of the hospice team.
- **Continuous Care:** Skilled nursing services that are provided in the patient's place of residence to help during a crisis period.
- **Inpatient Care:** This care is provided in a facility (hospital, nursing facility, or hospice freestanding inpatient facility) for symptoms or a crisis that cannot be managed in the patient's residence. Inpatient care is provided for a limited period of time, as determined by the physician and the hospice team.
- **Respite Care:** This service is provided in a facility (hospital, nursing facility, or hospice freestanding inpatient facility) and is designed to give caregivers a rest. Respite care is up to five days and nights at a time. This service is often used to provide a break so that caregivers can participate in other family activities, or just to relieve a tired caregiver for a few days.

Recommendations to Close Care Gaps:

- Expand Florida ADRD training requirements for hospice to include four hours of training upon hire and another four hours within 90 days. Also, include four hours of continuing education requirement.

Home Care

Home care encompasses a wide range of health and social services, and there are approximately 1,767 licensed home health care agencies in Florida.²⁵ These services are delivered at home to recovering, disabled, chronically, or terminally ill persons in need of medical, nursing, social, or therapeutic treatment and/or assistance with the essential activities of daily living. Generally, home care is appropriate whenever a person prefers to stay at home but needs ongoing care that cannot easily or effectively be provided solely by family and friends.

Home care is cost-effective. Numerous studies have shown that home care is generally the most cost-effective care option. Used prior to, in place of, or after hospitalization, home care can reduce the length of stay and save money over the course of an illness. Home care keeps people independent. With assistance, persons of all ages can continue to function as viable members of the community. Home care keeps families together. The joy of being with loved ones is particularly important in times of illness, and keeping families together has a positive social and economic impact on our communities. Home care is patient centered — it empowers individuals and their families to assume greater responsibility for their own health, and to assist them to make informed health care decisions.

The following types of home care are:

- **Homemaker or Companion Agencies** provide non-medical services to individuals in their homes or other independent living environments. Home care may include assistance with self-administered

medications; personal care assistance such as bathing, feeding and hygiene; assistance with housekeeping, shopping, meal planning and preparation, and transportation; and respite care including support for the family.

- **Home Health Care Agencies** provide health care services to ill, disabled or vulnerable individuals in their homes or places of residence, enabling them to live as independently as possible. Home health care services include nursing care, home health aide care, and physical therapy, occupational therapy and speech therapy services.

Recommendations to Close Care Gaps:

- Expand Florida ADRD training requirements for home health to include four hours of training upon hire and another four hours within 90 days. Also, include four hours of continuing education requirement.

Dementia Care and Cure Initiative (DCCI)

DCCI was established in 2015 to bring awareness to, education on, and sensitivity regarding the needs of those living with dementia in communities. Task forces create partnerships among community agencies, caregivers, people living with dementia, dementia advocates, and businesses to work together on strategies to make communities dementia caring. There are currently 14 DCCI task forces throughout the state that are working on breaking down barriers, reducing the stigma associated with dementia, and creating communities where people living with dementia feel comfortable to live in their communities and can live with dignity, independence, and respect. Some of the accomplishments of the DCCI task forces include:

- The Big Bend Task Force was the first task force established in the state and they were the first to provide dementia education to local restaurant staff. They worked with the Geriatric Workforce Engagement Program (GWEP) at FSU to establish a training video for local law enforcement.



- The Fort Myers Task Force successfully held a “Dementia Safety Event,” wherein they partnered with the United Way of Lee County, the Lee County Sheriff’s Office, and Scent Evidence K9 to provide information, safety tips, and local resources to caregivers and individuals living with dementia.
- The Jacksonville Task Force received a \$10,000 grant to help fund a Memory Café in an underserved neighborhood in Duval County – New Town. In addition to co-hosting and participating in educational events, this Task Force brought the Purple Angel Initiative to a local hospital and is hoping to get it into others in the area. The Purple Angel Initiative places purple hearts on charts of those individuals with a diagnosis of dementia.
- Martin County HUGS’ has been successful in offering a standing training for the community every month, as well as training managers at several area Publix supermarket stores.

Recommendations to Close Care Gaps:

- Increase the number of task forces throughout Florida.
- DOEA to create a toolkit for volunteers who participate in task forces to facilitate the work they do in their local communities.
- Establish the need for task forces to establish action plans with goals for sustainability.

BRAIN BUS

alzheimer's association®



Brain Bus

The Brain Bus, which is operated by the Alzheimer's Association and receive general revenue funding, is a mobile outreach initiative which provides information on healthy brain programs such as the 10 warning signs, benefits of early detection, early diagnosis, brain health, risk reduction, how to receive an accurate diagnosis, and latest advancements in Alzheimer's research.

The Brain Bus targets women, underserved, isolated and/or rural families dealing with, or at risk for, AD or a memory-related disorder. The services of the Brain Bus are open to all individuals who need services, and always free of charge. The Brain Bus makes over 300 stops and provides information and services to over 2,000 people each year.

Section 8: Subcommittee Work/Survey Outcomes

In July 2019, a subcommittee was formed to undertake the task of identifying the gaps that exist in accessing services by people living with dementia. Multiple meetings were held to design surveys. Two sets of surveys were drafted; one focused on the caregivers (short version for community events and long version distributed online) and the other focused on the agencies that provide services to those living with dementia and their caregivers. A copy of the caregiver surveys is included (see Appendix: Table 20 and Table 21), and a copy of the agency surveys is included (see Appendix: Table 22).

Agency survey focused on the following:

- Assisted Living Facilities
- Hospitals (results not included in the analysis – very low response rate due to COVID-19)
- Nursing Homes
- Home Health Care
- Crisis Stabilization Units (results not included in the analysis – very low response rate due to COVID-19)
- Hospice
- Adult Family Care Homes
- Adult Day Care Centers

Dissemination

Surveys were uploaded on Survey Monkey and participants could access them using a link provided through email or printed on the paper copy of the survey. Due to COVID-19, we were not able to reach our targeted number of 1,500 responses but still managed to gather over 1,338 responses. They were disseminated from January 2020 to May 2020 through the following:

- DOEA's website
- Agency for Persons with Disabilities
- Florida Assisted Living Association
- Florida Senior Living Association
- Florida Agency for Health Care Administration
- Florida Hospice & Palliative Care Association
- Area Agencies on Aging
- Memory Disorder Clinics
- ADAC Committee Members
- Community events/conferences:
 - » Open Forum with the Alzheimer's Association; Creating Dementia Capable Communities; Longwood Community Building
 - » DCCI/Capital Coalition Community Meeting/Listening Session; Tallahassee Senior Center
 - » African-American Alzheimer's Caregiver Training Workshop; Glenwood Community Center (Panama City)
 - » Mt. Sinai MCI Symposium; Mt. Sinai Medical Center (Miami)
 - » Jewish Family and Children's Services Group Meeting (Sarasota)
 - » Caregiver College (Sarasota)
 - » Alzheimer's Project 35th Annual Education Conference; FSU College of Medicine (Tallahassee)
 - » The Aging Brain (Melbourne)
 - » Think About it - Dementia Care Conference (Sarasota)
 - » More events were planned throughout the state but had to be canceled due to COVID-19

Summary of Caregivers Survey

Over 681 caregiver surveys were received from throughout Florida. The purpose was to determine how caregivers viewed the support system in their care of a family member with AD. This is a random survey from various areas of the state, and it does not provide a

specific picture of any region. The results are to be taken as an overview of the total state

Analysis

The major returns were from the urban, white, non-Hispanic population. If ADAC, with DOEA, were to develop public health policies regarding AD in Florida, there needs to be a strong concerted effort to use the same survey and target it to the rural population in Florida and the specific non-white and Hispanic populations.

The age distribution of those with AD who participated in the survey was 40% under the age of 60 and 60% over the age of 60. This indicates there is a much higher younger early onset of AD than recognized but this could also be an anomaly. If this is not an anomaly, then there is a need for a paradigm shift to educate health care practitioners making a diagnosis to become aware of early onset AD. Many in the health care profession have been looking at late onset (over 60) and may overlook the younger onset of AD and misdiagnosed the behaviors as mental health issue.

Survey results indicate that the highest number of AD diagnosis was done by primary care physicians followed by neurologists. This indicates towards low utilization of geriatricians and MDCs for the diagnosis. The low utilization of both geriatricians and MDCs may be due to the lack of referral from diagnosing practitioners. This needs to be examined further to determine if there is a problem with referrals.

Over 55% of the caregivers indicated it took them more than three weeks to get an appointment for diagnosis. This issue has been raised repeatedly.

There is an increase in complications while waiting for assessment which correlates with the wait time. A reduction in wait times for appointments can reduce complications and possible hospitalization.

Survey results indicate that caregivers are pleased with the assessment process. However,

20% of the respondents were not satisfied and stated that health care practitioners lacked proper training in assessing for dementia. More than 70% of responders indicated they were not referred by healthcare practitioners to community services or followed-up if services were received. This could be attributed to the communication gap between the health care practitioners and ADRCs.

Respondents stated that the most sought out services/needs of the targeted population are respite and home care services. This request has been consistent in every survey completed in recent years and there is a critical need to expand these services (65% of respondents indicated difficulty in accessing the required services). This could be due to the lack of knowledge about the HCBS offered by the ADRC.

A handful of people living with AD are involved in clinical trials or research focusing on AD. There is a critical need to conduct research on causes and intervention concerning AD, but equally important are the policy questions affecting quality of care for individuals with dementia and their caregivers. Policy questions need to be asked and research should be conducted around those questions.

Hospitals play a key role in transitioning patients who are admitted with acute or chronic health disabilities to being discharged back into the community as healthy individuals. Hospitals have traditionally focused on medical/physical conditions for admission (25% falls, 20% for pneumonia or infectious disease, and 20% for behavior which may be mistaken for mental health and not due to AD) and not with a non-medical condition such as AD. Survey results point towards a serious concern – hospitals are not prepared to address the issues of AD and their caregivers. In some instances, based on the survey, the individuals left the hospital sicker and with few HCBS services, resulting in an early return to the hospital with either the same or more complex problems.

Only 43% of respondents indicated that their loved one was admitted to the hospital and that they were satisfied with the staff services, 46% felt that the staff were not prepared to care for a person with AD. In addition, 60% identified lack of training of staff concerning AD. Another area of concern was with discharge. Only 36% of those responding were satisfied with discharge planning including HCBS and follow-up. Another concern was only 50% of the caregivers interacted with a case manager, navigator or a hospitalist.

Only 46% of respondents indicated that their loved one was admitted to an ER; however, the results were mixed – 55% felt the staff were knowledgeable and 75% felt their needs were met. It is still unclear if the 55% meant that the staff was knowledgeable about the condition in which they were admitted or with dementia.

With the increase in AD in Florida, there will be a concomitant increase in the need for ALFs to include Memory Care Units (MCU). It is imperative that the staff at ALFs are trained in dementia behavior, especially in MCU. Only 25% of respondents indicated their loved one entered an ALF, of those respondents 62% were in MCUs. And, 62% of caregiver's responding felt that the staff were fully trained and 45% did not feel there were appropriate services available for the individuals with AD.

Only 16% of respondents had a family member admitted to a SNF. Only 33% felt the staff of the SNF were effective in working with individuals with dementia and only 13% of those felt there were effective programs for individuals with AD. Only 38% of the SNFs identified and labeled the chart at intake if the patient was diagnosed with dementia. Only 10% of the SNF made referrals to the MDCs for assessment.

Recommendations to Close Care Gaps:

- Shorten long wait times for appointments.
- Proper training for medical professionals to diagnose AD.
- Increase referrals to Geriatricians and MDCs.

- Increase referrals to community services.
- Address communication gap between healthcare professionals and ADRCs.
- Increase funding for respite and home care services.
- Difficulty in accessing HCBS.
- Increase awareness of HCBS and how to access them.
- Policy development to take AD research in consideration when drafting statewide policies.
- Equip hospitals and their staff to respond appropriately to people living with AD.
- Increase training for ALF staff to care for people with AD and provide appropriate services for their AD clients.
- Increase training for SNF staff lack to care for people with AD and provide appropriate services for their AD clients.
- Standardize protocols for facilities taking care of people living with AD.

Summary of Agency Surveys

Agency surveys shed light on potential gaps in the Alzheimer's support system with possible recommendations. They highlighted the barriers in increasing the quality of care and an effective use of funds in developing a seamless approach linking the resources for the potential prevention, identification and treatment of AD in individuals and families.

Down Syndrome Network

It has been brought to light that there is a lack of information on how to manage adults with Down syndrome who are at risk for AD in the Medicaid waiver support coordinators training curriculum and 60% agreed to this statement. When asked if there is any support in the Down Syndrome network on the needs of the families with an Adult Down Syndrome individual with AD, 67% of respondents replied no to this question; 73% of respondents indicated that there was no protocol for

referring to MDCs; 90% indicated the MDCs did not have a proper protocol to assess for dementia in the Adult Down Syndrome population; and 60% of respondents indicated there is no protocol on contacting or working with ADRCs. When asked whether any training on using non-pharmacological protocols in addressing challenging behaviors related to AD, over 70% indicated there was none.

Recommendations to Close Care Gaps:

- Identify and disseminate protocols to work with MDCs and ADRCs.
- Workforce development.

Hospice

The hospice network offers hospice service to families of people living with dementia who have been diagnosed with "failure to thrive." Survey results pointed towards a major issue, there is a lack of communication between the hospice and the MDCs. Even if the patient has been diagnosed with dementia, they should work with the MDCs on training staff on medications that may abrogate some of the symptoms of dementia and behavioral interventions. There appears to be little robust effort to reach out to the rural communities to help families utilize hospice services.

Recommendations to Close Care Gaps:

- MDCs to increase their training and clinical outreach to the hospice programs.
- ADRCs to identify regional, urban and rural supportive resources.

Adult Day Care Centers

Survey respondents indicated a need to train ADCC staff on identifying behaviors that may be related to dementia and how to intervene with challenging behaviors related to dementia. Only 50% of the responding ADCCs reported that they were aware of the MDCs, but they have developed a relationship with the ADRCs.

Recommendations to Close Care Gaps:

- Workforce development.
- Alleviate communication gap between MDCs and ADCC.

Adult Family Care Homes

Only 40% of the responding AFCHs know or have contacted the MDCs for supportive services. There is a continuous need for training on recognition of dementia behavior and interventions. Only 50% of respondents either know or have any contact with the ADRCs.

Recommendations to Close Care Gaps:

- Alleviate communication gap between MDCs and AFCHs.
- Workforce development.
 - » Increase outreach by the ADRCs to create awareness regarding their referral services.

Assisted Living Facilities

Only 30% of respondents either have communicated or know about the services provided by MDCs. Only 55% of respondents had communicated or used ADRC referral services. Only 40% have Memory Care Units and only 50% have adequate staff ratios. Only 65% of respondents have policies on caring for individuals with dementia.

Recommendations to Close Care Gaps:

- Alleviate communication gap between MDCs and ALFs.
- Workforce development.
- Increase outreach by the ADRCs to create awareness regarding their referral services.
- Increase the number of ALFs with Memory Care Units.

Section 9: Community Listening Sessions

On December 5, 2019, the Alzheimer's Association hosted its first town hall listening session, "Building Dementia Capable Communities" with ADAC and DCCI. This event had over 150 individuals in attendance. This included key community leaders, state agency officials, family caregivers, individuals living with dementia, direct care workers, healthcare professionals, and the community at large. The speakers for the event were newly appointed State Surgeon General, Dr. Scott Rivkees, Secretary of the Department of Elder Affairs, Richard Prudom, Dr. Rosemary Laird, incoming Chair of the Alzheimer's Disease Advisory Committee (ADAC), Representative Scott Plakon and Alzheimer's Association's National Early Stage Advisory Member, Ed Patterson.

The purpose of this event was to partner with state agencies to engage the community at every level for an interactive listening session that focused specifically on how the community was responding to the needs of caregivers and persons living with ADRD. The concept of this "live listening series" was to collect information from all PSAs around the state. The listening session gave the community a public opportunity to share their concerns and ask questions related to Alzheimer's and other dementias in the greater Longwood, Florida area.

Through this community listening session, we have seen tremendous outcomes in the state in our efforts to make Florida dementia capable. During this session, Dr. Rivkees was inspired to have the Florida Department of Health (FDOH) respond to the Centers for Disease Control and Prevention (CDC) funding opportunity CDC-RFA-DP20-2003 – The National Healthy Brain Initiative (Grant). This commitment to apply would be in prelude to applying for the Building Our Largest Dementia (BOLD) center of

excellence application sometime in early spring 2020. To strengthen the FDOH's application, the department decided to co-apply with the Alzheimer's Association as a guiding partner, who would not receive funding, and the DOEA who co-chairs the State Health Improvement Plan Priority 9 – AD with the Association. The partnering entities all agreed that the application could spotlight and build upon Florida's current dementia network, including the Alzheimer's Association's programs and support services (such the Brain Bus, 10 Ways to Love Your Brain, and All About the Brain series).

This event set the stage for the dementia network to advocate for the creation of a dementia director position during the 2020 legislative session. Representative Scott Plakon was a cosponsor of legislation creating the position and DOEA included the position in its Legislative Budget Request (LBRs). This gave state agency leaders and the elected official the opportunity to discuss this coordinating effort, why the position would be so crucial to success in our state, how the position would assist with DOH applying to be a BOLD Center of Excellence and how the coordinating efforts had already begun. The listening session showcased how ADAC, agency leaders, the Executive Office of the Governor, and the state legislature are all working to make ADRD a top priority in Florida.

Another outcome of this listening session was the opportunity to showcase the state-funded Alzheimer's Association Brain Bus Mobile Outreach Initiative. The Brain Bus program prioritizes underserved and diverse populations that do not have direct access to care. The Brain Bus was parked outside the venue and served constituents with care consultations throughout the session.

The success of this event has had a ripple effect not only in our state but throughout the country. Policy leaders in the aging network are looking to Florida to replicate our listening sessions and develop partnerships with state agencies and professional and community leaders.



On December 18, 2019, another open forum was held in Tallahassee and was facilitated by DOEA and ADAC member Dr. Rob Glueckauf from the Florida State University College of Medicine. Similar open forums were planned throughout the state but had to be canceled due to COVID-19.

Participants shared their experiences and highlighted the areas that need improvement. Their feedback revolved around:

- Workforce development.
- Lack of funding.
- Increased focus on research.
- Creating awareness on AD and resources available in the community and how to access them.
- Coordination and continuity of care.
- Lack of volunteers.
- Development of a baseline tool to assist with early detection of ADRD.
- Lack of transportation and isolation for the rural populations.
- Long wait times for getting an appointment with the neurologists

Section 10: ADAC Priorities and State Plan Recommendations

ADAC was established by the Florida Legislature in 1986 – under the umbrella of the ADI – to serve as a major resource to it regarding issues involving ADRD and advise DOEA on legislative, programmatic, and administrative matters concerning people living with ADRD and their caregivers.

ADAC has three key values which are culminated below as the Priorities and Recommendations for the Year 2020-2021.

- We believe persons with ADRD deserve the full protections and liberties of the state as well as unique supportive programs and services given the nature of their disabling illness.
- We believe the state bears a responsibility to ensure efforts are made to bring access to appropriate quality care services to the ADRD patients and their family caregivers.
- We believe family and professional caregivers of persons with ADRD are a valuable asset to the care of persons with ADRD and deserve programs and services to support their efforts.

In determining our priorities for this year, we began by reviewing the last major priority statement of the ADAC, namely the Purple Ribbon Task Force (PRTF) from 2012-13. At our February 2020 meeting the ADAC reviewed the recommendations of the PRTF and categorized them as: (1) continued them as priority items on this list; (2) retired them as completed; (3) completed by another entity; (4) incorporated them into new priority areas.

In this current effort, ADAC members were asked to identify key areas of need across the state and assign relative priority levels

to each. Priority Areas 1 – 8 were identified during group discussion at the ADAC meeting in February of this year followed by individual committee members identifying their three highest priority recommendations. Each includes a recommendation and potential strategies to consider when subcommittees are established, and they begin working on goal statements, key objectives, and proposed strategies with set timelines.

Priority Area #1: Organize the Florida ADI Network to provide a single access point for all ADRD related services, resources, and referrals.

Recommendation 1: ADAC will work with DOEA to establish a single-entry access website for services and resources related to ADRD in Florida.

Strategies:

- Create position of Statewide Dementia Director to oversee all aspects of ADI programs and services in Florida and work collaboratively with government, education/ research, and community partners.
- Gather information on state, public and private agencies that currently provide public education, resources, research, and services to ADRD patients and caregivers.
- Develop links to the ADAC report, state plan and priority areas and accomplishments.
- Develop Florida ADI Network information card for statewide distribution.
- Consider how people who do not use technology will access services.
- Provide education to hospital discharge planners, primary care physician offices, and emergency rooms on available resources through the website and the importance to connect people living with dementia.
- Develop an electronic referral system for hospital discharge planners to make direct referrals to ADRCs (AAA) and MDCs.

- Establish designated dementia care specialists in each AAA to coordinate standardized information throughout the state and provide education on the availability of services through ADRC and how to access services.
- Promote the availability of support services available through DOEA such as the Elder Helpline, Senior legal helpline, legal services, SHINE, the Long-term Ombudsman Program, Guardianship, Elder Abuse and prevention.
- Promote the availability of the Alzheimer's Association 24/7 Helpline, Brain Bus, education modules, support groups.
- Ensure that updates related to ADRD are disseminated across the state through community partners.

Priority Area #2: Public Education and Awareness

Recommendation 1: The ADAC shall promote education about and increased awareness of ADRD in Florida by supporting the development of a coordinated, multi-faceted campaign catering to the educational and awareness needs of the illness with special attention to underserved service areas and populations.

Strategies:

- Collaborate with state and public partners to develop content for a statewide strategic plan for an education campaign.
- Promote the MDCs locations and services offered. (Focus on: ALF, NH, ADCC, Hospitals, ER, NH, ADFH, Home Health, Hospice, and APD).
- Create an annual statewide ADRD Family Caregiver Week in the month of November. This was recommendation #8 from the Purple Ribbon Task Force (PRTF).
- Promote awareness of the ADRCs and the services they provide for people living with dementia.

- Support ADRD conferences in the State of Florida. This was recommendation #11 in the PRTF.
- Promote education and awareness of the Brain Bank, clinical trials, research, and Trial Match.
- Work with statewide partners to promote the work of the DOH to become a Center of Excellence and promote the work from a public health approach and the vision of BOLD.
- Reduce stigma associated with ADRD by promoting messages from people living with dementia and caregivers of those living with ADRD.
- Develop an action plan to ensure the campaign addresses all race and ethnic backgrounds.
- Promote the Brain Bus and mission to promote healthy brain, educate on the 10 warning signs, promote early detection and the MDCs as designated diagnostic sites.

Recommendation 2: The ADAC shall work with DOEA to expand and network the statewide DCCI task forces to promote effective collaboration, communication, and awareness of task forces and their activities and ensure coverage includes underserved areas and populations.

Strategies:

- Gather data/information on the current status of DCCI task forces and develop a strategic plan to expand services and how to promote their ongoing work.
- Work with DCCI task forces to collect community action plans to identify collaborative efforts on actions among task force members for education, trainings, and outreach events.
- Create a DCCI network structure between task forces to share information: Quarterly co-leaders meeting and FTP shareable files.

Recommendation 3: Create Florida communities that promote quality of life for people living with dementia and their caregivers by creating dementia caring communities where people can remain engaged in their communities and remain in their own homes for as long as possible.

Strategies:

- Develop a Florida toolkit for Dementia caring communities.
- Establish collaboration between Age-Friendly and Dementia-Friendly task force networks across the state to work together on community action plans to integrate dementia caring priorities in the community action plans.
- Expand the number of Age-Friendly Health Systems in Florida.
- Work with AAAs, MDCs, and the Alzheimer’s Association to expand access to Memory Cafés in rural communities.
- Work with community partners to establish online training modules to create dementia caring businesses.
- Promote involvement the civic and faith-based organizations.
- Work with Florida’s Department of Education to offer curriculum and/or Virtual Dementia to educate young Floridians.
- Work with DOEA and community partners to create online training opportunities for community businesses. Videos can then be placed on the ADRD statewide website.

**Priority Area #3:
Workforce Development**

Recommendation 1: To be consistent with national standards the ADAC will expand training requirements to include eight hours of ADRD training and four hours of continuing education for healthcare professionals in all healthcare agencies that provide services to people living with dementia. This will require legislation.

Strategies:

- Review and revise current statutes for ALF, NH, HH, Hospice, ADCC, and Specialized ADCC and create new statutes for hospitals, urgent care clinics, primary care offices, ERs, and AFCH.
- Update ADRD statute: Update dementia-specific training requirements for employees in care settings. #18, #25 PRTF.
- Develop ADRD training requirements for Hospital/ER/Clinic staff to include mandatory training upon hire and annually.
- Increase hours upon hire and add continuing education requirement.
- Update Training Provider Application to require training providers to have a curriculum or develop one template to be used across the state.
- Consider developing a standard curriculum template for ADRD training to be used by the certified training providers.
- Develop a training curriculum specific for activities directors at NHs, ALFs, ADCCs.

Recommendation 2: The ADAC will create workforce training recommendations to address the training needs across the broad range of workers who encounter persons with ADRD.

Strategies:

- Gather and review current training requirements in place.
- Standardized required training (CE) for licensed professionals to include ADRD training for license renewals (examples: MD, PA, PT, OT, ST, RN, LPN, CNA, LCSW).
- Develop standardized assessment tools/ protocols for diagnosis of ADRD.
- Promote education for primary care providers on Healthy Brain Initiative: early detection, warning signs, benefits of early diagnosis, diagnosis tools, care planning, CPT code, and resources.
- Standardize training for law enforcement, including recognizing signs of persons with ADRD, communicating with

persons with ADRD, identifying different behaviors, offering Baker Act alternatives, understanding wandering behavior, and knowing local resources. This was recommendation #18, #25 from the PRTF.

- Work with agencies that provide CNA courses to develop and provide curriculum on effective and supportive approaches to caring for individuals living with ADRD.
- Develop curriculum on ADRD for universities/medical schools/nursing schools. Utilize Alzheimer's Association curriculum and modules that have already been established.
- Work with DCCI to develop action plans to educate businesses.

Priority Area #4: Respite Support Services

Recommendation 1: The ADAC will support improvement and expansion of respite support services for people living with dementia and their caregivers with special attention to underserved service areas and populations.

Strategies:

- Review current processes to identify gaps in access and quality respite care.
- Analysis of the current waiting list to determine the root cause and to increase availability, timeliness, and funding.
- Promote awareness on understanding respite care and the benefits of such services.
- Analysis of services available in each county.
 - » Include analysis of workforce capacity.
- Evaluate potential use of emergency respite care vouchers for family caregivers of persons having ADRD. #14, #15 PRTF.
- Educate and empower caregivers through evidence-based trainings to provide them with the proper tools to care for the person at home for as long as possible.
- Ensure all family caregivers have access to respite services if needed.

- Evaluate availability of emergency respite services.
- Evidence-based guidelines for Alzheimer's Specialized Adult Day care centers and the benefits of such programs.
- Access the availability of programs/services for the young-onset population.

Priority Area #5: Clinical Care

Recommendation 1: Create an ADAC subcommittee to identify gaps in access and quality of clinical care services across the continuum of care for people living with dementia and their caregivers with special attention to underserved service areas and populations.

Strategies:

- Review current processes to identify highest priority gaps in access and quality care for people who complain of memory loss or have been diagnosed with ADRD.
- Identify barriers that prevent access to medical and social services.
- Promote early detection about brain health, access to screenings, and 10 warning signs and timely and accurate diagnosed by primary care physicians or referrals.
- Improve access to early detection by increasing outreach in rural, low-income and minority areas: MDC, DCCI, ADI, Brain Bank.
- Pilot the use of telehealth screening in rural areas.
- Implement cognitive screening as a regular part of annual physical.
- Develop and promote Dementia Care practice recommendations.
- Promote the utilization of CPT Code 99483.
- Develop a statewide protocol to identify people living with dementia on medical charts.
- Collaborate with APD to identify gaps within the DD network.

Recommendation 2: Improve operational excellence of the MDCs to a timely and accurate diagnosis and treatment plan for patients living with ADRD and provide support for family caregivers.

Strategies:

- Fully engage the resources of the MDC network to develop and deploy statewide screening practices as well as evidence-based diagnosis, treatment, and ongoing care support for patients with symptoms of cognitive impairment.
- Develop a systems approach to care coordination.
- Ensure persons and family caregivers affected by ADRD have better access to memory screening and support. #6 PRTF
- Fund MDCs according to performance standards and benchmark goals (#29 PRTF) and review MDC and Brain Bank Quarterly reporting and annual reports.
- Establish MDC strategic plans for coverage in rural counties/telehealth.
- Develop a strategic plan for training and outreach in underserved communities.
- Promote improved collaboration between MDCs and AAAs. Direct referral system for patients and caregivers.
- Evaluate the need for additional MDCs.
- Promote awareness of person-centered care.
- Evaluate and update reporting data for MDCs and the Florida Brain Bank.
- There is a need to adopt a Comprehensive and Specialized Care, Life Course, Individualized, Holistic Approach while providing clinical care and supportive services for persons living with ADRD and their family caregivers.

Recommendation 3: Establish an ADAC subcommittee to complete a comprehensive review of the issues related to crisis care for persons with ADRD to include Baker Act, natural disasters, and caregiving crises.

Strategies:

- Establish a system of acute crisis care for persons having ADRD to be accurately diagnosed and treated for medical issues and ADRD conditions simultaneously, (#16, #17, #18 PRTF) which would eliminate inappropriate Baker Acts.
- Provide a Community-Based Emergency Crisis Intervention Program for emergency intervention services that institutes a “course of action” to mitigate ADRD issues for families of all cultures and economic means who find themselves at immediate risk. #16, #17, #18 PRTF.
- Implement additional emergency intervention in care facilities for when caregiver is in crisis. #16, #17, #18 PRTF.

Priority Area #6: Research

Recommendation 1: The ADAC will promote education and awareness on the availability, purpose and value of research and encourage participation in clinical trials and other research studies.

Recommendation 2: ADAC will work with the ADRD priority area in the SHIP to carry out research priorities.

Strategies:

- Develop a plan to distribute state-wide information on the research opportunities available across the state through community partnerships: MDC, AAA, DCCI, Brain Bus, Alzheimer’s Association, DOH, Community Health Departments, AARP.
- Review state funded research priorities to date to identify key categories of inquiry and ensure funding is appropriately apportioned across the broad needs including basic science, industry-sponsored pharmacologic clinical trials, care models and delivery of care, and caregiver support and educations.
- Review the process of distribution of Ed and Ethel Moore awards to ensure it is without bias and resulting in equitably

distributed funds based on merit and state need with special attention to underserved service areas and populations.

- Promote awareness for Alzheimer's Disease Research Centers (ADRCs) #9 PRTF.
- Assessing the effectiveness of community-based models of care for persons with dementia.
- Develop a statewide database system or utilize and promote a current database already in place to track people in Florida who have been diagnosed with ADRD, evaluating the effects of tailoring lifestyle interventions (e.g., exercise and diet) to the socio-cultural characteristics and delivery preferences (e.g., telecommunication-based or in-person), on cognitive decline and health quality of life for adults with mild cognitive impairment.
- Identify and test best methods for promoting the completion of advanced directives across Florida.
- Develop and evaluate the impact of a tiered program of intervention (i.e., providing information and support, care planning, brief problem-solving intervention to intensive skills training) for family caregivers of older adults with dementia across Florida.
- Compare the effects of different models for delivering memory and cognitive care services (e.g., clinic-based versus community-based) on utilization, costs, and consumer appraisals of benefits.

Priority Area #7: Public Policy

Recommendation 1: The ADAC will work with local legislators to develop legislation to increase general revenue funding to support the services of the Florida Brain Bank.

Strategies:

- Collaborate with DOEA and Florida Brain Bank staff to identify the areas of need to continue to provide effective and efficient services to the citizens of Florida.

- Provide sustainable funding for the Florida Brain Bank. Funding reductions that occurred during the State financial crisis should be restored and statewide activities should be funded at increased, appropriate levels. # 30 PRTF.
- Revise and update the ADRD training statutes.
- Develop a plan for increased respite funding across the state.
- Raise the standard of care for ALFs providing care and services to persons with ADRD. # 28 PRTF.
- Assess and determine the need for additional MDCs across the state to decrease wait times.
- Develop a plan for more funding and grant opportunities for MDCs/DCCI.

Priority Area #8: Elder Neglect and Abuse

Recommendation 1: The ADAC will work with the ADRD priority area of the SHIP to promote awareness statewide of the types of elder abuse, how to report, and where to go for help.

Strategies:

- Work with statewide partners to provide educational events.
- Develop a strategic plan to promote more outreach and education (AAA coordinators).
- Develop collaborative relationships with community partners to expand education and outreach.
- Promote World Elder Abuse Awareness Day across the state.
- Design Domestic Violence Shelters for the older population and focus on creating education and awareness. #31 PRTF.
- Promote awareness of scams/fraud.

Section 11: COVID-19 Response

While the COVID-19 pandemic has presented considerable challenges for everyone, patients and family caregivers facing ADRD face a unique set of additional challenges. Fortunately, DOEA and all its assets quickly marshaled resources and developed creative partnerships to support these highly vulnerable Floridians.

- **Meal Delivery** DOEA partnered with the Florida Department of Business and Professional Regulation (DBPR) and the Florida Restaurant and Lodging Association (FRLA) that allows the needs of the business community and workers in the restaurant business to be matched with the needs of the elderly and meal delivery services. DOEA's 11 AAAs throughout the state have been working with local volunteers and other local service providers to ensure meal delivery to Florida's most vulnerable population. A total of 1.2 million meals have been delivered.
- **Project: VITAL** While it is imperative for individuals to practice social distancing as we combat COVID-19, social distancing does not have to result in complete social isolation. To mitigate these circumstances



DOEA and the Alzheimer's Association have developed an initiative called Project: VITAL (Virtual Inclusive Technology for All).

This project supports the well-being of seniors, their families and caregivers by allowing them to remain virtually engaged and connected through specially designed tablets that can access resources like music, books, games and the ability to video chat and email with family. It also facilitates educational and support opportunities for staff through a video-based learning platform and offers opportunities for virtual and online education and support for families/caregivers at home.

- **MP3 Players** The Florida Alzheimer's Association donated pre-loaded MP3 Players and DOEA began delivering them to socially isolated seniors and adults living with ADRD in April. Studies suggest that listening to music can have numerous positive effects on health, including:²⁶
 - » Improving mood
 - » Reducing stress;
 - » Lessening anxiety;
 - » Improving memory;
 - » Easing pain;
 - » Providing comfort; and
 - » Improving cognition.

Even in the late stages of AD, a person may be able to tap a beat or sing lyrics to a song from childhood. Music provides a way to connect, even after verbal communication has become difficult. Many caregivers have sheltered in place with their loved ones. Music may benefit both the caregiver as well as their loved one by reducing stress or distress and enhancing their moods.

- **Therapeutic Robotic Pets** "There is a 45% increased risk of mortality in seniors who report feeling lonely."²⁷ Reducing the exposure of seniors to the coronavirus by "social distancing" and remaining isolated



is imperative, but nonetheless poses its own challenge. DOEA has, and continues to, address this challenge by investing in therapeutic robotic Joy for All® Companion Pets and distributing them to socially isolated seniors and the caregivers of individuals living with ADRD. The pets are making an immediate impact by reducing the negative health effects – physical as well as mental and emotional – associated with loneliness.

Robotic companion pets offer an alternative to traditional pet therapy, and research shows they provide many of the same benefits of the interactive companionship of traditional pet therapy. Recent research has demonstrated that robotic pets:

- » reduce social isolation, depression, expressions of sadness, and agitation in older adults;
- » enhance interactions for caregivers and family members of older adults; and
- » enhance the well-being, sense of purpose and quality of life of individuals living with a form of dementia.

The therapeutic robotic pets have also made an immediate impact by providing some respite to family caregivers of those living with ADRD; those family caregivers “are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions.”²⁸ Robotic pets have been utilized in many countries for over 16 years²⁹ and they have become more common in the United States to supplement interactions between those living with ADRD and their caregivers. Thus far, DOEA has invested in 1,803 pets and the response has been overwhelmingly positive. Introduction letters and user guides are provided in English and in Spanish.

- **Scent Kits** DOEA has partnered with Scent Evidence K9 to distribute 3,000 Scent Preservation Kits® to caregivers of those living with ADRD. As Florida seniors stay at home to limit their risk of exposure to COVID-19, those older adults with ADRD may have an increased tendency to wander and become lost. If that happens, proactive family safety measures, such as the Scent Preservation Kit®, are providing effective response systems to locate missing persons and return them to safety. These kits provide K9 responders with uncontaminated scent articles that significantly reduce the time it takes to locate someone. Introduction letters and user guides are provided in English and in Spanish. The MDCs assisted with this initiative by distributing 1,350 of the kits (please see below for additional information).
- **Memory Disorder Clinics** DOEA’s 17 designated MDCs quickly responded to establish alternative ways to continue to provide services to patients and caregivers during COVID-19. MDCs worked together to transition to provide telehealth visits, check-in calls, virtual support groups and virtual trainings statewide. DOEA also worked with Scent Evidence K-9 to provide MDCs with 1,350 Scent Evidence kits to distribute to their most vulnerable patients who are at a high risk for elopement.

ENDNOTES

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ALZHEIMER'S DISEASE INITIATIVE



ADI Program Components

Alzheimer's Disease Advisory Committee (ADAC):

The ADAC, composed of 15 members, advises the Department of Elder Affairs on legislative, programmatic, and administrative matters concerning people living with ADRD and their caretakers.

Other duties include:

- An annual report
- Propose updates to the Alzheimer's disease state plan
- Make recommendations on Alzheimer's disease policy and research, clinical care, institutional, home-based and community-based programs

ADI Respite Care Program: The ADI respite program provides services to meet the needs of caregivers and individuals with ADRD. ADI respite care is available for caregivers of adults age 18 and older who have been diagnosed as having probable ADRD.

Services are provided through the 11 Area Agencies on Aging and include:

- In-home/In-facility respite
- Adult day care
- Emergency and extended care for caregivers
- Training

Memory Disorder Clinics (MDC): There are 17 designated Memory Disorder Clinics in Florida. Memory Disorder Clinics provide the following services for persons with ADRD:

- Diagnostic evaluations
- Education
- Referral services
- Service-related research
- Develop caregiver training materials

The Alzheimer's Disease Initiative (ADI) was legislatively created in 1985 to provide a continuum of services to meet the changing needs of individuals and families affected by Alzheimer's Disease and Related Disorders (ADRD).



Brain Bank: The Florida Brain Bank at Mount Sinai Medical Center conducts research aimed at finding a cure for Alzheimer's disease. The Brain Bank is a service, education, and research-oriented network. It facilitates brain donation to confirm an ADRD diagnosis and to conduct research upon the donor's death.

ADI Supporting Components

Florida Silver Alert: MDCs collaborate with Florida law enforcement to facilitate a fast and safe return for persons with ADRD.

Alzheimer's Disease and Related Disorders (ADRD) Training: Individuals living with ADRD have unique needs which require paid caregivers to have additional ADRD training to meet those unique needs.

Dementia Care and Cure Initiative (DCCI): The

Department of Elder Affairs created DCCI in order to bring awareness to, education on, and sensitivity regarding the needs of those affected by dementia throughout local communities.

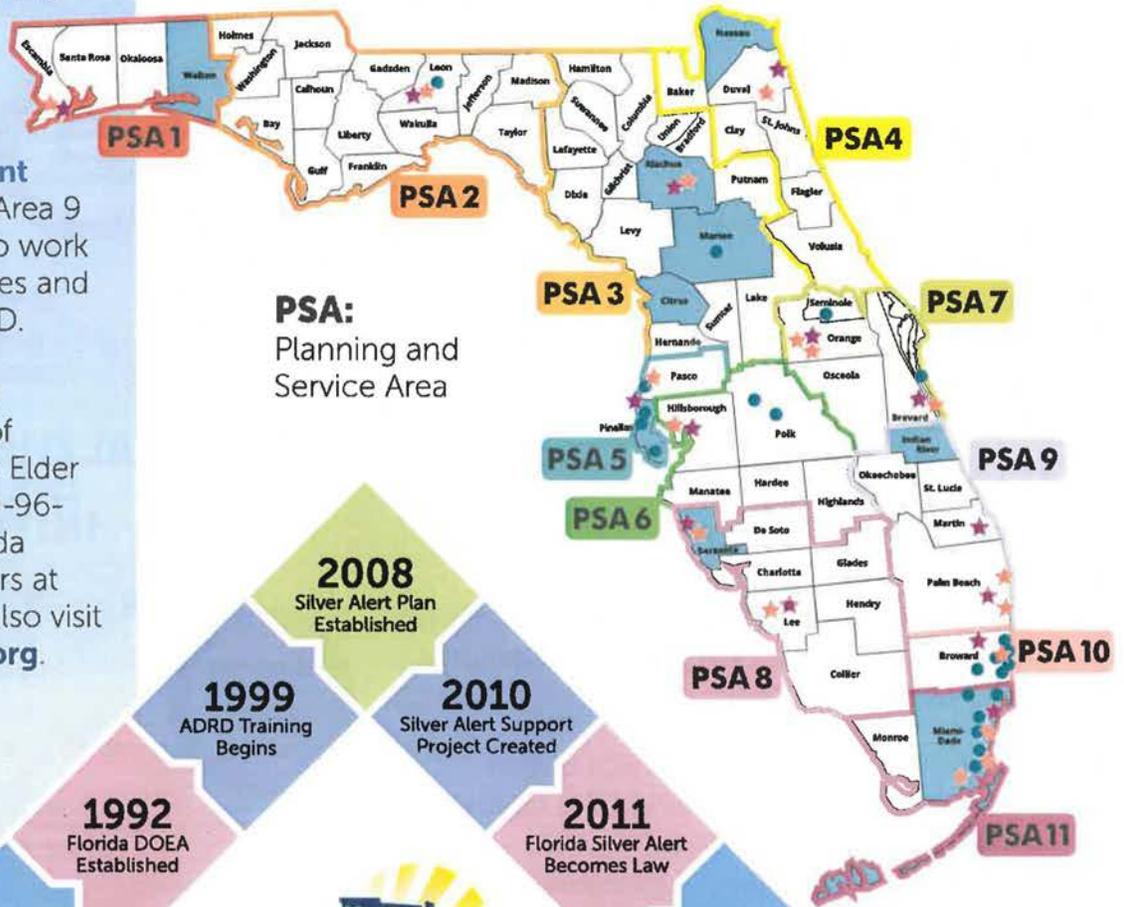
State Health Improvement Plan (SHIP) PA9: Priority Area 9

was created in the SHIP to work on specific goals, strategies and objectives related to ADRD.

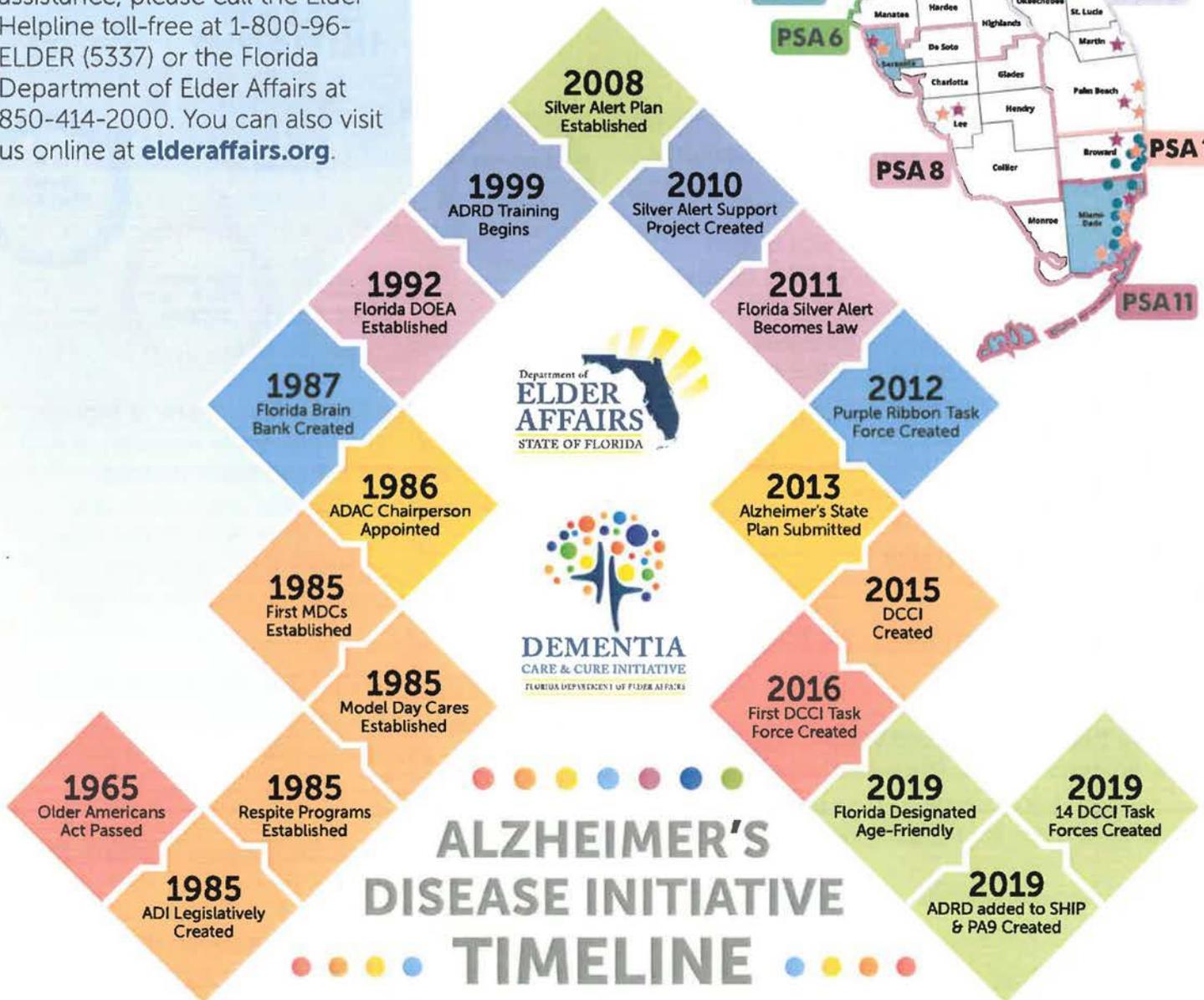
If you aren't receiving any services but are in need of assistance, please call the Elder Helpline toll-free at 1-800-96-ELDER (5337) or the Florida Department of Elder Affairs at 850-414-2000. You can also visit us online at elderaffairs.org.

MAP KEY

- Age-Friendly County
- Age-Friendly City
- ★ DCCI Task Force
- ★ Memory Disorder Clinic



PSA:
Planning and Service Area



Number of Facilities in each PSA:

PSAs	ALFs License Capacity	Hospitals	Nursing Homes	HHA	Hospice	CSU	ADCC	AFCH
1	57	15	29	43	2	1	3	4
2	53	21	33	40	2	3	3	4
3	185	30	69	147	4	6	10	33
4	252	30	84	165	4	4	18	39
5	225	26	87	144	4	3	16	22
6	353	30	75	21	4	8	22	63
7	336	38	76	172	6	10	22	48
8	210	24	72	199	3	6	19	49
9	306	29	78	279	8	5	35	28
10	273	23	35	247	3	2	27	14
11	831	38	56	310	8	6	167	13

Number of Beds in each PSA:

PSA beds	ALFs License Capacity	Hospitals	Nursing Homes	HHA	Hospice	CSU	ADCC	AFCH
1	3,623	2,609	3,469	0	0	10	90	17
2	2,487	3,244	3,878	0	12	52	134	16
3	10,032	6,991	8,278	0	166	140	424	152
4	11,348	7,554	10,057	0	136	114	668	179
5	11,460	5,381	9,961	0	198	90	747	102
6	13,711	7,213	9,368	0	92	218	1,369	287
7	11,141	8,535	9,593	0	88	282	1,125	223
8	13,540	5,240	7,903	0	197	141	986	219
9	11,890	6,312	9,066	0	130	95	2,167	125
10	8,728	6,816	4,537	0	0	51	1,769	66
11	9,892	9,651	8,585	0	13	112	9,139	64

Department of

ELDER AFFAIRS

STATE OF FLORIDA



ALZHEIMER'S DISEASE INITIATIVE



**MEMORY DISORDER CLINICS
AND FLORIDA BRAIN BANK**

2018-2019 Year End Summary

INTRODUCTION

In 1985, the Florida Legislature launched the Alzheimer's Disease Initiative (ADI), an integrated system of dementia-specific services to prepare for the increase in the number of Floridians affected by Alzheimer's disease and related dementias (ADRD). As a direct result of that foresight, today Florida has the infrastructure in place to provide clinical care and support for individuals with ADRD and caregivers, education and training for families and health providers, and research.

One of the foundational components of Florida's ADI is a network of 16 statewide Memory Disorder Clinics (MDCs). The MDCs provide comprehensive assessments, diagnostic services, and treatment to individuals who exhibit symptoms of ADRD. The clinics develop training programs and provide education on understanding and providing care to address the challenges of ADRD for family and direct service caregivers, respite care providers, and healthcare professionals in the care of persons with ADRD, and the general public. The MDCs also participate in research toward effective treatments and, ultimately, a cure for Alzheimer's disease.

MDCs work closely with the Florida Brain Bank, another component of the ADI, to confirm a clinical diagnosis of ADRD, collaborate in research, and inform patients and families about research opportunities. The intent of the Florida Brain Bank is to ultimately find a cure by collecting and autopsying the brains of deceased patients previously diagnosed with dementia.

The state of Florida leads the nation in its longstanding approach to coordinated care for individuals with ADRD. Florida has the second highest number of residents over the age of 65 with Alzheimer's disease in the U.S; approximately 560,000 persons in Florida are living with Alzheimer's disease today, and this figure is estimated to increase to 720,000 by 2025. Florida is experiencing a surge in Alzheimer's cases as the population increases and Baby Boomers age; thus, it is our responsibility to be innovative leaders, charting the course for the rest of the nation in our approach to this disease. To find contact information or to learn more about Florida's MDCs and the ADI, please visit <http://elderaffairs.state.fl.us/doea/alz.php>.

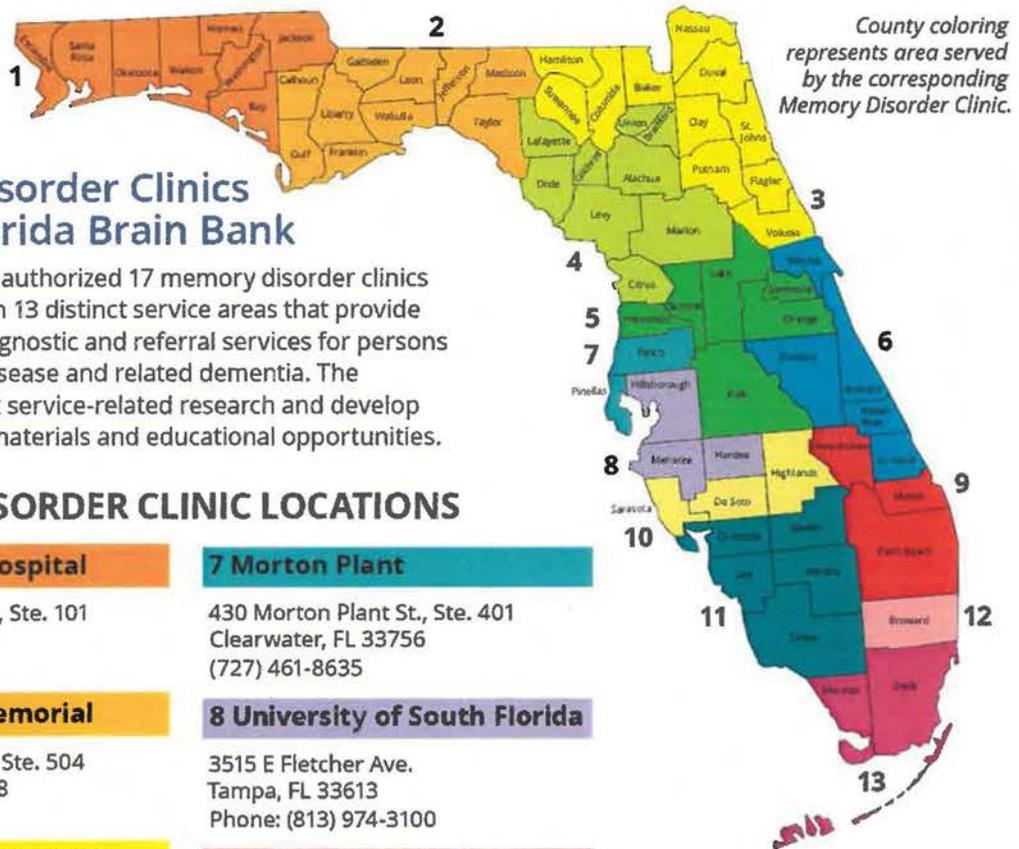
¹ National Alzheimer's Association 2019 Alzheimer's Disease Facts & Figures report. Available at <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>.

2018-2019 State of Florida Memory Disorder Clinics Facts

From July 1, 2018 to June 30, 2019, the Memory Disorder Clinics completed the following:

- Memory Clinics across the state completed 12,672 medical memory evaluations, saw 7,048 new patients, with 18,621 office visits made by patients and their caregivers.
- Of the new patients evaluated, 11 percent were Hispanic, 5 percent were African-American, 16 percent were 85 and older, and more than half indicated their primary caregiver is a spouse.
- 1,537 free memory screenings were conducted by trained Memory Clinic staff.
- 28,349 referrals were made to medical or community services for Memory Clinic patients and families.
- 8,311 family caregivers received educational training from the clinics' staff on how to care for a loved one at home who has dementia.
- 3,171 hours of training were provided to 25,034 family caregivers, medical professionals, health students, social service workers, and the general public.
- An additional 13,673 phone contacts were made to provide information and referrals to community resources that assist individuals affected by dementia.
- The Memory Clinics followed up with 154 family members upon the cancellation of a Silver Alert to provide education, resources, and referrals to assist the recovered person and to prevent future reoccurrences.
- 14 MDCs received extra funding for completing bonus tasks above and beyond the minimum requirements in 2018-2019, including providing additional outreach to low income and minority neighborhoods, increasing the numbers of patients evaluated, and participating in additional research projects and studies.
- The State of Florida funds 16 MDCs located across the state to provide statewide coverage. Additionally, the Florida legislature designated Miami Jewish Health in Miami as a new Memory Disorder Clinic starting July 1, 2019.

Map of the Memory Disorder Clinics



Memory Disorder Clinics and the Florida Brain Bank

The legislature has authorized 17 memory disorder clinics (MDCs) operating in 13 distinct service areas that provide comprehensive diagnostic and referral services for persons with Alzheimer's disease and related dementia. The clinics also conduct service-related research and develop caregiver training materials and educational opportunities.

MEMORY DISORDER CLINIC LOCATIONS

1 West Florida Hospital

2120 E. Johnson Ave., Ste. 101
Pensacola, FL 32514
(850) 494-6490

2 Tallahassee Memorial

1401 Centerville Rd., Ste. 504
Tallahassee, FL 32308
(850) 431-5037

3 Mayo Clinic Jacksonville

4500 San Pablo Rd.
Jacksonville, FL 32224
(904) 953-2677

4 University of Florida

3009 SW Williston Rd.
Gainesville, FL 32608
(352) 294-5400

5 Orlando Health Center for Aging

21 W Columbia St.
Orlando, FL 32806
(321) 841-9700

5 AdventHealth Orlando

601 E Rollins Street
Orlando, FL 32803
(407) 392-9237

6 East Central Florida

3661 S Babcock St.
Melbourne, FL 32901
(321) 434-7612

7 Morton Plant

430 Morton Plant St., Ste. 501
Clearwater, FL 33756
(727) 461-8635

8 University of South Florida

3515 E Fletcher Ave.
Tampa, FL 33613
Phone: (813) 974-3100

9 St. Mary's Medical Center

901 Village Blvd., Ste. 702
West Palm Beach, FL 33409
(561) 990-2135
8756 Boynton Beach Blvd., Ste. 2500
Boynton Beach, FL 33472
(561) 990-2135

9 Florida Atlantic University

777 Glades Rd., Bldg. AZ-79
Boca Raton, FL 33431
(561) 297-0502

10 Sarasota Memorial

1515 S Osprey Ave., Ste. A-1
Sarasota, FL 34239
(941) 917-7197

11 Lee Memorial

12600 Creekside Ln., Ste. 7
Fort Myers, FL 33919
(239) 343-9220

12 Broward Health North

201 E Sample Rd.
Deerfield Beach, FL 33064
(954) 786-7392

13 University of Miami

1695 NW 9th Ave., Ste. 3202
Miami, FL 33136
(305) 355-9065

13 Mt. Sinai Medical Center

4302 Alton Rd., Ste. 360
Miami Beach, FL 33140
(305) 674-2543 ext. 54461

13 Miami Jewish Health

5200 NE 2nd Avenue
Miami, FL 33137
(305) 514-8652

State of Florida Brain Bank

Wien Center for Alzheimer's
Disease and Memory Disorders
4302 Alton Road, Suite 650
Miami Beach, Florida 33140
(305) 674-2018
In Central Florida:
(800) 330-1910 ext. 308

2018 Alzheimer's Data

From the Planning and Evaluation Department at DOEA: There are two main sources of population data available, and we use the same prevalence estimate formula for Alzheimer's disease against both sources depending on the application. The Alzheimer's formula is taken from Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer Disease in the United States (2010–2050) Estimated Using the 2010 Census. *Neurology*, 80(19), 1778-1783.

We calculate the probable Alzheimer's cases at the county-level (the most recent data is attached for your use) based on a formula by age group that is multiplied by the Bureau of Economic and Business Research. *Population Projections by Age, Sex, Race, and Hispanic Origin for Florida And Its Counties, 2020–2045, With Estimates for 2018*. Distributed by the University of Florida, 2018.

<https://www.bibr.ufl.edu/population/population-data/population-projections-age-sex-race-and-hispanic-origin-florida-and-its-3>

The same formulary is applied to data in the five-year population estimates in the American Community Survey, for use in mapping population trends in the distribution of probable Alzheimer's disease at the census tract level. These are hosted on the Department website, here:

http://elderaffairs.state.fl.us/doea/eni/eni_files/Supplemental-maps-2018.kmz and
[http://elderaffairs.state.fl.us/doea/eni/eni_files/Aging and Service Network Locations 2018.kmz](http://elderaffairs.state.fl.us/doea/eni/eni_files/Aging_and_Service_Network_Locations_2018.kmz)

	65-74	75-84	85+	Total Population	ALZ 65-74	ALZ 75-84	ALZ 85+	Probable Alzheimer's Cases
Alachua	22,220	10,505	4,697	263,291	813	1,831	2,038	4,682
Baker	2,337	1,080	325	27,652	86	188	141	415
Bay	17,478	9,279	4,140	181,199	640	1,618	1,796	4,053
Bradford	2,821	1,559	660	28,057	103	272	286	661
Brevard	72,527	44,091	19,360	583,563	2,654	7,687	8,400	18,740
Broward	177,304	91,215	46,911	1,897,976	6,488	15,902	20,353	42,743
Calhoun	1,558	913	308	15,093	57	159	134	350
Charlotte	34,392	22,311	9,369	177,987	1,258	3,890	4,065	9,213
Citrus	26,330	17,050	6,863	145,721	963	2,972	2,978	6,914
Clay	19,237	9,509	3,235	212,034	704	1,658	1,404	3,765
Collier	52,887	36,736	14,679	367,347	1,935	6,404	6,369	14,708
Columbia	7,710	3,976	1,428	69,721	282	693	620	1,595
Miami-Dade	239,078	145,097	64,060	2,779,322	8,748	25,295	27,794	61,837
Desoto	3,770	2,275	723	35,520	138	397	314	848
Dixie	2,326	1,136	318	16,489	85	198	138	421
Duval	80,639	37,141	16,746	952,861	2,951	6,475	7,266	16,691
Escambia	31,683	16,769	7,010	318,560	1,159	2,923	3,041	7,124
Flagler	16,727	9,808	3,310	107,511	612	1,710	1,436	3,758
Franklin	1,516	827	266	12,009	55	144	115	315
Gadsden	5,029	2,365	794	47,828	184	412	344	941
Gilchrist	2,116	1,088	505	17,424	77	190	219	486
Glades	1,726	1,169	304	13,002	63	204	132	399
Gulf	1,971	1,062	365	16,499	72	185	158	416
Hamilton	1,646	767	240	14,621	60	134	104	298
Hardee	2,277	1,175	453	27,296	83	205	197	485
Hendry	3,025	1,709	674	39,586	111	298	292	701
Hernando	27,331	17,472	7,355	185,604	1,000	3,046	3,191	7,237
Highlands	17,261	12,426	5,164	102,525	632	2,166	2,241	5,038
Hillsborough	112,782	56,865	23,733	1,408,864	4,127	9,913	10,297	24,337
Holmes	2,340	1,390	406	20,133	86	242	176	504
Indian River	23,326	14,998	7,377	151,825	854	2,615	3,201	6,669
Jackson	5,252	3,047	1,229	50,435	192	531	533	1,257

Jefferson	2,012	820	315	14,33	74	143	137	353
Lafayette	747	408	142	8,501	27	71	62	160
Lake	47,471	29,645	10,992	342,917	1,737	5,168	4,769	11,674
Lee	102,002	59,399	20,874	713,903	3,732	10,355	9,057	23,144
Leon	23,645	10,468	4,352	292,332	865	1,825	1,888	4,578
Levy	5,634	3,008	824	41,054	206	524	358	1,088
Liberty	662	324	105	8,915	24	56	46	126
Madison	2,230	1,110	452	19,473	82	194	196	471
Manatee	53,445	31,784	13,066	377,826	1,956	5,541	5,669	13,166
Marion	54,502	34,649	12,507	353,898	1,994	6,040	5,426	13,461
Martin	23,547	15,615	7,746	155,556	862	2,722	3,361	6,945
Monroe	10,615	4,686	1,442	73,940	388	817	626	1,831
Nassau	10,789	5,314	1,723	82,748	395	926	748	2,069
Okaloosa	18,604	10,341	4,143	198,152	681	1,803	1,798	4,281
Okeechobee	4,147	2,553	894	41,120	152	445	388	985
Orange	95,621	44,808	18,811	1,349,597	3,499	7,812	8,162	19,472
Osceola	28,223	13,579	4,896	352,496	1,033	2,367	2,124	5,524
Palm Beach	167,903	109,229	60,092	1,433,417	6,144	19,042	26,072	51,258
Pasco	64,259	37,402	15,779	515,077	2,351	6,520	6,846	15,718
Pinellas	129,564	74,264	35,744	970,532	4,741	12,947	15,508	33,196
Polk	77,159	44,149	15,433	673,028	2,823	7,697	6,696	17,216
Putnam	9,215	4,884	1,896	72,981	337	851	823	2,011
Saint Johns	26,792	13,319	5,731	238,742	980	2,322	2,487	5,789
Saint Lucie	35,896	20,874	8,686	302,432	1,314	3,639	3,769	8,721
Santa Rosa	16,409	8,234	2,614	174,887	600	1,435	1,134	3,170
Sarasota	71,015	49,812	22,939	417,442	2,599	8,684	9,953	21,235
Seminole	40,503	19,945	9,591	463,560	1,482	3,477	4,161	9,120
Sumter	36,092	24,011	5,338	124,935	1,321	4,186	2,316	7,823
Suwannee	5,261	3,164	1,265	44,879	193	552	549	1,293
Taylor	2,800	1,507	409	22,283	102	263	177	543
Union	1,327	525	141	15,867	49	92	61	201
Volusia	70,804	38,663	18,011	531,062	2,591	6,740	7,814	17,146
Wakulla	2,900	1,243	377	31,943	106	217	164	486
Walton	7,790	3,680	1,285	67,656	285	642	558	1,484
Washington	2,662	1,404	415	25,129	97	245	180	522



University of South Florida Memory Disorders Clinic

3515 East Fletcher Avenue, MDC 14

Tampa, Florida 33613

Phone: (813) 974-3100; 813-974-5951

ybannon@health.usf.edu or cheryl27@health.usf.edu

Visit us at: <https://health.usf.edu/care/psychiatry/services-specialties/memory-disorders>

Serving Hillsborough, Hardee, and Manatee Counties

There are an estimated **37,988 residents with probable Alzheimer's disease in PSA 6.**

2018-2019 Highlights: University of South Florida Memory Disorder Clinic

- The USF MDC completed **228 total evaluations** and **127 free memory screens**.
- The USF MDC evaluated **196 new patients for memory loss**.
- The USF MDC made over **2,024 referrals to community resources**.
- The USF MDC referred **279 participants to various research studies**.
- The USF MDC provided **85.5 hours of education/training to 1546 caregivers, health care Professionals, first responders, social services and to the general public**.
- The USF MDC responded to **15 Silver Alerts**.

- The USF MDC collaborated with Hillsborough County Aging Service on their annual adult day care center caregiver outreach event. This year over **200 caregivers attended**.
- The USF MDC Medical Director, Jean Fils, MD and Pharmacist, Thea Moore, PharmD, published an article in the Elder Update, May/June 2019, entitled "Why we should care about Alzheimer's Disease Clinical Trial Research."
- The USF MDC Medical Director is multi-lingual and provides clinical evaluations and treatment to patients whose first language is Creole, French, Spanish, or English. Translation services are available at USF for other languages.
- Each year the USF MDC updates a community resource handout. The handout provides a quick reference for new patients/caregivers to resources and important phone numbers within the community. The USF MDC also facilitated Caregiver Support Groups.
- The USF MDC facilitated the initiation of the DCCI Task Force in Hillsborough County. The newly established DCCI task force received a special proclamation and recognition from Hillsborough County, Board of County Commissioners on June 27, 2019. The Hillsborough County DCCI Task Force is also working toward bringing Purple Table to local restaurants.



University of Florida Memory Disorder Clinic

Norman Fixel Institute for Neurological Diseases
3009 SW Williston Rd.
Gainesville, FL 32608
Phone: 352-294-5400 Fax: 352-627-4373
Clinic Evaluation Appointment: 352-294-5400

Serving Alachua, Bradford, Citrus, Dixie, Gilchrist, Lafayette, Levy, Marion, & Union Counties

There are an estimated 28,074 people with probable Alzheimer's disease in the UF service area.

2018-2019 Highlights: University of Florida Memory Disorder Clinic

- The MDC completed **1,403 evaluation and 6 free memory screenings.**
- The MDC evaluated **692 new patients** for memory loss.
- The MDC made approximately **1,669 referrals** to community programs and family resources.
- The MDC **provided education to approximately 814 individuals**, including medical professionals, health students, social services providers, family caregivers, ADI services providers, model day care providers, and members of the general community.
- The MDC partnered with Al'z Place Model Day Care, ElderCare of Alachua County, Elder Options, Alzheimer's Association, Next Step Senior Solutions, Nurse on Call, and HarborChase of Gainesville to provide a **free, public, half-day workshop for caregivers of those with Alzheimer's and other related dementias.**
- The MDC trained a **behavioral neurology fellow** as an **academic dementia specialist.**
- The MDC conducted **21 support groups.**
- The MDC completed **39 journal articles.**
- The MDC responded to **14 Silver Alerts in the nine-county service area** and provided counseling to these families about safety, resources, and dementia care to minimize the likelihood of a reoccurrence.
- The MDC partnered with Elder Options to create a Dementia Care and Cure Initiative Task Force in the Greater Gainesville area.



UNIVERSITY OF MIAMI
MILLER SCHOOL
of MEDICINE

University of Miami Memory Disorder Clinic

1695 N.W. 9th Avenue, Suite 32048

Miami, Florida 33136

Phone: (305) -355-9065

<http://cnsa.med.miami.edu/memory-disorders-clinic>

Serving Miami-Dade and Monroe Counties

There are an estimated **63,668** people with probable Alzheimer disease in the UM service area.

2018-2019 Highlights: University of Florida Memory Disorder Clinic

- ❖ UM-MDC completed **987 diagnostic evaluations** and provided **nine9** events where we offered free community screenings.
- ❖ UM-MDC evaluated **361 new patients** for memory loss.
- ❖ Made **over 442** referrals to community resources.
- ❖ We have enrolled over 600 participants in various research studies.
- ❖ Participated in seven clinical research trials sponsored by pharmaceutical companies and the NIH for the treatment and prevention of Alzheimer's disease. These trials include Prevention of Alzheimer's disease, Treatment of Psychosis and Agitation in AD, Novel Markers for Cognitive Impairment in the Elderly and Caregiver and Care recipient studies.
- ❖ Staff at the UM-MDC provided over **678 hours of education and training to 553** individuals, including health care and social service professionals, medical students, and direct care staff.
- ❖ Conducted our **Hispanic ADI Educational & Training Seminar in Spanish**, providing education and support to South Florida's Hispanic families dealing with Alzheimer's.
- ❖ UM-MDC has created and translated Spanish Brochures and handouts for the Hispanic Community.



Mount Sinai Medical Center

Wien Center for Alzheimer's Disease and Memory Disorders

4302 Alton Road, Suite 650

Miami Beach, Florida 33140

Phone: 305-674-2543

<https://www.msmc.com/neurosciences/wien-center-for-alzheimers-disease-memory-disorders/>

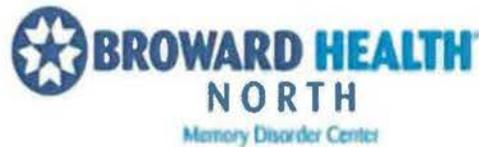
Serving Miami-Dade and Monroe Counties

There are an estimated 63,668 people with probable Alzheimer's disease in the Mt. Sinai service area.

The Wien Center participates in National and International research and clinical trials for Alzheimer's disease treatment and prevention. The Wien Center is the lead institution for the Florida Brain Bank, which helps researchers gain a better understanding of Alzheimer's and other memory disorders.

2018-2019 Highlights: Mount Sinai Memory Disorder Clinic

- The Wien Center completed **3,148** full Neurological evaluations and **50** Free Memory Screenings.
- A total of **547** new patients were evaluated for complaints of memory loss.
- Community resources and referrals were provided for **717** patients.
- The Wien Center provided education/training to **1362** caregivers and health care workers, first responders, and the general public. The clinic held a total of **106** events, which included presentations, programs, and support groups for caregivers and the community.
- Participated in **12** clinical research trials sponsored by pharmaceutical companies and the NIH for the treatment and prevention of Alzheimer's disease.
- Collaborated with the **University of Miami, University of Florida, Florida International University, Florida Atlantic University, and Albizu University** to administer an ongoing Alzheimer's disease Research Center Grant study awarded on **August 15, 2015**. Successfully enrolled **418** participants as of **June 2019**.
- Sponsored the **17th Annual Mild Cognitive Impairment Symposium** for **190** physicians and scientists held on **January 2019** (<http://www.mcisymposium.org>). This event also included a public educational forum for the community that was attended by **168** individuals and caregivers.
- The Wien Center published a total of **13** research articles, on topics involving Alzheimer's disease, and Mild Cognitive Impairment.
- A brochure was designed to promote the **Attentive Mind Program** study, which aims to provide memory, communication and mindfulness training to individuals with Mild Cognitive Impairment.
- The Wien Center responded to **Silver Alerts** generated for the area of **Miami-Dade and Monroe**.
- The Wien Center administers the **State of Florida Brain Bank** with the collaboration of the **Mayo Clinic** and the **Alzheimer's disease Resource Center (ADRC)**. A total of **70** participants were enrolled in the Brain Bank Program, and a total of **52** diagnoses were completed and provided to families of our donors. **417** families were provided counseling and information on the Brain Bank Program and an estimated **259** hours of training were provided.



201 East Sample Road
Deerfield Beach, FL 33064
(954) 786-7392

Serving Broward County

There are an estimated 42,743 people with probable Alzheimer's disease in the Broward service area.

2018-2019 Highlights: Broward Health North Memory Disorder Clinic

- ❖ Staff at BHNMDCC provided over 294 hours of education in the community to over 1,555 individuals.
- ❖ The BHN MDC interdisciplinary team evaluated 114 new patients
- ❖ Our interdisciplinary medical team, including neurologist, psychiatrist and neuropsychologists completed 130 evaluations this year, with a total of 436 visits providing diagnosis, follow-up and recommendations for treatment and care in English and Spanish.
- ❖ Referrals were made to 1245 community resources including Research and drug trials
- ❖ Provided support to around 200 caregivers through support groups, workshops and counseling.
- ❖ Completed 118 memory screenings to the community.
- ❖ Responded to 25 Silver Alerts in Broward County.
- ❖ The Center offers the "Care Assistance Program" a 16-hour educational program for caregivers held ten times a year. Program speakers discuss the disease process, or behavior strategies, medications, legal issues and resources available in the community.
- ❖ Provided four hours of Alzheimer's Disease Training to respite providers in the county
- ❖ Initiated a Dementia Care & Cure Initiative Task Force in Broward County with the assistance of the Aging & Disability Resource Center.
- ❖ Joined the Institute for Healthcare Improvements Age-Friendly Action community and piloting age-friendly care to acute care patients age 65+
- ❖ Implemented a safe driver assessment program.

EAST CENTRAL FLORIDA

Memory Disorder Clinic

3661 S. Babcock Street, Melbourne, Florida 32901

Sandy Stauffer, Program Manager

Phone: (321) 434-7613

Serving Brevard, Osceola, St. Lucie, Indian River, & Southern Volusia counties

There are an estimated 49,916 people with probable Alzheimer's disease in the East Central Florida Memory Disorder Clinic service area.

2018-2019 Highlights: East Central Florida Memory Disorder Clinic

- The ECFMDC provided **419 full diagnostic evaluations and testing** in partnership with the Health First Aging Services Geriatric medical clinic and the Florida Institute of Technology School of Psychology doctoral students trained to complete neuropsychological exams.
- The ECFMDC provided **324 free memory screens** in the community providing information on memory health and resources for next steps in indicated.
- The ECFMDC made over **3702 referrals** to medical services and community resources.
- **The ECFMDC provided 235 dementia training programs and educated 3,580 individuals including: 1,778 family caregivers, 549 general public, and 473 health care professionals.**
- **The ECFMDC is the first organization in Florida to offer the evidence-based Stress-Busting Program for Family Caregivers of People with Dementia.** This is a nine-week program, which provides family members with education, discussion, and emotional support. Teaching caregivers stress management techniques since many are at greater risk as a caregiver.
- **The ECFMDC leads the Brevard Dementia Care & Cure Initiative Task Force (DCCI).** The ECFMDC along with our community partners focus to promote through education a dementia friendly community in Brevard County.
- **The ECFMDC focused educational programs in the community and at senior centers around brain health and wellness with the six-week Total Memory Workout for Seniors series and other brain health initiatives.**
- **The ECFMDC responded to 31 Silver Alerts for five counties,** counseling families about safety, resources, and dementia care to assist them and minimize the likelihood of a reoccurrence.
- **The ECFMDC creates and distributes a monthly Brain Wellness Newsletter** to over 1,700 individuals with helpful tips and other information about our educational programs and resources to family caregivers and professionals throughout the community.
- **The ECFMDC is the first Memory Disorder Clinic offering Dementia Live Experience** with community partners to increase sensitivity to the needs of people with Alzheimer's and related dementias.



4500 San Pablo Road
 Jacksonville, FL 32224
 Phone: (904) 953-2677

Serving Baker, Clay, Columbia, Duval, Flagler, Hamilton, Nassau, North Volusia, Putnam, St. Johns and Suwannee counties

There are an estimated **54,830** residents with probable Alzheimer's disease in service area.

2018-2019 Mayo Clinic Memory Disorder Clinic Highlights

- ❖ The MDC completed **219** Total Evaluations.
- ❖ The MDC's multidisciplinary medical team, including neurologists and neuropsychologists, accurately evaluated **181 new patients** for memory loss, providing diagnosis and recommendations for treatment and care. All patients and families seen were provided information on services for those with Alzheimer's disease and related disorders available in the **State of Florida**.
- ❖ The MDC made **601 referrals** to community resources including **ADI and ADRC partners**.
- ❖ The MDC enrolled **251** participants in various research studies.
- ❖ **The MDC provided 75.5 hours of education and training to 2,083 individuals, caregivers and health care workers, first responders, and the general public.**
- ❖ The MDC Partnered with ElderSource, the Alzheimer's Association, Jacksonville Area DCCI and local ADI Providers including the City of Jacksonville. Our participation with the Northeast Florida Caregiver Coalition continued until August 2018 when that program was modified. The MDC continues to participate in community caregiver workshops.
- ❖ The MDC's Director, Dr. Neill Graff-Radford, published **27** articles.
- ❖ The MDC provides a handout entitled "15 Healthy Brain Tips," created by its director, Dr. Neill Graff-Radford.
- ❖ The MDC responded to **25 Silver Alerts**, counseling families about safety and resources.
- ❖ All patients and families were provided with information on the **Silver Alert Program**.
- ❖ Conducted monthly caregiver support groups, open to the public and with no charge or registration required.
- ❖ The Memory Disorder Clinic at Mayo Clinic Florida has established a DCCI task force along with ElderSource and other community providers. Our **DCCI task force** has been accepted to the Dementia Friendly America Network of Communities.



West Florida Hospital Memory Disorder Clinic

8383 North Davis Highway

Pensacola, FL 32514

(850) 494-6497

Serving Escambia, Santa Rosa, Walton, Okaloosa, Holmes, Jackson, Washington, and Bay Counties

There are an estimated 22,395 people with probable Alzheimer's disease in the West Florida MDC service area.

2018-19 Highlights: West Florida Hospital Memory Disorder Clinic

- The MDC **completed 205 Total Evaluations.**
- The MDC **evaluated 93 new patients for memory loss.**
- The MDC made **over 727 referrals to community resources.**
- The MDC enrolled five participants in various research studies
- The MDC provided **111.5 hours of education/training to 834 caregivers and health care workers, first responders, and to the general public.**
- The MDC Partnered with Brain Bank and University of West Florida for research.
- Published Vaccines for a Lifetime in *Elder Update*, March/April 2019.
- MDC responded to two Silver Alerts in the West Florida service area.
- The MDC and its community partners conducted 50 Special Trainings/Seminars/Support Groups.



901 Village Blvd, Suite 702
 West Palm Beach, Florida 33409
(561) 990-2135

8756 Boynton Blvd, Suite 2500
 Boynton Beach, FL 33472

Serving Palm Beach, Martin, and Okeechobee counties,

There are an estimated 59,188 people with probable Alzheimer's disease in the St. Mary's service area.

2018-2019 Highlights: St. Mary's Memory Disorder Clinic

- The MDC completed 325 total evaluations and provided 333 free community screenings.
- The MDC made 1,041 community referrals.
- The MDC provided education in the community for professionals, students, caregivers and the general public to over 1,031 individuals.
- The MDC responded to 18 Silver Alerts in the areas served, counseling families regarding safety, services, and care.
- The MDC Coordinator has been trained in the MindSet curriculum that helps individuals exercise their brain, create healthy habits and improve communication. These classes will be offered to individuals with Mild Cognitive Impairment and Early Stage Dementia.
- The MDC has partnered with community senior centers, senior assisted living communities, primary care offices and hospitals to provide free monthly memory screenings.
- The MDC Coordinator was featured on ESPN 106.3 radio show to discuss the memory disorder clinic, and the importance of memory screenings.
- The MDC Coordinator was featured on an iHeart radio show in conjunction with a Facebook live show to discuss the memory disorder clinic, and the importance of memory screenings.
- The MDC Coordinator was a featured speaker for the 5th Annual Caregiver Workshop
- The MDC/PBNI hosted the Fearless Caregiver training series



Tallahassee Memorial HealthCare Memory Disorder Clinic

1401 Centerville Road, Suite 504

Tallahassee, Florida 32308

Phone: (850) 431-5002

www.tmh.org/mdc

Serving Leon, Calhoun, Gulf, Liberty, Franklin, Gadsden, Leon, Wakulla, Jefferson, Madison, and Taylor Counties

There are an estimated **8,579** people with probable Alzheimer disease in the TMH service area.

2018-2019 TMH Memory Disorder Clinic Highlights

- MDC completed **661 total evaluations and 202 Free Memory Screens.**
- MDC made **799 referrals to community resources and programs.**
- MDC along with Ageless Grace exercise presented **228 hours of education to 2,543 participants in our 10 County Service Area.**
- MDC partnered with **Florida State University College of Medicine** to assist in recruitment of a **research projects** addressing caregiver burden and individuals with dementia.
- MDC partnered with **Mayo Clinic- Jacksonville and University of Florida** to provide the **PEACEOFMND** research project to the Big Bend area. **721 Participants** were referred to research projects.
- MDC responded to four **Silver Alerts**, counseling families about safety, resources and care.
- MDC continues to work with the **DOEA DCCI** to **increase awareness, provide assistance, and continue advocacy** throughout the Tallahassee Area.
- Started a **new support group** in the Tallahassee area specifically for individuals living with dementia.
- Collaborated with the ACTS II program to hold **annual caregiver conference** in Tallahassee, **specifically focused on the needs of the African-American community.**
- The MDC continues partnership with Marghi McClearn of **Ageless Grace** exercise program to promote **body and brain health** in this service area.

ORLANDO HEALTH®

21 W. Columbia St Ste 201
Orlando, FL 32806
Telephone: 321-841-9700
Fax: 321-843-5989
 OrlandoHealth.com

Serving Orange, Seminole, Lake, Polk, Sumter and Hernando Counties

There are an estimated 72,542 people with probable Alzheimer's disease in the Orlando Health service area.

The Orlando Health Memory Disorder Clinic provides comprehensive assessments to individuals with possible Alzheimer's disease and related dementias, education for caregivers, health professionals, and the general public and participates in service-related research. Caregiver support, counseling and linkages to community resources are integral components of the program.

2018-2019 Highlights: Orlando Health Memory Disorder Clinic

- The Orlando Health MDC completed 192 Total Evaluations and provided care to 426 individuals and their care partners.
- The Orlando Health MDC evaluated 202 new patients for memory loss.
- The Orlando Health MDC made over 1,484 referrals to medical and community resources.
- The Orlando Health MDC provided 1,004 interventions of counseling, information, and support by phone and email.
- The Orlando Health MDC referred 78 patients and families to the Florida Brain Bank
- The Orlando Health MDC provided 46.5 hours of education/training to 1,323 caregivers and health care workers, first responders, and to the general public.
- The Orlando Health MDC partnered with the Alzheimer's Association to provide education and support programs in the community.
- The Orlando Health MDC responded to 20 Silver Alerts, counseling families about safety, resources and care to minimize the likelihood of recurrence.
- The Orlando Health MDC co-led the Orlando DCCI task force.



Lee Health

LPG Memory Care (MDC)

12600 Creekside Lane Ste 7

Fort Myers, Florida 33919

Phone: (239) 343-9220

Serving: Lee, Hendry, Glades, Collier and Charlotte Counties

There are an estimated 48,165 people with probable Alzheimer disease in PSA 8-Lee Memorial Health System's service area. Each one of these individuals touches the lives of multiple friends and family.

2018-2019 Highlights: LEE Health Memory Disorder Clinic

- ❖ Completed **2892 total evaluations** and evaluated **2,170 new** patients for memory loss.
- ❖ Provided **106 free screenings** in the office and throughout the community.
- ❖ LPG Memory Care made 1,192 referrals to community resources.
- ❖ Provided **105 hours of education to 386** individuals.
- ❖ Lead actionable **DCCI Task Force** to complete **14 community trainings** to include **443 participants** throughout PSA 8. These trainings also include 214 Cape Coral Police Department staff and 9 new Fort Myers Fire Department staff.
- ❖ Our MSW and DCCI Co-Chair lead a subcommittee drafting a video template for a future **educational video project** with several Task Force members.
- ❖ Our MSW created **companion/communication cards** (final draft approved by Task Force members). The cards have been submitted to our program coordinator and are currently awaiting production. The purpose of these cards is to assist caregivers in the community and as a marketing tool for DCCI.
- ❖ LPG Memory Care held twice per month **support groups** in the service area to better serve family caregivers by providing education and exposure to multiple community resources. Support group topics included: Geriatric Polypharmacy, Elder Law, Estate Planning, Coping Strategies, Effective Communication with a patient with Dementia/AD, Caring for Self in Caregiving, Pet Therapy, and many more.
- ❖ Responded to **22 Silver Alerts**, counseling families about safety and resources.
- ❖ Enrolled **59 participants in various research studies**.
- ❖ Partnered with The Brain Bank and Neuropsychiatric Research Center.



1515 S Osprey Avenue, Suite A-1

Sarasota, FL 34239

941-917-7930

Danielle-Valery@smh.com

<https://www.smh.com/Home/Services/Memory-Disorders>

Serving: Sarasota, Desoto and Highlands counties

There are 143,766 residents over the age of 65 and an estimated 27,121 residents with probable Alzheimer's disease.

2018-2019 Highlights: Sarasota Memory Disorder Clinic

- The SMH MDC Completed **864** Total Evaluations and **97** Free Memory Screenings.
- The SMH MDC evaluated **465** new patients for memory loss.
- The SMH MDC made **3,252** referrals to our community partners and other resources for clients and their families and caregivers.
- The SMH MDC referred **56** participants to various research studies.
- The MDC responded to **18** Silver Alerts in our service area and counseled families about diagnosis, driving safety, transportation resources, and care options in the community.
- The MDC provided over **100** hours of education, training and support to **1,981** caregivers, health care workers, first responders and the general public. Part of this education included three monthly dual support groups for both patients and care partners to help families with Mild Cognitive Impairment and Early Stage Dementia.
- The MDC published and distributed the monthly ***On Your Mind*** newsletter with helpful tips and information about local educational programs.
- The Sarasota County ***Dementia Care and Cure Initiative*** (DCCI) task force continues to work on the mission of DCCI: providing education and awareness to employees of local businesses, law enforcement and the community.



**Madonna Ptak Center for
Alzheimers and Memory Loss**

430 Morton Plant Street, Suite 401
Clearwater, Florida 33756
Phone: (727) 298-6384
celisa.bonner@baycare.org

Serving Pinellas and Pasco Counties

There are an estimated 48,914 residents with probable Alzheimer's disease in Pasco and Pinellas counties.

2018-2019 Madonna Ptak Center for Alzheimer's and Memory Loss Clinic Highlights

- The clinic completed 441 Comprehensive Memory Loss Evaluations.
- A total of 4,383 referrals were made to community resources.
- A total of 184 hours of trainings, education programs, and support groups were conducted to caregivers, medical professionals, local police, first responders, and the general public.
- The clinic participated in two research projects: XanADu: A mild Alzheimer's disease 12-week clinical drug trial; The H8A-US-B004 (GERAS-US) study for amyloid positive participants with early stages of Alzheimer's disease.
- Facilitated two Caregiver Support Groups on a biweekly basis.
- An 11-year partner with UCLA Center on Aging in Memory Fitness Training.
- An 11-year partner with DriveABLE: A cognitive driving assessment.
- Responded to 24 Silver Alerts in our service area. Information was given on Memory Disorder Clinic assessments, community resources, caregiver support groups, and counseling about Alzheimer's disease and related dementias.
- Began initial steps of Dementia Care and Cure Initiative (DCCI).



**LOUIS AND ANNE GREEN
 MEMORY AND WELLNESS CENTER**
 Christine E. Lynn College of Nursing
 Florida Atlantic University

777 Glades Road Bldg. AZ-79, Boca Raton, FL 33431
 Phone: (561) 297-0502 Fax: (561) 297-0505
 Email: memorylane@health.fau.edu
 Web: www.fau.edu/memorywellnesscenter

Serving Palm Beach, Okeechobee, and Martin Counties

There are an estimated 59,188 residents with probable Alzheimer's disease in our service area.

2018-2019 FAU Louis and Anne Green Center – Memory Disorder Clinic

- Academic based Nurse-led Memory Disorder Clinic completed **316 Comprehensive Diagnostic Memory and Wellness Evaluations, 151 Comprehensive Driving Evaluations, and 140 free Memory Screenings.**
- The MWC Day Center was the first adult day center in Florida designated as *Specialized Alzheimer's Service Center.*
- Comprehensive Memory and Wellness Evaluations in English, Spanish, and Haitian Creole.
- Comprehensive Geriatric Memory and Wellness Assessments at Home – A program supported by a federal grant that helps to bridge the gap in providing dementia specific care and supportive services to unserved and underserved populations in their homes and communities. Serving the Hispanic and Haitian population; providing culturally responsive and linguistically appropriate programs.
- Translated the Florida Alzheimer's Disease Initiative Educational Manual into Spanish.
- Many opportunities for individuals and families to participate in Clinical and Translational Research, such as Aging, Driving, and Preventing and Mitigating Geriatric Syndromes such as Falls and Delirium.
- Practicum site for students: Nursing, Medicine, Social Work, Communication, Psychology, Business, and others.
- Evidence-based and informed programs for persons with Alzheimer's Disease and Related Dementias, other memory disorders, and/or Parkinson's disease, as well as their formal and informal caregivers.
- **Responded to 26 Silver Alerts** in our service area.
- Psychiatric evaluation and treatment in English and Spanish at home and at the MWC MDC.
- Self Preservation Activites (SPA): Monthly psychoeducational program for caregivers: **311 participants.**
- Sustaining the Caregiver Program: 5 Caregiver Support Groups weekly or biweekly, including specialized groups for Adult Children and Younger Onset; **1,106 visits to support groups.**
- **Provided 27 Caregiver Consultations** with a Certified Care Manager.
- Cognitive Rehabilitation Program for individuals with Mild Cognitive Impairment; **15 participants encountered in 203 initial and follow-up visits.**
- Caregiver Resource Library; **provided 3432 referrals to community resources.**
- Community outreach – Educational programs; **provided 436.5 hours of training and education to 3236 individuals.**
- Our mission is to meet the complex needs of individuals with memory disorders and their families through a comprehensive array of personalized services, compassionate and innovative programs of care, research and education. Person-centered interprofessional team approach through patient/family-provider-community partnering framework.



601 East Rollins Street
 Orlando, FL 32803
 (407) 392-9237
ORL.MDC@AdventHealth.com
AHMaturingMinds.com

AdventHealth Maturing Minds program received its state designation in 2017 becoming the 16th Memory Disorder Clinic in the state of Florida.

Serving 6 counties that include: Orange, Seminole, Lake, Polk, Sumpter and Hernando counties.

There are an estimated 72,542 residents with probable Alzheimer's disease in the MDC service area.

2018-2019 AdventHealth Memory Disorder Clinic Highlights

- The MDC completed 433 Total Evaluations.
- The MDC evaluated 288 new patients for memory loss.
- The MDC made 1,049 referrals to community resources.
- The MDC enrolled 80 number of participants in various research studies.
- The MDC provided 59.5 hours of education/training to 698 caregivers and health care workers, first responders, and to the general public.
- The MDC is actively working with the University of Central Florida on a research project directed towards caregiver education and support.
- Have created several new education presentations including translating and presenting 2 into to Spanish. Have also translated several educational information sheets that are utilized in the clinic to Spanish.
- Created a community resource guide that lists many resources the Senior population can benefit from. This is not only being utilized within the clinic but other areas within the system.
- Responded to 16 Silver Alerts within the six-county area, which is shared with another MDC.
- Started a support group in the East side of Orange county, that was identified as an area of need. Also started a Spanish support group in Orange County as when assessed there was no other Spanish support groups within the county.
- Currently co-lead the DCCI group within the MDC service area.



**State of Florida Brain Bank
Mount Sinai Medical Center
Wien Center for Alzheimer's disease and Memory Disorders**

4302 Alton Road, Suite 650

Miami Beach, Florida 33140

Phone: 305-674-2543

<https://www.msmc.com/neurosciences/wien-center-florida-brain-bank/>

The State of Florida, through its Alzheimer's disease Initiative, formed the Brain Bank in 1987. Its purpose is to study the brains of individuals with progressive dementia, to provide the family with a definitive diagnosis, and to acquire brain tissue for research. Through a network of researchers, we share common goals of finding a cure, improving diagnostic tools and treatment options, and providing education.

2018-2019 State of Florida Brain Bank Highlights

- The **Wien Center** administers the **State of Florida Brain Bank** with the collaboration of the **Mayo Clinic** and the **Alzheimer's disease Resource Center (ADRC)**.
- A total of **70 participants** were enrolled in the Brain Bank Program (**40 females** and **30 males**).
- **12 participants** enrolling in the Brain Bank program during this period are of **Hispanic Background**.
- A total of **52 diagnoses** were completed and provided to families of Brain Donors.
- The median age of death of participants autopsied was of **80 years (range: 63-98 years old)**.
- **417 families** were provided counseling and information on the Brain Bank Program via **educational presentations to the public** and during **one-on-one visits** to the **Alzheimer's disease Research Center (ADRC)**, and the **Wien Center for Alzheimer's disease**.
- The Mayo Clinic reported that the primary pathologic diagnosis was **Alzheimer's disease** in at least **29 cases**, **Lewy Body Disease** in **eight cases** and **one case of Vascular Dementia**. **Vascular disease** was a secondary finding in **seven additional cases** with Alzheimer's disease as the primary diagnosis. **Vascular disease** was a secondary diagnosis in **10 cases**, **three with Lewy Body Disease** and seven **with Alzheimer's disease** as a primary diagnosis. **Two cases had non-Alzheimer's disease pathology**, **one with Progressive Supranuclear Palsy (PSP)** and **one with Normal Pressure Hydrocephalus (NPH)**.
- **268 samples of frozen brain tissue** were shared with Florida Investigators, including **Mayo Clinic** research scientists and the **University of Florida**.
- The Florida Brain Bank Program contributes to the field of Neuroscience with publications generated from the research conducted on Brain Tissue. During the 2018-2019 reporting period, a total of **five publications** were released.

DEPARTMENT OF ELDER AFFAIRS
Wien Center for Alzheimer's disease and Memory Disorders
2018-2019 Brain Bank Annual Report

1. GOALS

- A. Evaluating premorbid (before death) diagnosis and compare it with post-mortem (after death) diagnosis in patients suspected of having died of Alzheimer's disease or other related disorders.

During the last fiscal year, 52 neuropathology reports were completed and provided to families of brain donors participating in the State of Florida Brain Bank Program. The Mayo Clinic processed a total of 41 brains during the 2018-2019 reporting period. There were a total of 26 brain specimens from male donors and 15 specimens from female donors. Among the donors the median age at death was of 80 years (range: 63-98 years). In this group, there were 5 Hispanics, and 36 Caucasians.

The primary pathology at diagnosis was Alzheimer's disease in 29 cases, Lewy body disease in 8 cases and vascular dementia in 1 case. Lewy bodies were a secondary finding in 7 additional cases with Alzheimer's disease as the primary diagnosis. Vascular disease was a secondary diagnosis in 10 cases, 3 with Lewy body disease and 7 with Alzheimer's disease as primary diagnosis. Two cases had non Alzheimer's disease pathology, 1 with progressive supranuclear palsy (PSP) and 1 with normal pressure hydrocephalus (NPH).

All active donors files at the Wien Center have been transformed into electronic form in a password protected database thus making it available to all professionals involved in the Brain Bank Protocol to facilitate and expedite autopsy procedures.

- B. Making a definitive diagnosis for Alzheimer's disease, a related dementia disorder, or a mimic disease.

The donor's next-of-kin received a letter providing the final diagnosis and a summary of the neuropathology findings within three months of the donor's death. In this letter, the next-of-kin was provided information regarding how these findings corresponded to the clinical features in each case, as well as to the clinical diagnosis. The presence and cause of any discrepancies between clinical and pathological findings were explained. The relationship between the pathological findings and other clinical illnesses and treatments were also explained. The next-of-kin was given the option of speaking with the neurologist if any further questions needed to be answered.

During this last fiscal year, there were 52 diagnostic reports sent to families. For cases from the Wien Center, the neuropathology reports were accompanied by a letter from Dr. Ranjan Duara, Medical Director, as explained above. At the Alzheimer's disease Resource Center, Edith Gendron discussed the results in detail with families before

the report was mailed. In addition, they encouraged families to share the results with the donor's neurologist. Dr. Ranjan.

Dr. Duara was available to speak with families from the various subcontractors if further explanation was required.

C. Promoting a better understanding of Alzheimer's disease and how to effectively treat the disease.

In an effort to increase recruitment of Brain Bank donors as well as a better understanding of Alzheimer's disease across the State of Florida, coordinators conducted the following events: 1) discussed with family members the benefits of obtaining a definite diagnosis as well as the importance of their family's medical history to their children and grandchildren; 2) presented information regarding the State of Florida Brain Bank to the memory disorder clinics, adult day care centers, respite care centers, caregivers support groups, churches, healthcare agencies (hospitals, nursing homes, hospice centers, assisted living facilities), health fairs, seminars, and conferences; 3) encouraged memory disorder centers clinicians, nurses, social workers, and/or neurologists to educate the patients' caregivers on the importance of brain donation and the value it represents to medical research; 4) Memory disorder centers clinicians conducted memory screenings; 5) educated pharmacy, nursing, and medical students on the benefits of brain donation, accurate diagnosis, improvement of diagnostic tools and treatments.

During the last fiscal year, 70 new donors were accepted by the Wien Center and Alzheimer Disease Resource Center in the State of Florida Brain Bank. As part of the Brain Bank acceptance criteria, new donors underwent a comprehensive evaluation and Neuro-cognitive testing either at the Memory Disorder Clinics or the office of an experience neurologist/psychiatrist/geriatrician to determine the cause of the memory disorder. Follow-up examinations and copies of previous neuroimaging studies or reports were requested or collected as available.

The Annual Early Alzheimer's Public Education Forum is an annual activity organized by the Wien Center and it is open to caregivers and patients where renowned specialists in the Alzheimer's and Dementia field approach new research with dynamic and interactive presentations adapted to general public followed by Q&A sections. This year was the third consecutive edition of the Forum. The importance of brain donation was underscored during their presentations and Florida Brain Bank personnel were available during the activity to accept donations.

Caregivers were educated about the diagnosis and treatment of Alzheimer's disease, and the potential benefit of brain donation. The MDC neurologists, nurses and mental health professionals also educated caregivers about managing behavioral problems related to Alzheimer's disease. Clinicians in the MDC also discussed the progression of Alzheimer's disease and future care.

Caregivers and participants in the Alzheimer Disease Research Center (ADRC) study at the Wien Center were educated on the benefits of brain donations by the new brain bank coordinator (Carlos Quinonez).

- D. Evaluating possible risk factors for Alzheimer’s disease and other related disorders, by studying the relatives of donors who have died of the disease.

During the previous years, many Brain Bank donors and their relatives were enrolled into the Florida Alzheimer’s Disease Research Center. These subjects were over the age of 65, and had annual physical and neurological evaluations, along with testing of memory, thinking and mood. At baseline, these subjects had an MRI scan of the brain, blood labs, APOE genotyping, an assessment of family history of dementia and a review of potential risk factors for Alzheimer’s disease.

Many of the participants in this cohort were recruited into the 1 Florida Alzheimer’s disease Center an NIA funded grant. Participants in this well documented cohort in undergo bi-annual neuropsychological testing and clinical and neurological work out, Amyloid PET Scan and Brain MRI with volumetric acquisition was collected during a 10 year since 2006. These Florida Brain Bank donors, along with others who donated their brain in this initial cohort, offer a comprehensive and detailed set of variables that will be eventually enrich by their final neuropathological results, offering a privileged set of data that will further the understanding of the disease.

- E. Providing researchers with specimens of Alzheimer’s disease brain tissue to further research and enhance the understanding of this disease. Priority will be given to researchers in Florida, but requests from other states may be fulfilled.

In this reporting period 2018-2019, The ADI Brain Bank program shared 268 samples of frozen brain tissue with Florida investigators, mostly Mayo Clinic research scientists, but also with the University of Florida. Also, 48 samples of frozen brain tissue with research centers around the United States.

Institution	State	Number of Samples
Mayo Clinic	Florida	268
Mayo Clinic	Arizona	6
Rush Medical Center	Illinois	2
Harvard/Beth Israel	Massachusetts	2
Boston University	Massachusetts	3
Albert Einstein	New York	2
University of Pennsylvania	Pennsylvania	3
St. Jude Children’s Hospital	Tennessee	27

F. Publications from the Brain Bank Tissue and Records

Publications

- 1: Sakae N, Josephs KA, Litvan I, et al. Neuropathologic basis of frontotemporal dementia in progressive supranuclear palsy. *Mov Disord*. 2019 Aug 21. doi: 10.1002/mds.27816. [Epub ahead of print] PubMed PMID: 31433871.
- 2: Kunkle BW, Grenier-Boley B, Sims R, et al. Genetic meta-analysis of diagnosed Alzheimer's disease identifies new risk loci and implicates A β , tau, immunity and lipid processing. *Nat Genet*. 2019 Aug 15. doi: 10.1038/s41588-019-0495-7. [Epub ahead of print] PubMed PMID: 31417202.
- 3: Sakae N, Josephs KA, Litvan I, et al. Clinicopathologic subtype of Alzheimer's disease presenting as corticobasal syndrome. *Alzheimers Dement*. 2019 Aug 6. pii: S1552-5260(19)30115-3. doi: 10.1016/j.jalz.2019.04.011. [Epub ahead of print] PubMed PMID: 31399334.
- 4: Santos OA, Pedraza O, Lucas JA, et al. Ethnoracial differences in Alzheimer's disease from the Florida Autopsied Multi-Ethnic (FLAME) cohort. *Alzheimer's Dement*. 2019 May;15(5):635-643. doi: 10.1016/j.jalz.2018.12.013. Epub 2019 Feb 18. PubMed PMID: 30792090; PubMed Central PMCID: PMC6511501.
- 5: Liesinger AM, Graff-Radford NR, Duara R, et al. Sex and age interact to determine clinicopathologic differences in Alzheimer's disease. *Acta Neuropathol*. 2018 Dec;136(6):873-885. doi: 10.1007/s00401-018-1908-x. Epub 2018 Sep 15. PubMed PMID: 30219939; PubMed Central PMCID: PMC6280837.

G. Developing explicit linkage and promote active cooperation with memory disorder clinics, model day care programs, and respite care programs.

The Coordinators, with the staff of the ADI designated Memory Disorder Clinics throughout The State of Florida, will encourage the neurologist, social workers and nurses in the clinic to educate their patients/families on the benefits of the Brain Bank. As requested by the Memory Disorder Clinics, the MDC Coordinators will provide on-site education on brain bank donation, enrollment procedures, and protocol after the death of a donor.

In response to the decreasing number of institutions willing to provide autopsy services in the State of Florida and elsewhere, dieners associated with various medical examiners and hospitals in the state, as well as services such as 1-800-AUTOPSY, will be identified to enable autopsies to take place in funeral homes. Such services have already been identified in the Naples/ Sarasota/ Tampa area, in the Pensacola area in NW Florida and in the Gainesville- north-central Florida area. The

MDC coordinators will be educated as to the availability of such services in the regions which they serve so that subjects may be recruited for the Brain Bank by each and every MDC and rapid autopsy service can be coordinated via the Wien Center at Mount Sinai Medical Center.

MDC Coordinators will also provide information on the Brain Bank through the clinic's newsletters, speaking engagements on the clinic's caregiver support groups, annual trainings to the community and encouraging memory disorder clinicians to use the ADI website as a point of reference as to contact information for the area the donor lives in for enrollment.

The Wien Center Brain Bank coordinator participated in "17th Annual Mild Cognitive Impairment (MCI) Symposium" and at "Focus on Caregiving Conference" Friday, June 7th, 2019 at Mount Sinai Medical Center. Brochures and information on the Brain Bank were available to those attendees who requested it.

H. Sharing specimens upon request from other qualified researchers.

Samples in major genetic studies:

I. Brain Bank Activity during 2018-2019:

1. The number of donors enrolled:	70
2. The number of brains received:	52
3. The number of autopsies performed:	49
4. The number of diagnoses completed:	52
5. The number of reports sent to families:	52

The above mentioned service units include the efforts of the Wien Center as well as the Alzheimer's disease Resource Center.

2. TRAINING

Develop specialized training programs for caregiver groups/organizations, caregivers, direct service staff (i.e., respite care workers, adult day care staff, and health care professionals), and the general public, and make resources available for replication. The Brain Bank must provide:

- A. A summary of the training objectives and training process.
- B. A summary of the methodology for determining training needs and providing notification of training to trainees.

OBJECTIVE ONE: Coordinators scheduled training in their area by contacting via telephone or in writing the ADI memory disorder clinic, model daycare, and respite care site in advance. Objectives included providing two in-service training meetings

twice a year for the staff of the ADI memory disorder clinic, model daycare, and respite care site. The training materials that were used were power point presentation, lecture, and handouts.

TRAINING NEEDS: Semi-annual updates of the progress of the Brain Bank activities, the research component and a review on the donor's registration process and meeting the program's criteria prior to enrollment, were used to keep the memory disorder clinic up-to-date on current happenings.

OBJECTIVE TWO: Coordinators contacted via telephone or in writing the model day care and respite care sites in advance. Objectives included participation in a full day ADI Training Seminars (English and Spanish). This presentation took place in conjunction with the full day training seminars outlined in the MDC Plan for the Wien Center. Objective included: 1) The importance of the State of Florida Brain Bank for families and health care providers; and 2) How to enroll in the brain bank. Training material used included power point presentations, lectures, and handouts.

TRAINING NEEDS: The ADI model adult day care and respite care centers, and the Clinic Coordinator of the MDC and the Brain Bank Coordinator will meet to determine specific topics for seminar training. ADI Day Care Staff will be surveyed for suggestions for specific training needs.

OBJECTIVE THREE: Coordinators contacted in writing their area community agencies, service providers, caregivers, and communities at large. Objectives included the education of community agencies, appropriate service providers, caregivers, and communities at large in order to increase knowledge of The State of Florida Brain Bank Program. The training materials used were power point presentations, lectures, newsletters, and handouts.

TRAINING NEEDS: To learn the importance of providing brain tissue to researchers and the importance of the family receiving a definitive diagnosis.

C. The total number of persons trained by category in the Quarterly Training Report:

1. Medical/Other Health Professionals:	316
2. Health Students:	131
3. Social Services:	311
4. Family Caregivers:	891
5. General Public	1548
6. Total Trainees	3197
7. Day Care/ADI Agency Trainings	
a. Model Day Care Center	0
b. ADI Service Provider	10
8. Total Agency Trainings	0

As reflected on the Quarterly Training Reports, Brain Bank coordinators participated in 12 Public Awareness/Education Events. These events involved presentations and Q&A on radio talk shows and special event, and the distribution of printed material at health fairs, churches and other venues. Overall, Brain Bank Director, Brain Bank Coordinators, Wien Center MDC Neurologist and personnel, and Alzheimer's disease Resource Center personnel were involved in providing almost 399.5 hours of training and education to over 5505 people in their service areas and beyond.

- D. The total number of hours of training provided in the Quarterly Training Report.

Total 399.5

3. RESEARCH

- A. Conduct research activities as part of this contract.

1. Describe the scope of the project, research methodology and timeframe.

A resident physician from Mumbai, India and a 5th year medical student from Cambridge University, UK reviewed recent cases from the State of Florida Brain Bank with the goal of obtaining 20 or more cases with a post-mortem diagnosis of Lewy Body Dementia, with or without concomitant Alzheimer's Disease, and an equal number of cases with a post-mortem diagnosis of pure AD. The primary purpose of this study was to obtain compare the rate of progression of DLBD to the rate of progression of AD, both early and late in the disease. The inclusion criteria: presence of 2 or more cognitive assessments (e.g., MMSE score) in the prodromal or mild stage of disease and 2 or more assessments in the moderate to severe stage of disease. In addition to the compilation of cognitive measures, the students extracted ante-mortem data on the use of medications (cholinesterase inhibitors, Memantine and neuroleptics), medical history, neuropsychiatric features (apathy, disinhibition, visual hallucinations, etc.), extrapyramidal signs, and atrophy on MRI scans. This project was started in June 2014 and was finished during this fiscal year. We examined whether these pathologies affected rate of progression as per Braak stage, TDP-43 and Lewy Body Dementia Neuropathological findings. There were methodological limitations due to the fact that the data was collected retrospectively from records limiting the validity of the conclusions of the study in reference to early and late rate of progression.

2. Provide the total number of persons involved in research (combine totals of all research projects).

Six (Dr. Ranjan Duara, M.D.; Dr. Barbara McManus, M.D.; Maria Greig-Custo M.D., Warren Barker M.S.; Carlos Quinonez, M.D. M.P.H, Rosemarie Rodriguez Ph.D.)

- B. Plan for the public dissemination of research findings. In addition to professional papers, key information should be prepared for distribution to lay persons. Any information disseminated in association with this contract shall comply with the sponsorship clause of this contract, and shall be submitted to the department's grant manager before circulation.

The major research issues addressed by these studies included 1) The natural history of Normal Cognition, Early Mild Cognitive Impairment, Mild Cognitive Impairment to Alzheimer's disease (AD) and 2) The role of other pathologic processes in the progression of cognitive decline.

Information disseminated in association with this agreement shall comply with Section 18, the sponsorship clause of this agreement.

4. ADDITIONAL REQUIREMENTS

- A. Discuss the status of each of the subcontracts for the 2019– 2020 contract year.

Alzheimer Disease Resource Center:

The subcontract is currently in the approval process by both.

Mayo Clinic Jacksonville, d/b/a Mayo Clinic College of Medicine:

The subcontract is currently in the approval process by both institutions. We expect to obtain final Executive Management approval and signatures.

- B. Describe plans to implement the written protocol established by the Brain Bank. Explain how the Brain Bank will ensure subcontractors will be required follow the protocol.

The Brain Bank Protocol is under review. The Department of Elder Affairs as well as the Wien Center continues to work towards a final revision of this protocol.

The Brain Bank continues to monitor the activities of both of its subcontractors.



**Mount Sinai Medical Center
Wien Center for Alzheimer's disease and Memory Disorders
State of Florida Brain Bank**

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Miami Beach, Florida 33140
Phone: 305-674-2543

Serving Miami-Dade and Monroe Counties

<https://www.msmc.com/neurosciences/wien-center-florida-brain-bank/>

The State of Florida, through its Alzheimer's disease Initiative, formed the Brain Bank in 1987. Its purpose is to study the brains of individuals with progressive dementia, to provide the family with a definitive diagnosis, and to acquire brain tissue for research. Through a network of researchers we share common goals of finding a cure, improving diagnostic tools and treatment options, and providing education.

2018-2019 State of Florida Brain Bank

- The **Wien Center** administers the **State of Florida Brain Bank** with the collaboration of the **Mayo Clinic** and the **Alzheimer's disease Resource Center (ADRC)**.
- A total of **70 participants** were enrolled in the Brain Bank Program, (**40 females** and **30 males**).
- **12 participants** enrolling in the Brain Bank program during this period are of **Hispanic Background**.
- A total of **52 diagnoses** were completed and provided to families of Brain Donors.
- The median age at death of participants autopsied was of **80 years (range: 63-98 years old)**.
- **417 families** were provided counseling and information on the Brain Bank Program via **educational presentations to the public** and during **one-on-one visits** to the **Alzheimer's disease Research Center (ADRC)**, and the **Wien Center for Alzheimer's disease**.
- The Mayo Clinic reported that the primary pathologic diagnosis was **Alzheimer's disease** in at least **29 cases**, **Lewy Body Disease** in **8 cases** and **1 case of Vascular Dementia**. **Vascular disease** was a secondary finding in **7 additional cases** with Alzheimer's disease as the primary diagnosis. **Vascular disease** was a secondary diagnosis in **10 cases**, **3 with Lewy Body Disease** and **7 with Alzheimer's disease** as primary diagnosis. **Two cases had non Alzheimer's disease pathology**, **1 with Progressive Supranuclear Palsy (PSP)** and **1 with Normal Pressure Hydrocephalus (NPH)**.
- **268 samples of frozen brain tissue** were shared with Florida Investigators, including **Mayo Clinic** research scientists and the **University of Florida**.
- The Florida Brain Bank Program contributes to the field of Neuroscience with publications generated from the research conducted on Brain Tissue. During the 2018-2019 reporting period a total of **5 publications** were released.

Silver Alerts for 2019

Total Alerts for 2019	274
Total Alerts Since Inception in 2008	2243
Director Recoveries to date	244
Indirect Recoveries to date	45

Recoveries: A direct recovery is defined as a person recovered due to the activation of the State Silver Alert, primarily through the use of dynamic highway message signs or other actions initiated by state agencies. An indirect recovery is defined as a person recovered through the actions of the local agency in coordination with the Silver Alert Plan, primarily through law enforcement communications or media.



July 10, 2019

Secretary Richard Prudom
 Department of Elder Affairs
 4040 Esplanade Way
 Tallahassee, FL 32399

Dear Secretary Prudom:

We are pleased to submit this letter, which constitutes The University of South Florida's Training Academy at the Florida Policy Exchange Center's fiscal yearly report for contract #XQ792.R2. As you will see from reported data, we have met or exceeded all of the contractual goals for the first, third and fourth quarters of fiscal year of July 1, 2018 to June 30, 2019.

Second Quarter (October –December 2018) required an issuance of a Corrective Action Plan. This was the first time that the minimum number of applications fell below goal. In partnership with the Department of Elder Affairs the review process is continually discussed at the Memory Disorder Clinic Initiative meetings, through discussion at the quarterly Alzheimer's Disease Initiative meetings and promoted through the Florida Alzheimer's Advisory Council. Subsequent quarters have met or exceeded requirements.

This report covers a number of initiatives critical to the quality of the ADRD program and the ongoing partnership of our two organizations. Namely, the inter-rater agreement review, enhanced technology and accurate database information, day-to-day applicant servicing and the identification of needed projects to ensure our focus remains on the commitment to person-centered care to persons living with Alzheimer's disease and related disorders in the State of Florida.

Inter-Rater Agreement Process

As part of our quality control and contractual agreement, on June 21, 2019, we conducted a two hour meeting to assess the consistency of our review process. Prior to the conference call, all current reviewers received a curriculum for independent review. Once returned, the information provided by each of our five subject matter experts was combined into one document. The comments and ratings were listed by name. This allowed for discussion on areas of agreement and disagreement to create consensus on subsequent curriculum reviews. Our goal is to ensure that the approval of curriculum is independent of assigned reviewer.

Inter-Rater Results for Home Health 2 Hour

Our annual inter-rater agreement meeting creates synergy among our reviewers. While we are confident that our reviewers are aligned in their routine assessments, the meeting is critical to calculate our internal quality and consistency in evaluation of curriculum. Conclusions from the meeting:

- There was unanimous agreement that the content did not do an adequate job covering all required category content.
- Slide titles needed to be aligned with content.
- Notes pages were requested to further understand intent of the content.
- Reviewers confirmed to maintain a previous decision from last year to distinguish between the two concepts: "required content" information that must be included to fulfill the legislative intent

and *Rule* while “recommended content” are suggestions the reviewers believe would enhance the curriculum. We will continue to provide both types of feedback to those submitting curriculum. However, only “required” content must be included for final approved curriculum.

Inter-Rater Agreement Outcomes to improve all curricula reviews

Related to all curricula, the reviewers felt strongly about the following items. Agreements are in place among the reviewers for the following items.

- The focus on person centered care will continue and curricula will be highly scrutinized for word choice. Human dignity is to be preserved. For example: symptoms vs problems, challenging vs distressing, person with dementia vs patient or any comparison to children. Labeling or negativity will be pointed out.
- Assessment for pain is always required with discussion of the non-communicative/non-responsive person.
- Curriculum requiring problem solving strategies for challenging behavior will always require a “model.” ABC or similar.
- The Global Deterioration Scale is an excellent requirement for any curriculum with disjointed presentation of the stages of AD.
- Upon receiving curriculum the initial review, in addition to objectives, time allotments and didactic approach, will include: learning objective wording/structure, required content areas, general flow and organization of content. If the curriculum appears inadequate, it will be considered incomplete and not be sent for review until it passes the initial review.
- PowerPoint curriculum presented as broad base bullet points will be required to provide notes pages. It is important to understand what is being taught.

Importantly, this meeting confirmed that our reviewers are using the most up-to-date information in dementia and Alzheimer’s treatment and care. It is important to note that reviewers routinely email each other raising questions and issues from their individual curriculum reviews. This ongoing dialogue also reinforces uniform assessment of curricula and enhances the overall quality of the reviews. The openness and willingness of the reviewers to provide this feedback and review is critical to the program.

Active and Proposed Joint Projects with DOEA-Tracy Aittama and staff

- Issue recommendations and clarifications within the Content Area guidelines for each facility type without changing the Rule intent.
- Through a combined effort with USF Information Technology-Web Services and our team, continue to look for ways to improve functionality of both our back office database and the public/user experience.
- A collaborative project is underway, to clean up the public view of available training providers. Currently, training provider certifications do not expire. Working lists of email and phone numbers, we are contacting individuals to determine if they are still training, if their contact information is still correct or if they would prefer to be removed from the public view of our website. Progress is being made but work continues.
- Identify clarifications and/or changes needed to enhance Rule and Statute understanding so we are ready when the process opens.

Day to Day Activity

This section recaps the many activities required to offer excellent customer service: email, phone and a wide assortment of written correspondence managing the six programs. Record retention, as outlined in the contract, is included.

- Received and responded to approximately 591 telephone calls, assisting callers with application inquiries, navigating our website, and finding approved providers. Some of the more time consuming inquiries involve directing callers to resources other than our office, helping training provider applicants understand credentialing requirements and explaining to curriculum developers what is requested in their “need more information” letters. This category decreased by 7.37% year-over-year.
- Received and responded to nearly 1,180 e-mail messages, including web application notifications, requests to update contact information, general application inquiries, and follow-up communication with applicants. This category has decreased 3.44% year-over-year.
- Received 13 fax communications regarding both training provider applications and curriculum applications. This category stays roughly the same year-over-year with no significant increase or decrease.

During this fiscal year, we received 183 training provider applications and 76 curricula. We approved 170 training provider applications and 52 curricula. Training provider applications were down 32.97% year-over-year while curriculum applications were down 5% year-over-year. Specific details about each type of program are reported below.

Each program’s data are provided for the period from July 1, 2018 - June 30, 2019.

For the ALF program:

- Training Providers: 73 new applications were received and 65 applications were approved.
- Curricula: 33 new applications were received and 21 applications were approved.

For the Nursing Home Program:

- Training Providers: 31 new applications were received and 31 applications were approved.
- Curricula: 11 new applications were received and 6 applications were approved.

For the Hospice program:

- Training Providers: 11 new applications were received and 9 applications were approved.
- Curricula: 10 new applications were received and 10 applications were approved.

For the Home Health program:

- Training Providers: 54 new applications were received and 50 applications were approved.
- Curricula: 21 new applications were received and 13 applications were approved.

For the Adult Day Care program:

- Training Providers: 14 new applications were received and 15 applications were approved.
- Curricula: 1 new applications were received and 2 applications were approved.

For the Specialized Alzheimer’s Adult Day Care program:

- Training Providers: no special credentials; same application as Adult Day Care
- Curricula: 0 new application was received and 0 applications were approved.

Applicants are given 90 days to respond to request for additional information. If they do not follow up, a disapproval letter is sent certified mail. A combined total of 42 training provider and curricula applicants were sent such letters during this fiscal year.

Lastly, the document retention strategy laid out in the contract, (i.e. curriculum files are maintained current year plus six) will be up to date by month end. All training provider files are maintained within the database.

We continue to believe the contract results in improved care for residents who have dementia whether they reside in nursing homes or assisted living facilities, participate in structured day care programs, or receive home health care within budget constraints. We are also confident that we are providing a well-organized, high quality and extremely cost-effective service to the DOEA and the State of Florida as our partnership continues to strengthen year after year.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Kathryn Hyer'.

Kathryn Hyer, PhD, MPP
Professor and Director
USF Training Academy on Aging
Florida Policy Exchange Center on Aging

CC: Tracey Aittama, MSW
Community for a Lifetime
Program Manager
Department of Elder Affairs

Catherine Avery, Chief
Bureau of Elder Rights
Department of Elder Affairs

Jeanne Curtin, Division Director
Department of Elder Affairs

Ross Andel, PhD.
Director, School of Aging Studies
College of Behavioral and Community
Sciences

Gregory Ungru, Deputy Secretary
And Chief of Staff
Department of Elder Affairs



SHIP Priority 9 – Alzheimer’s Disease & Related Dementias (ADRD)

2020 – 2021

Subcommittee AD 1.1

Goal AD 1	Identify a statewide system of resources and support to formalize the ADRD network.
Strategy AD 1.1 (Ongoing)	Establish the Department of Health as a Center of Excellence pursuant to the federal Building Our Largest Dementia Infrastructure for Alzheimer’s Act (BOLD Act).
Objective AD 1.1.1	By October 31, 2020, have a dedicated Dementia Director for Florida.
Activity AD 1.1.1.1	Chair Braisted will draft a letter for committee review, to be sent out by July 1, 2020 to identified state and local Alzheimer’s advocacy organizations explaining the role and purpose of the Florida Dementia Director. (Because of COVID-19, the due date of this objective may need to be revised.)
Proposed Objective AD 1.1.2	By December 31, 2020, the new Dementia Director to send a letter of introduction to identified state and local Alzheimer’s advocacy organizations, including information on her/his role and job duties and how s/he may facilitate the work being done by those organizations and opportunities to collaborate.
Proposed Objective AD 1.1.3	By October 31, 2020, provide information on the Alzheimer’s Association TrialMatch® clinical studies matching service and the Brain Bus to identified state and local Alzheimer’s advocacy organizations.

Revised: May 5, 2020

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Subcommittee AD 1.2

Goal AD 1	Identify a statewide system of resources and support to formalize the ADRD network.
Strategy AD 1.2 (Ongoing)	Create public awareness of modifiable risk factors that reduce the likelihood of developing ADRD and create public awareness of health disparities between populations.
Proposed Objective AD 1.2.1	By July 15, 2020, subcommittee to meet with UF/IFAS Extension to discuss partnering and outreach activities that the Cooperative Extension trainers in each county may incorporate into existing activities to create awareness of modifiable risk factors and also to address health disparities.
Objective AD 1.2.2	By December 31, 2020, incorporate the Center for Disease Control's Healthy Brain Initiative (HBI) Public Health Road Map to establish local and state partnerships to address dementia using the Four Essential Services of Public Health: Monitor and Evaluate, Educate and Empower the Nation, Develop Policies and Mobilize Partnerships, and Assure a Competent Workforce.
Proposed Objective AD 1.2.3	By September 1, 2020, DOEA to host the first bi-annual Dementia Care and Cure Initiative (DCCI) Task Force leadership conference call to facilitate networking and sharing of best practices/lessons learned amongst the task forces.
Proposed Objective AD 1.2.4	By December 31, 2020, (see 2.1.4), disseminate to stakeholders the interactive map on DOEA's Livable Florida webpage which contains information on the DCCI task forces, Memory Disorder Clinics (MDCs), local Memory Cafes, and Age-Friendly communities in Florida.
Proposed Activity AD 1.2.4.1	Subcommittee to identify stakeholders to achieve proposed objective AD 1.2.4.

Subcommittee AD 2.1

Goal AD 2	Strengthen the capacity of care organizations to assess, diagnose and treat individuals with ADRD and expand support for their caregivers.
Strategy AD 2.1 (Ongoing)	Engage with the hospitals and universities that house the state's MDCs so that they each answer Governor DeSantis' challenge to provide matching funding annually to the clinics to allow for an increase in the number of individuals they serve with evaluation and diagnostic testing for dementia.
Proposed Objective AD 2.1.1	By July 1, 2021, partner with ADRD experts to facilitate a caregiver conference.
Proposed Objective AD 2.1.2	By December 31, 2020, incorporate an educational component into the quarterly meetings of the MDC Coordinators.
Objective AD 2.1.3 (Ongoing)	By July 1, 2020, increase evaluations and diagnostic services conducted by each MDC by 15%. (Because of COVID-19, the due date of this objective may need to be revised.)
Proposed Objective AD 2.1.4	By December 31, 2020, identify additional resources to include on the interactive Livable Florida map created and maintained by the Department of Elder Affairs and disseminate the map to identified stakeholders and partners.

Subcommittee AD 2.2

Goal AD 2	Strengthen the capacity of care organizations to assess, diagnose and treat individuals with ADRD and expand support for their caregivers.
Proposed Strategy AD 2.2	Provide to and increase education, tools, training, and respite options for providers and caregivers of individuals living with ADRD, and identify and reduce barriers to caregivers that prevent or delay utilization of services.
Objective AD 2.2.1 (Ongoing)	By December 31, 2021, develop a patient/caregiver toolkit to be provided by identified organizations to individuals who have been diagnosed with ADRD and those who are caregivers of individuals diagnosed with ADRD.
Proposed Objective AD 2.2.2	By December 31, 2020, ensure all licensed physicians, physician assistants, nurse practitioners, and clinical nurse specialists in Florida receive a summary of Medicare Code 99483 which provides reimbursement to physicians and other eligible billing practitioners for a comprehensive clinical visit that results in a written care plan.
Proposed Objective AD 2.2.3	By October 31, 2020, provide identified caregiver resources document to each of the Area Agencies on Aging, MDCs, DCCI task forces, County Health Departments, The Florida Bar Elder Law Section, Bay County Council on Aging, and other stakeholders and partners throughout Florida.
Activity AD 2.2.3.1	By February 21, 2020, provide the caregiver resources document to each of the DCCI task forces and provide them the opportunity to identify other local caregiver resources. Requesting reply within two months. (Because of COVID-19, the due date of this objective may need to be revised.)
Proposed Objective AD 2.2.4	TBD – Proposed objective will support identifying and reducing barriers to caregivers that prevent or delay utilization of services.

Subcommittee AD 3.1

GOAL AD 3	Protect individuals with ADRD from further vulnerability.
Strategy AD 3.1	Enhance the capacity and resiliency of communities to protect individuals with ADRD and reduce negative health impacts to individuals with ADRD by protecting them from abuse, neglect and exploitation.
Proposed Objective AD 3.1.1	By August 15, 2020, identified resources regarding care of individuals with ADRD before and after disasters will be sent to the Area Agencies on Aging, MDCs, DCCI task forces, the Florida Department of Health (to distribute to the County Health Departments), and the Florida Division of Emergency Management (to distribute to local and county emergency management offices), and other organizations throughout the state.
Activity AD 3.1.1.1	Subcommittee to determine which of the identified resources will be disseminated.
Proposed Objective AD 3.1.2	By December 31, 2020, engage with Florida's Division of Emergency Management, Department of Health, Department of Children and Families, Agency for Health Care Administration, Agency for Persons with Disabilities, Area Agencies on Aging, MDCs, Brain Bus, and DCCI task forces to facilitate the registration of individuals living with ADRD in their county's special needs shelter program.
Proposed Objective AD 3.1.3	By August 30, 2021, the Florida Department of Elder Affairs to host Governor Ron DeSantis' Elder Abuse Awareness Summit to stop the abuse, neglect, and exploitation of older adults by raising awareness of the issue with the public and coordinating programs and services to most efficiently direct resources at stopping abuse before it occurs.
Activity AD 3.1.3.1	<p>Subcommittee to review draft list of potential Summit participants.</p> <ul style="list-style-type: none"> • The United States Department of Justice (DOJ), including its Elder Justice Initiative, Elder Justice Coordinators, and Transnational Elder Fraud Strike Force; • The U.S. Administration for Community Living's Prevention of Elder Abuse, Neglect, and Exploitation program; • The Consumer Financial Protection Bureau and the Federal Deposit Insurance Corporation, including their joint project – Money Smart for Older Adults; • The United States Postal Inspection Service; • The United States Special Committee on Aging; • The National Center on Elder Abuse; • Tribal governments; • Federal and State courts, attorneys, prosecutors, and non-profit legal service providers; • Law enforcement, including the Florida Fusion Center (FFC) which is housed in the Office of Statewide Intelligence at the

- Florida Department of Law Enforcement, and FFC's state, local, tribal, and federal agency partners, and other first responders;
- Serving Health Insurance Needs of Elders and the statewide Senior Medicare Patrol Program and its state and federal partners, which include Centers for Medicare & Medicaid Services, state Medicaid fraud control units, and state Attorneys General;
 - The Office of Public and Professional Guardians, and the Long-Term Care Ombudsman Program;
 - The Florida Department of Children and Families, the Florida Department of Health and the County Health Departments, and the Florida Department of Financial Services, including its On Guard for Seniors Program and Operation S.A.F.E. (Stop Adult Financial Exploitation);
 - The Office of the Attorney General (OAG), including its Senior Protection Team which is comprised of members of the OAG's Office of Statewide Prosecution, Consumer Protection Division and Medicaid Fraud Control Unit, and its Seniors vs. Crime Project which operates as a special project of OAG;
 - State units on aging, Area Agencies on Aging, lead agencies, the medical community (including medical schools), and universities (including law schools);
 - The financial services industry and federal and state regulators;
 - Faith-based organizations;
 - Advocates, including AARP, Alzheimer's Association, domestic violence advocates, sexual assault advocates;
 - The insurance industry and federal and state regulators;
 - Elected officials; and
 - Media.

To consider in all objectives: Resources in rural and lower-income areas throughout Florida.

Subcommittee AD 3.2

GOAL AD 3	Protect individuals with ADRD from further vulnerability.
Strategy AD 3.2 (Ongoing)	Reduce health disparities by expanding access and utilization of ADRD-specific care and support services across targeted sub-populations including racial and ethnic minorities, low income individuals, individuals living in rural areas, individuals with Limited English Proficiency, and individuals with disabilities.
Objective AD 3.2.1 (Ongoing)	By December 31, 2021, increase mobile outreach to targeted sub-populations.
Proposed Activity AD 3.2.1.1	Encourage the Alzheimer's Disease Advisory Committee to recommend in its annual report due on September 1, 2020, to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the Secretary of the Department of Elder Affairs, appropriate and sufficient investment in existing mobile outreach infrastructure to ensure targeted sub-populations are served.
Proposed Activity AD 3.2.1.2	Subcommittee to identify outreach activities of Florida medical schools and assess opportunities for collaboration.
Proposed Activity AD 3.2.1.3	By March 31, 2021, identify geographic areas which may be underserved by a MDC or other current ADRD resources, and target outreach to those areas.
Objective AD 3.2.2 (Ongoing)	By December 31, 2021, increase by 10% clinical trial access to racial and ethnic minorities, low income individuals, individuals living in rural areas, individuals with Limited English Proficiency, and individuals with disabilities.
Revised Objective AD 3.2.2	By December 31, 2021, increase by 10% the clinical trial participation rate of racial and ethnic minorities, low income individuals, individuals living in rural areas, Veterans, individuals with Limited English Proficiency, and individuals with disabilities.
Proposed Activity AD 3.2.2.1	Explore culturally competent communication strategies to increase participation rates by underserved and/or underrepresented communities.
Proposed Activity AD 3.2.2.2	Explore how age and/or age-related disease is understood or addressed in underserved and/or underrepresented communities.
Proposed Activity AD 3.2.2.3	Build awareness of and support for treatment related to ADRD in underserved and/or underrepresented communities.
Proposed Activity AD 3.2.2.4	Build partnerships with community and faith-based leaders to conduct culturally competent outreach events to racial and ethnic minorities at risk or currently living with ADRD.

- Proposed Activity AD 3.2.2.5 Effective July 1, 2020, the annual Funding Opportunity Announcement for the Ed and Ethel Moore Alzheimer's Disease Research Grant Program ("Moore") will prioritize clinical trial recruitment and participation for the special populations outlined in the objective.
- Proposed Activity AD 3.2.2.6 Beginning in FY 20-21, quarterly reporting requirements for the Administrator of the Biomedical Research Section of Public Health Research at the Florida Department of Health will be expanded to include the number of individuals from the special populations who are participating in clinical trials and will be reported back to subcommittee semi-annually.

Dementia Care and Cure Initiative 2019 Year End Update

In response to the rapidly increasing incidence of Alzheimer's disease in Florida, the Department of Elder Affairs created the Dementia Care and Cure Initiative (DCCI) in 2015. DCCI seeks to bring education, awareness, and sensitivity to the local community regarding the needs of those affected by dementia. In partnership with Florida's 11 Area Agencies on Aging and 17 Memory Disorder Clinics, communities participating in DCCI organize volunteer-based Task Forces consisting of local stakeholders, professionals in the aging network, and community advocates, including those living with Alzheimer's disease or a related dementia, and care partners.

Task Forces create actionable plans to bring dementia sensitivity education and awareness to their communities. This information includes the signs and symptoms of dementia, communication techniques to utilize when interacting with those living with dementia, and how and where families and individuals can access local resources for support, diagnostic services, and education. Communities participating in these activities are known as Dementia-Caring Communities. This free education has been provided to over 8,000 individuals from various community sectors, including law enforcement agencies, faith networks, fire and rescue stations, health care entities, community groups, social services agencies, and more throughout the state.

The three goals of DCCI are:

- 1. Increase awareness of dementia, services, and supports:*
Accomplished through educational events, the media, and joint efforts with community leadership and stakeholders, including partnering state agencies.
- 2. Provide assistance to dementia-caring communities:*
Each participating community is supported by DOEA to produce and implement community-specific action-oriented plans.
- 3. Continue advocacy for care and cure programs:*
Advocating for the funding of programs that care for both those diagnosed with dementia and their care partners, as well as research efforts that work towards finding a cure.

The City of Tallahassee / Leon County was named the first Dementia-Caring Community in Florida, in the spring of 2016. This Task Force piloted the DCCI dementia sensitivity, is continuing to push education to various sectors of the community and were the first Task Force in the state to provide dementia education to local restaurant staff. They have changed their name to the DCCI of the Big Bend and are reaching beyond Leon County with the work they are

doing. This year, they are working with law enforcement to try to create a registry system for individuals living with dementia in Leon County, and are creating materials specific to wandering and what to do should your loved one go missing. They are also working with Apalachee Behavioral Health to develop a training that is specific for their Mobile Response Team (MRT) to help deescalate situations involving persons with dementia. If this training is successful with the local MRT, they hope to share what they've created with the other DCCI Task Forces throughout the state.

The City of Fort Myers / Lee County was the second entity to come onboard with DCCI, and this Task Force has accomplished much in the way of providing dementia sensitivity training to various sectors of the community. This Task Force had a marketing video created for them by Lee Health and has an educational video in its final editing stages by professors at Florida Gulf Coast University, and this video will be used in place of in-person dementia sensitivity trainings. This Task Force also successfully held a "Dementia Safety Event", wherein they partnered with the United Way of Lee County, the Lee County Sheriff's Office, and Scent Evidence K9 to provide information, safety tips, and local resources to caregivers and individuals living with dementia.

The Sarasota DCCI Task Force was third to come onboard with this initiative and they are doing a fantastic job of training various sectors of the community. They held a "Community Kickoff" event in the past to get area businesses and community entities interested in the work DCCI is doing. This Task Force created a voice-over video of the DCCI dementia sensitivity training and have had success with getting this video embedded in several companies in the area for staff training, and a local Task Force partner houses this training on their website.

Orlando was the fourth community to join this network, and this Task Force, renamed the Central Florida DCCI Task Force, originally held focus groups to get a better understanding of what people affected by Alzheimer's disease and related dementias (ADRD) need in the community. From these focus groups and Task Force member input, a report was created and used a means to guide their efforts. At present, this Task Force is working on a dementia friendly dining initiative in Orange County, which kicked off in January 2020. They have also been successful in getting an "in" with the Orlando VA Clinic's Dementia Committee and are planning a future event to take place at the VA for veterans and their care partners affected by dementia.

The DCCI Task Force housed in Pensacola covers the area of Northwest Florida and has focused their efforts over the years on providing dementia sensitivity training to various sectors of the community. They have focused heavily on providing this training for local congregate meal sites and faith-based organizations, and share information about DCCI at a variety of events throughout their service area. They are wanting to focus Task Force efforts on training first responders this calendar year.

The sixth-named Dementia-Caring Community in Florida was Jacksonville, and this Task Force co-branded with Dementia Friendly America (DFA). This Task Force operates with three

subcommittees in place: Education/Training, Engagement, and Communications, and in 2019 the Engagement Subcommittee applied for and received a \$10,000 grant to help fund a Memory Café in an underserved neighborhood in Duval County, New Town. In addition to co-hosting and participating in educational events, this Task Force brought the Purple Angel Initiative to a local hospital and is hoping to get it into others in the area, and created a discharge toolkit with area resources that is being utilized at a local rehabilitation facility.

The Tampa DCCI Task Force was presented with a plaque from the Hillsborough County Board of County Commissioners, proclaiming June 2019 as “Dementia Care and Cure Initiative Community Month” in Hillsborough County. This year, they are in the process of launching the Purple Dining Initiative, to train restaurant staff in the area on dementia sensitivity, and the PDQ restaurant group has been identified as their first participant.

The Miami-Dade DCCI Task Force works closely with the Mayor’s Initiative on Aging, and last summer hosted two researchers from a university in California who presented their findings from the study, “The Experience of Alzheimer’s Disease for Family Caregivers in a Latino Community: Cultural Congruence and Disparities in Utilization of Support Services” and discussed potential next steps for improving access to and quality of services for Latino family caregivers in the Miami-Dade area. They are also working closely with the Miami-Dade Age-Friendly Initiative and will be co-hosting an event for Age-Friendly municipalities this year.

The Gainesville Task Force was named the ninth Dementia-Caring Community in Florida and has also gone through a name change to better reflect the area they serve and are now calling themselves the Mid-Florida DCCI Task Force. A few months after joining this network, they created a video version of the DCCI dementia sensitivity training, and it is available for community entities in their service area. They also had grandiose plans for a Dementia Resource Expo in Ocala, scheduled to attract hundreds of participants, nearly 50 community partners, and speakers and breakout sessions, all relating to ADRD. This event was postponed due to COVID-19.

The Brevard DCCI Task Force is housed in Melbourne, and something unique about them is their Task Force decal. They held an art class for persons living with dementia, asking them to create their design, and the only requirement was that it contain a rocket, as they’re on the Space Coast of Florida. They had ten submissions, and the Task Force voted anonymously for the winning design, which was of a watercolor rocket ship, and was created by a man living with Alzheimer’s. This Task Force also provides dementia sensitivity training to various sectors of the community, and several members are trained to facilitate Dementia Live®, which is a transformative first-hand dementia experience which heightens understanding, deepens empathy, and elevates care.

Martin County HUGS (Help, Understanding, Guidance, Support) joined the network in August 2019, and is run a bit differently from our other Task Forces. Martin County HUGS was established two years ago in collaboration with Dementia Friendly America (DFA), and is operational through grant funding, whereas all of the other Task Forces are not funded by any

entity. Martin County HUGS' work is specific to Martin County, and they have been successful in offering a standing training for the community every month, as well as training managers at several area Publix supermarket stores. They are currently working with staff at Treasure Coast Hospice and Seacoast Bank, and are trying for a third year of funding from the Community Foundation in Martin County.

The DCCI Task Forces in Pasco-Pinellas, Broward, and Palm Beach Counties are all the newest to join this initiative, and in doing so, fulfilled Governor DeSantis' challenge for all Area Agencies on Aging in Florida to be participating in at least one DCCI Task Force by the end of 2019. They have all hit the ground running with regularly scheduled meetings, and are in the planning processes of creating action plans, finalizing education materials, and are looking to launch their Task Forces in their respective communities.

2018-2019 Ed & Ethel Moore Grants Awarded

Grant #	Organization	PI Name	Project Title	Award Amount
9AZ01	Florida Atlantic University	Rosselli, Monica	Neuroimaging and Sensitive Novel Cognitive Measures in Detection of Early Alzheimer's Disease in Bilingual and Monolingual Hispanic Americans	\$235,018.60
9AZ02	Florida Atlantic University	Van Praag, Henriette	The Role of Exercise-Induced Systemic Factors in Alzheimer's Disease.	\$237,500.00
9AZ03	Florida Atlantic University	Tappen, Ruth	Fit2Drive: Development and Testing of a Driver Risk Predictor for Individuals with AD	\$237,500.00
9AZ04	Florida Atlantic University	Galvin, James	Peripheral Biomarkers to Define the Amyloid, Tau, Neurodegeneration (ATN) Research Framework	\$94,709.30
9AZ05	Florida Atlantic University	Ghoraani, Behnaz	Technology-based Systems to Measure Dual-task (motor-cognitive) Performance as a Biomarker for Early Detection of Alzheimer's Disease	\$95,000.00
9AZ06	Florida Atlantic University	Wei, Jianning	Effect of Neuronal Activity on Synaptopathy in Alzheimer's Disease using a Novel Multi-electrode Microfluidic Platform	\$94,998.82
9AZ07	Florida International University	Burke, Shanna	Shared Neuroanatomical Models of Psychiatric Conditions and Alzheimer's Disease Spectrum Disorders: The Effects of Depression, Anxiety, and Sleep Disturbance and Associated Changes in Brain Morphology Leading to Alzheimer's Disease.	\$237,500.00
9AZ08	Mayo Clinic Jacksonville	Ebbert, Mark	Identifying Functional Mutations in Top Alzheimer's Disease GWAS Genes using Long-read Sequencing in Brain Tissue	\$237,500.00
9AZ09	Mayo Clinic Jacksonville	Li, Yonghe	Therapeutic Roles of Surrogate Wnt Agonist in Alzheimer Disease	\$95,000.00
9AZ10	Mayo Clinic Jacksonville	Springer, Wolfdieter	Validation of Novel, Selective Autophagy Biomarkers in Alzheimer Disease	\$87,181.82
9AZ11	Mount Sinai Medical Center	Greig-Custo, Maria	Impact of the MindSight Training Program on Patients with MCI and Early Stage Dementia	\$237,500.00
9AZ12	University of Central Florida	Wharton, Tracy	The Florida REACH Translation Project: Translating an EBP for an Outpatient Clinical Setting to Reach Diverse Community Members	\$94,998.91
9AZ13	University of Florida	Garvan, Cynthia	Is Cortisol Really a Factor in Cognitive Decline?	\$95,000.00

9AZ14	University of Florida	Maraganore, Demetrius	Utilizing Data from the Electronic Medical Record to Predict Alzheimer's and Dementia Risk	\$237,500.00
9AZ15	University of Florida	Smith, Glenn	Association of PET Amyloid Status with Cognitive and Functional Outcomes of Behavioral Interventions in Mild Cognitive Impairment	\$237,500.00
9AZ16	University of Florida	Mitchell, Gordon	The Two Faces of Hypoxia in Alzheimer's Disease	\$237,497.89
9AZ17	University of Florida	Giasson, Benoit	Mechanisms of Abnormal Neuronal Tau Accumulation, Interactions with Amyloid-beta and Pathological Sequelae.	\$237,500.00
9AZ18	University of Florida	Weisbrod, Neal	Responses to a Standardized Approach to Advance Care Planning in Cognitive Disorders Clinic	\$87,181.82
9AZ19	University of Florida	Price, Catherine	Impact of Total Knee Replacement Surgery on Trajectory of Cognitive Decline in Individuals with Mild Cognitive Impairment (MCI)	\$237,080.10
9AZ20	University of Miami	Govind, Varan	Role of Gut Microbiota on the Brain Metabolism, Cognition, Immune Function and Inflammation in Alzheimer's Disease: Novel Biomarkers and Understanding Mechanisms	\$87,181.82
9AZ21	University of Miami	Curiel, Rosie	Postdoctoral Research Fellowship In Neuropsychology	\$84,301.00
9AZ22	University of Miami	Harvey, Philip	Postdoctoral Fellowship in Cognitive Neuroscience and Neuropsychology	\$87,830.00
9AZ23	University of Miami	Brown, Scott	Impacts of Neighborhood Greenness & Greening Initiatives on Alzheimer's Disease in Medicare Beneficiaries	\$95,000.00
9AZ24	University of Miami	Loewenstein, David	Middle-aged Offspring of Late Alzheimer's Proband: Novel Cognitive and Biomarker Assessment	\$237,171.38
9AZ25	University of Miami	Rundek, Tatjana	Brain Vascular Imaging Phenotypes, Vascular Comorbidities and the Risk for Alzheimer Disease: The Florida VIP Study of AD Risk	\$237,500.00
9AZ26	University of South Florida	Dobbs, Debra	Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia	\$237,496.20
9AZ27	University of South Florida	Conner, Kyaien	A Pilot Study to Examine the Impact of an African Drumming for Dementia Program on African Americans with Mild Cognitive Impairment and Early Alzheimer's Disease and their Caregivers	\$95,000.00
9AZ28	University of South Florida	Meng, Hongdao	Visually-Assisted Mindful Music Listening Intervention for Persons Living with Dementia and their Caregivers: A Pilot Study	\$94,860.35

9AZ29	University of South Florida	Webster, Jack	Intracellular anti-Tau Proteins Engineered on a Hyperthermophilic Scaffold	\$95,000.00
9AZ30	University of South Florida	Bennett, Crystal	Impact of Adapted Dance on Mood and Physical Function among Alzheimer's Disease Assisted Living Residents	\$94,991.99

2018-2019 Active Ed & Ethel Moore Grants

Grant #	Organization	Principal Investigator	Award Amount	Life To Date Expenditure	Unspent Funds	Executed Date	End Date
8AZ01	Ave Maria University	Barbosa, Antonio	\$100,000	\$54,167	\$45,833	02/07/2018	02/28/2019
8AZ02	Florida Atlantic University	Modi, Jigar	\$100,000	\$32,000	\$68,000	03/19/2018	02/29/2020
8AZ03	Florida Institute of Technology	Liao, Yi	\$100,000	\$31,250	\$68,750	02/09/2018	02/28/2020
8AZ04	Florida International University	Nair, Madhavan	\$224,643	\$32,760	\$191,883	02/28/2018	02/28/2022
8AZ05	Florida State University	Carretta, Henry	\$100,000	\$29,166	\$70,834	02/01/2018	02/28/2020
8AZ06	Mayo Clinic Jacksonville	Murray, Melissa Erin	\$221,000	\$42,973	\$178,027	02/12/2018	02/28/2021
8AZ07	Mayo Clinic Jacksonville	Liu, Chia-Chen	\$221,000	\$42,973	\$178,027	02/14/2018	02/28/2021
8AZ08	Mayo Clinic Jacksonville	Lucas, John A.	\$200,000	\$38,704	\$161,296	02/08/2018	02/28/2021
8AZ10	Mayo Clinic Jacksonville	Ebbert, Mark T. W.	\$100,000	\$33,332	\$66,668	02/13/2018	02/28/2019
8AZ11	Mount Sinai Medical Center	Duara, Ranjan	\$96,643	\$8,053	\$88,590	05/21/2018	04/30/2020
8AZ12	University of Central Florida	Teter, Kenneth	\$200,000	\$25,002	\$174,998	04/09/2018	02/28/2022
8AZ13	University of Central Florida	Hernandez, Florencio	\$200,000	\$58,331	\$141,669	03/05/2018	02/28/2020

8AZ14	University of Central Florida	Sikorska-Simmons, Elzbieta	\$95,784	\$27,937	\$67,847	03/05/2018	02/28/2020
8AZ15	University of Florida	Kesavalu, Lakshmyya	\$221,000	\$64,456	\$156,544	02/21/2018	02/28/2020
8AZ16	University of Florida	Chakrabarty, Paramita	\$221,000	\$32,228	\$188,772	02/08/2018	02/28/2022
8AZ17	University of Florida	Cottler, Linda B.	\$200,000	\$38,892	\$161,108	03/05/2018	02/28/2021
8AZ18	University of Florida	Yachnis, Anthony T.	\$99,987	\$16,664	\$83,323	01/25/2018	02/28/2020
8AZ19	University of Florida	Streit, Wolfgang J.	\$96,643	\$28,189	\$68,454	02/01/2018	02/28/2020
8AZ20	University of Florida	Xu, Guillian	\$99,577	\$29,043	\$70,534	02/21/2018	02/28/2020
8AZ21	University of Miami	Curriel, Rosie	\$89,304	\$52,094	\$37,210	02/28/2018	02/28/2019
8AZ22	University of Miami	Alperin, Noam	\$221,000	\$64,456	\$156,544	02/16/2018	02/28/2020
8AZ23	University of Miami	Loewenstein, David	\$450,844	\$131,495	\$319,349	02/14/2018	02/28/2020
8AZ24	University of Miami	Toborek, Michal	\$221,000	\$32,228	\$188,772	02/07/2018	02/28/2022
8AZ25	University of Miami	Griswold, Anthony	\$100,000	\$58,331	\$41,669	02/27/2018	02/28/2019
8AZ26	University of Miami	Dykhhoorn, Derek	\$200,000	\$58,331	\$141,669	02/14/2018	02/28/2020
8AZ27	University of South Florida	Selenica, Maj-Linda B.	\$100,000	\$29,169	\$70,831	02/09/2018	02/28/2020
8AZ28	University of South Florida	Nash, Kevin	\$100,000	\$29,169	\$70,831	02/08/2018	02/28/2020

8AZ29	University of South Florida	Kang, David E.	\$221,000	\$64,459	\$156,541	02/06/2018	02/28/2020
8AZ30	University of South Florida	Lee, Daniel C.	\$200,000	\$29,167	\$170,833	02/23/2018	02/28/2022
8AZ32	The Roskamp Institute, Inc.	Keegan, Andrew	\$99,576	\$29,043	\$70,533	03/02/2018	02/28/2020

A sampling of these research findings includes:

- (1) Relative frequencies of different types of dementias among nearly 400 cases who came to autopsy in the first decade of the brain bank. Alzheimer's disease was present in about three quarters of cases, followed by Lewy Body Dementia, then Hippocampal Sclerosis, then Frontotemporal Dementia and finally Vascular Dementia. About two thirds of Lewy Body Dementia cases had coexisting Alzheimer's disease.
 - (2) An important finding was the discovery that Hippocampal Sclerosis was not caused by vascular disease, as had previously been thought, but was an independent neurodegenerative disease, discovered to be associated with a protein called TDP43. Hippocampal Sclerosis was discovered to found to be a relatively frequent cause of very late-onset Dementia (above the age of 85 years), tending to progress very slowly and have mild memory impairment which can be difficult to distinguish for normal aging effects;
 - (3) Identification of a unique form of familial Fronto-temporal Dementia with Amyotrophic Lateral Sclerosis caused by a mutation in a gene on Chromosome 9, known as C9ORF72;
 - (4) Identification of pathological and clinical subtypes of Alzheimer's disease (those subtypes that affect primarily the hippocampus) and those that spare the hippocampus. Knowledge of these subtypes has improved the clinical diagnosis of Alzheimer, including the identification on MRI scans of the subtypes, and have allowed better understanding of the age of onset and the rate of progression of Alzheimer's disease;
 - (5) The Florida BB has been the host to testing the accuracy and utility of various agents used in conducting PET scans for determining the presence location and amount of amyloid protein in the brain. The autopsied brains are used to assess pathologically the amount of amyloid present in the brain among Individuals who have had amyloid PET scans before death. The PET scan findings are then correlated with the pathological findings on autopsied brains;
 - (6) Utilizing the detailed clinical histories and pathological specimens available in the Brain Bank it has been possible to identify that a small structure in the base of the brain, namely the Nucleus Basalis, is strongly associated as a marker of the various subtypes of Alzheimer's disease, which may also have a bearing on predicting the response to treatment in each subtype (references 1 to 14, below).
1. Sakae N, Josephs KA, Litvan I, Murray ME, Duara R, Uitti RJ, Wszolek ZK, Graff-Radford NR, Dickson DW. Neuropathologic Basis of Frontotemporal Dementia in Progressive Supranuclear Palsy. *Movement Disorders*, In Press August 2019.
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3. Fadi S, Hanna Al-Shaikh BS1, Ranjan Duara MD2, Julia E. Crook PhD3, Elizabeth R. Lesser MS3, Jolien Schaevebeke PhD1, Kelly M. Hinkle MS1, Owen A. Ross PhD1, Nilufer Ertekin-Taner MD PhD1,4, Otto Pedraza PhD5, Dennis W. Dickson MD1, Neill R. Graff-Radford MBBCh FRCP4, Melissa E. Murray PhD. Selective Vulnerability of the Nucleus Basalis of Meynert among Neuropathologic Subtypes of Alzheimer's Disease. *JAMA Neurology*, 2019 (In Press)
4. Liesinger AM, Graff-Radford NR, Duara R, Carter RE, Hanna Al-Shaikh FS, Koga S, Hinkle KM, DiLello SK, Johnson MF, Aziz A, Ertekin-Taner N, Ross OA, Dickson DW, Murray ME. Sex and age interact to determine clinicopathologic differences in Alzheimer's disease. *Acta Neuropathol*. 2018 Dec;136(6):873-885. doi: 10.1007/s00401-018-1908-x. Epub 2018. PMID: 30219939.
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Most IRB-approved research studies, labeled B and C below, are state and federally funded investigations, such as randomized clinical trials, demonstration projects and archival studies.

Research Information					
Number of clients referred to Brain Bank	482	681	740	748	2,651
Number clients referred to Project B	261	321	267	185	1,034
Number of clients referred to Project C	69	59	138	529	795
Total	611	919	961	1,267	4,480

Alzheimer's Disease Data by County

County	65-74	75-84	85+	Total Population	ALZ 65-74	ALZ 75-84	ALZ 85+	Probable Alzheimer's Cases
Alachua	22,220	10,505	4,697	267,306	813	1,831	2,038	4,883
Baker	2,337	1,080	325	28,249	86	188	141	434
Bay	17,478	9,279	4,140	167,283	640	1,618	1,796	3,826
Bradford	2,821	1,559	660	28,682	103	272	286	689
Brevard	72,527	44,091	19,360	594,469	2,654	7,687	8,400	19,382
Broward	177,304	91,215	46,911	1,919,644	6,488	15,902	20,353	43,627
Calhoun	1,558	913	308	14,067	57	159	134	338
Charlotte	34,392	22,311	9,369	181,770	1,258	3,890	4,065	9,543
Citrus	26,330	17,050	6,863	147,744	963	2,972	2,978	7,112
Clay	19,237	9,509	3,235	215,246	704	1,658	1,404	3,932
Collier	52,887	36,736	14,679	376,706	1,935	6,404	6,369	15,434
Columbia	7,710	3,976	1,428	70,492	282	693	620	1,653
Miami-Dade	239,078	145,097	64,060	2,812,130	8,748	25,295	27,794	63,572
Desoto	3,770	2,275	723	36,065	138	397	314	870
Dixie	2,326	1,136	318	16,610	85	198	138	436
Duval	80,639	37,141	16,746	970,672	2,951	6,475	7,266	17,398
Escambia	31,683	16,769	7,010	321,134	1,159	2,923	3,041	7,335
Flagler	16,727	9,808	3,310	110,635	612	1,710	1,436	3,947
Franklin	1,516	827	266	12,273	55	144	115	323
Gadsden	5,029	2,365	794	46,277	184	412	344	928
Gilchrist	2,116	1,088	505	17,766	77	190	219	510
Glades	1,726	1,169	304	13,121	63	204	132	414
Gulf	1,971	1,062	365	13,082	72	185	158	401
Hamilton	1,646	767	240	14,600	60	134	104	310
Hardee	2,277	1,175	453	27,385	83	205	197	497
Hendry	3,025	1,709	674	40,120	111	298	292	736
Hernando	27,331	17,472	7,355	188,358	1,000	3,046	3,191	7,423
Highlands	17,261	12,426	5,164	103,434	632	2,166	2,241	5,141
Hillsborough	112,782	56,865	23,733	1,444,870	4,127	9,913	10,297	25,218
Holmes	2,340	1,390	406	20,049	86	242	176	516
Indian River	23,326	14,998	7,377	154,939	854	2,615	3,201	6,870
Jackson	5,252	3,047	1,229	46,969	192	531	533	1,234

Jefferson	2,012	820	315	14,776	74	143	137	364
Lafayette	747	408	142	8,482	27	71	62	168
Lake	47,471	29,645	10,992	357,247	1,737	5,168	4,769	12,273
Lee	102,002	59,399	20,874	735,148	3,732	10,355	9,057	24,255
Leon	23,645	10,468	4,352	296,499	865	1,825	1,888	4,763
Levy	5,634	3,008	824	41,330	206	524	358	1,115
Liberty	662	324	105	8,772	24	56	46	127
Madison	2,230	1,110	452	19,570	82	194	196	486
Manatee	53,445	31,784	13,066	387,414	1,956	5,541	5,669	13,699
Marion	54,502	34,649	12,507	360,421	1,994	6,040	5,426	13,935
Martin	23,547	15,615	7,746	158,598	862	2,722	3,361	7,174
Monroe	10,615	4,686	1,442	76,212	388	817	626	1,942
Nassau	10,789	5,314	1,723	85,070	395	926	748	2,209
Okaloosa	18,604	10,341	4,143	201,514	681	1,803	1,798	4,445
Okeechobee	4,147	2,553	894	41,808	152	445	388	1,020
Orange	95,621	44,808	18,811	1,386,080	3,499	7,812	8,162	20,320
Osceola	28,223	13,579	4,896	370,552	1,033	2,367	2,124	5,897
Palm Beach	167,903	109,229	60,092	1,447,857	6,144	19,042	26,072	51,702
Pasco	64,259	37,402	15,779	527,122	2,351	6,520	6,846	16,243
Pinellas	129,564	74,264	35,744	978,045	4,741	12,947	15,508	33,951
Polk	77,159	44,149	15,433	690,606	2,823	7,697	6,696	17,888
Putnam	9,215	4,884	1,896	73,268	337	851	823	2,057
Saint Johns	26,792	13,319	5,731	254,412	980	2,322	2,487	6,302
Saint Lucie	35,896	20,874	8,686	309,359	1,314	3,639	3,769	8,972
Santa Rosa	16,409	8,234	2,614	179,054	600	1,435	1,134	3,323
Sarasota	71,015	49,812	22,939	426,275	2,599	8,684	9,953	22,022
Seminole	40,503	19,945	9,591	471,735	1,482	3,477	4,161	9,458
Sumter	36,092	24,011	5,338	128,633	1,321	4,186	2,316	8,334
Suwannee	5,261	3,164	1,265	45,423	193	552	549	1,344
Taylor	2,800	1,507	409	22,458	102	263	177	563
Union	1,327	525	141	15,505	49	92	61	206
Volusia	70,804	38,663	18,011	538,763	2,591	6,740	7,814	17,530
Wakulla	2,900	1,243	377	32,976	106	217	164	507
Walton	7,790	3,680	1,285	70,071	285	642	558	1,565
Washington	2,662	1,404	415	25,387	97	245	180	536

2018-2019 Total ADI Funding and Clients Served per County.

PSA	County	Total Individuals Served	Total Spending	Clients on Waitlist for ADI Services	Total Population	Probable Alzheimer's Cases
1	Escambia	41	\$419,576.19	183	321,134	7,335
1	Okaloosa	24	\$84,358.17	84	201,514	4,445
1	Santa Rosa	11	\$57,857.37	82	179,054	3,323
1	Walton	9	\$58,356.34	20	70,071	1,565
2	Bay	35	\$125,666.35	36	167,283	3,826
2	Calhoun	2	\$33,746.64	7	14,067	338
2	Franklin	2	\$10,731.98	6	12,273	323
2	Gadsden	10	\$21,689.06	26	46,277	928
2	Gulf	1	\$10,699.40	1	13,082	401
2	Holmes	3	\$46,883.89	8	20,049	516
2	Jackson	8	\$25,195.69	9	46,969	1,234
2	Jefferson	5	\$24,337.88	11	14,776	364
2	Leon	17	\$229,503.22	82	296,499	4,763
2	Liberty	3	\$9,846.81	2	8,772	127
2	Madison	4	\$24,660.73	7	19,570	486
2	Taylor	4	\$36,397.32	7	22,458	563
2	Wakulla	5	\$40,697.49	10	32,976	507
2	Washington	5	\$53,120.64	9	25,387	536
3	Alachua	238	\$376,342.00	153	267,306	4,883
3	Bradford	29	\$28,622.54	15	28,682	689
3	Citrus	216	\$177,947.11	122	147,744	7,112
3	Columbia	83	\$107,050.97	50	70,492	1,653
3	Dixie	20	\$50,867.41	4	16,610	436
3	Gilchrist	13	\$18,257.67	10	17,766	510
3	Hamilton	16	\$50,716.09	11	14,600	310
3	Hernando	125	\$221,226.10	144	188,358	7,423
3	Lafayette	4	\$24,716.95	6	8,482	168
3	Lake	274	\$292,844.41	256	357,247	12,273
3	Levy	57	\$50,743.01	33	41,330	1,115
3	Marion	288	\$334,929.74	253	360,421	13,935
3	Putnam	71	\$53,254.52	45	73,268	2,057
3	Sumter	100	\$120,583.46	54	128,633	8,334

3	Suwannee	48	\$41,948.84	34	45,423	1,344
3	Union	12	\$43,156.89	9	15,505	206
4	Baker	3	\$64,455.15	13	28,249	434
4	Clay	15	\$126,165.00	197	215,246	3,932
4	Duval	56	\$471,010.66	701	970,672	17,398
4	Flagler	28	\$205,176.49	135	110,635	3,947
4	Nassau	14	\$92,065.34	89	85,070	2,209
4	Saint Johns	34	\$175,095.15	132	254,412	6,302
4	Volusia	117	\$508,981.86	460	538,763	17,530
5	Pasco	315	\$730,662.33	197	527,122	16,243
5	Pinellas	541	\$1,122,338.03	266	978,045	33,951
6	Hardee	30	\$16,078.87	8	27,385	497
6	Highlands	122	\$172,833.02	64	103,434	5,141
6	Hillsborough	898	\$1,052,716.16	708	1,444,870	25,218
6	Manatee	290	\$443,039.88	115	387,414	13,699
6	Polk	521	\$505,672.69	325	690,606	17,888
7	Brevard	83	\$494,558.43	197	594,469	19,382
7	Orange	316	\$614,738.50	567	1,386,080	20,320
7	Osceola	14	\$189,441.69	233	370,552	5,897
7	Seminole	118	\$279,854.50	172	471,735	9,458
8	Charlotte	48	\$264,147.94	118	181,770	9,543
8	Collier	70	\$561,511.40	143	376,706	15,434
8	Desoto	8	\$34,988.71	16	36,065	870
8	Glades	3	\$10,728.91	1	13,121	414
8	Hendry	5	\$58,538.94	24	40,120	736
8	Lee	54	\$692,463.49	463	735,148	24,255
8	Sarasota	46	\$555,097.12	184	426,275	22,022
9	Indian River	18	\$187,472.18	69	154,939	6,870
9	Martin	40	\$204,365.79	89	158,598	7,174
9	Okeechobee	8	\$24,191.38	13	41,808	1,020
9	Palm Beach	1,375	\$5,478,680.97	785	1,447,857	51,702
9	Saint Lucie	45	\$299,379.58	221	309,359	8,972
10	Broward	299	\$1,930,324.76	511	1,919,644	43,627
11	Miami-Dade	287	\$1,800,675.53	332	2,812,130	63,572
11	Monroe	21	\$183,756.14	12	76,212	1,942

County	Active Adult Day Care Centers Per County (Florida)	Total Population	Probable Alzheimer's Cases
Alachua	2	267,306	4,883
Brevard	8	594,469	19,382
Broward	27	1,919,644	43,627
Charlotte	4	181,770	9,543
Citrus	1	147,744	7,112
Clay	1	215,246	3,932
Columbia	1	70,492	1,653
Duval	11	970,672	17,398
Escambia	1	321,134	7,335
Flagler	2	110,635	3,947
Gadsden	1	46,277	928
Hernando	2	188,358	7,423
Highlands	1	103,434	5,141
Hillsborough	17	1,444,870	25,218
Indian River	2	154,939	6,870
Lake	4	357,247	12,273
Lee	13	735,148	24,255
Leon	2	296,499	4,763
Manatee	1	387,414	13,699
Marion	2	360,421	13,935
Martin	2	158,598	7,174
Miami-Dade	166	2,812,130	63,572
Monroe	2	76,212	1,942
Nassau	1	85,070	2,209
Okaloosa	1	201,514	4,445
Orange	8	1,386,080	20,320
Osceola	3	370,552	5,897
Pasco	4	527,122	16,243
Pinellas	12	978,045	33,951
Polk	3	690,606	17,888
Sarasota	2	426,275	22,022
Seminole	4	471,735	9,458
St. Johns	1	254,412	6,302
St. Lucie	4	309,359	8,972
Volusia	3	538,763	17,530

PACE Centers	Counties Funded	Funded Slots
Florida PACE	Broward	125
Florida PACE	Miami-Dade	809
Hope Select Care PACE	Lee, Charlotte, and Collier	650
Palm Beach PACE	Palm Beach	656
Suncoast PACE	Pinellas	325
PROGRAM TOTAL		2,565

Fiscal Year	Combined Federal and State Funding	Clients Served
2009-2010	\$10,278,683	550
2010-2011	\$9,960,079	900
2011-2012	\$14,269,333	795
2012-2013	\$25,207,786	1,018
2013-2014	\$28,330,951	1,100
2014-2015	\$36,526,016	1,108
2015-2016	\$39,550,155	1,539
2016-2017	\$50,282,883	1,866
2017-2018	\$47,718,123	1,882
2018-2019	\$62,045,114	2,150

Service Descriptions

Program Codes Used in This Section

Acronyms/abbreviations for programs with data captured by the Department's Client Information and Registration Tracking System (CIRTS) and the Agency for Health Care Administration's (AHCA) Florida Medicaid Management Information System (FMMIS).

AC	AmeriCorps	OAA	Older Americans Act
ACFP	Adult Care Food Program	OPPG	Office of Public and Professional Guardians
ADI	Alzheimer's Disease Initiative	PACE	Program of All-Inclusive Care for the Elderly
CARES	Comprehensive Assessment and Review for Long-Term Care Services	PEARLS	Program to Encourage Active Rewarding Lives for Seniors
CCE	Community Care for the Elderly	PSA	Planning and Service Area
CIRTS	Client Information and Registration Tracking System	RELIEF	Respite for Elders Living in Everyday Families
DOEA	Department of Elder Affairs	SCP	Senior Companion Program
DRI	Dietary Reference Intake	SCSEP	Senior Community Service Employment Program
	Emergency Alert Response	SFMNP	Senior Farmers' Market Nutrition Program
EHEAP	Emergency Home Energy Assistance for the Elderly Program	SHINE	Serving Health Insurance Needs of Elders Program
HCE	Home Care for the Elderly	SMMC LTC	Statewide Medicaid Managed Care Long-term Care Program
LSP	Local Services Programs	SMP	Senior Medicare Patrol
LTCOP	Long-Term Care Ombudsman Program	USDA	United States Department of Agriculture
MIPPA	Medicare Improvements for Patients and Providers Act		
MMIS	Medication Management Improvement System		

Service	Description	Unit Type	Program(s)	Units of Service
A Matter of Balance	Adapted from Boston University's Roybal Center by Maine's Partnership for Healthy Aging, "A Matter of Balance" uses practical coping strategies to reduce fear of falling and to diminish the risk of falling, including group discussions; mutual problem-solving exercises to improve strength, coordination, and balance; and home safety evaluations.	Episodes	OAA	166
Active Living Every Day	Step-by-step behavior change program that helps individuals overcome their barriers to physical activity . As participants work through the course, they learn lifestyle management skills and build on small successes – methods that have proven effective in producing lasting change.	Episodes	OAA	7
Adult Day Care	Therapeutic social and health activities and services provided to adults who have functional impairments in a protective environment as non-institutional as possible .	Hours	CCE, HCE, LSP, OAA	758,045
Adult Day Health Care	Services furnished four or more hours per day on a regularly scheduled basis for one or more days per week in an outpatient setting, encompassing both health and social services needed to ensure the optimal functioning of the individual.	Hours	CCE, OAA	5,849
	Services furnished in an outpatient setting that encompass both the health and social services needed to ensure optimal functioning of the individual, including social services to help with personal and family problems, planned group therapeutic activities, and nutritional meals.		SMMC LTC	7,995,405
Arthritis Foundation Exercise Program	Recreational exercise program designed specifically for people with arthritis and related diseases . The program uses gentle activities to help increase joint flexibility and range of motion, maintain muscle strength, and increase overall stamina .	Episodes	OAA	27

Service	Description	Unit Type	Program(s)	Units of Service
Arthritis Foundation Tai Chi Program	Also known as Tai Chi for Arthritis, this program is offered in community settings and has been proven to improve movement, balance, strength, flexibility, and relaxation. Other benefits associated with this program include decreases in pain and falls .	Episodes	OAA	72
Assisted Living	Personal care services, homemaker services, chore services, attendant care, companion services, medication oversight, and therapeutic social and recreational programming provided in a home-like environment in an assisted living facility . This service does not include the cost of room and board furnished in conjunction with residing in the facility .	Hours	SMMC LTC	4,021,512
Attendant Care	Hands-on supportive and health-related care specific to the needs of a medically stable, physically handicapped individual. Supportive services are those which substitute for the absence, loss, diminution, or impairment of a physical or cognitive function . This service may include skilled or nursing care to the extent permitted by state law . Housekeeping activities that are incidental to the performance of care may also be furnished as part of this activity .	Hours	SMMC LTC	749,453
		Episodes		14,138
Basic Subsidy	Fixed-sum cash payment made to an eligible caregiver each month to reimburse some of his/her expenses incurred while caring for the client . A basic subsidy is provided for support and maintenance of the care recipient, including medical costs not covered by Medicaid, Medicare, or any other insurance.	Months of Service	HCE	22,301

Service	Description	Unit Type	Program(s)	Units of Service
Behavioral Management	Behavioral health care services address mental health or substance abuse needs of members . Services are used to maximize reduction of the enrollee's disability and restoration to the best possible functional level and may include, but are not limited to, the following: an evaluation of the origin and trigger of the presenting behavior; development of strategies to address the behavior; implementation of an intervention by the provider; and assistance for the caregiver in being able to intervene and maintain the improved behavior .	Hours	SMMC LTC	Group: 1,697 Individual: 105,289
		Episodes		Group: 4,498 Individual: 836
Caregiver Training and Support	Training of caregivers, individually or in group settings, to reduce stress, increase coping skills, provide strategies for effective management of caregiving tasks, and enable them to provide high quality care to recipients within the home . Caregiver training and support may be provided through forums, including community seminars; support groups; and other organized local, regional, or statewide events .	Hours	ADI, CCE, OAA	Group: 3,739 Individual: 2,243
			SMMC LTC	20
Case Aide	Services that are supplemental to case management services and are provided by paraprofessionals under the direction of case managers or designated supervisory staff.	Hours	ADI, CCE, HCE, OAA	27,182
Case Management	Client-centered service that seeks to identify physical and emotional needs and problems through an interview and assessment process, including discussing and developing a plan for services that addresses these needs; arranging and coordinating agreed-upon services; and monitoring the quality and effectiveness of the services. Case management is a service for actively enrolled clients that provides continuing support and addresses the changing needs of clients .	Hours	ADI, CCE, HCE, LSP, OAA, SMMC LTC	285,895
		Episodes	SMMC LTC	265,787
		Months	SMMC LTC	32

Service	Description	Unit Type	Program(s)	Units of Service
Child Day Care	Services provided to a minor child no older than 18 or a child with a disability who resides with a grandparent or other related caregiver age 55 or older .	Hours	OAA	3,913
Chore	Services include routine house or yard tasks, including seasonal cleaning; yard work; lifting and moving furniture, appliances, or heavy objects; household repairs that do not require a permit or specialist; and household maintenance . Pest control may be included when not performed as a distinct activity .	Hours	CCE, LSP, OAA, HCE	28,441
Chore – Enhanced	Performance of any house or yard task beyond the scope of regular chore services due to more demanding circumstances requiring more intensified, thorough cleaning.	Hours	CCE, HCE, OAA	8,195
Chronic Disease Self-Management Program	Developed by Stanford University, community setting workshops are provided for individuals with chronic health problems. Workshops cover techniques to deal with problems such as frustration, fatigue, pain, and isolation; appropriate exercise for maintaining and improving strength, flexibility, and endurance; appropriate use of medications; communicating effectively with family, friends, and health professionals; nutrition; and how to evaluate new treatments .	Episodes	OAA	25
Chronic Pain Self-Management Program	Developed by Stanford University for individuals living with chronic pain, participants receive information and practical skills for chronic pain management . This program is for people who have a primary or secondary diagnosis of chronic pain that lasts 3-6 months or longer than the normal healing time of an injury .	Episodes	OAA	18

Service	Description	Unit Type	Program(s)	Units of Service
Companionship	Visiting a client who is socially and/or geographically isolated for the purpose of relieving loneliness and providing the client with continuing social contact with the community . It includes engaging in casual conversation; providing assistance with reading and writing letters; playing entertaining games; escorting a client to a doctor's appointment; and conducting diversion activities such as going to the movies, mall, library, or grocery store. Companions may also assist the recipient with such tasks as meal preparation, laundry, and light housekeeping tasks that are incidental to the individual's care and supervision.	Hours	CCE, OAA, SCP	218,764
Congregate Meals	Meals or snacks provided at eligible Adult Care Food Program centers .	Meals or Snacks	ACFP	3,014,210
	Meals provided at a congregate meal site that comply with the Dietary Guidelines for Americans and provides one-third of the daily Dietary Reference Intake (DRI) for a female age 70 or older (the predominant statewide demographic recipient), as established by the Food and Nutrition Board of National Academy of Sciences .	Meals	LSP, OAA	3,720,436
Congregate Meals Screening	Assessments for congregate meal applicants or recipients with referral and follow-up as needed .	Hours	LSP, OAA	14,683
Counseling	Contacts with beneficiaries, family members, caregivers, or others, where program or Medicare information is shared, or for the purpose of discussing or gathering information about potential health care fraud, errors, or abuse . Depending on the program, individual interactions may also include counseling, investigation, and/or referrals to other agencies or target special beneficiary groups such as individuals with low-income or those living in rural areas.	Clients	SHINE, MIPPA, SMP	126,749

Service	Description	Unit Type	Program(s)	Units of Service
Counseling	Education and training for patient self-management by a qualified, non-physician health care professional .	Hours	SMMC LTC	50
Counseling – Gerontological	Emotional support, information, and guidance through a variety of modalities, including mutual support groups for older adults who are having mental, emotional, or social adjustment problems as a result of the process of aging.	Hours	ADI, CCE, HCE, LSP, OAA	Group: 1,289 Individual: 6,909
Counseling – Medicare and Health Insurance	Medicare and health insurance education, counseling, and assistance to Medicare beneficiaries, their families, and caregivers .	Client Contacts	SHINE	53,296
Counseling – Mental Health Counseling and Screening	Services focus on the unique treatment of psychiatric disorders and rehabilitation for impairments for persons suffering from a mental illness, including depression and anxiety . These services include specialized individual, group, and family therapy provided to clients using techniques appropriate to this population .	Hours	ADI, CCE, LSP, OAA	Group: 69 Individual: 5,731
Counseling – Reintegration Training	Community/work reintegration training, including shopping, transportation, money management, avocational activities and/or work environment/ modification analysis, work task analysis, and use of assistive technology device/adaptive equipment .	Hours	SMMC LTC	20
Diabetes Empowerment Education Program	Provides residents in the community with tools to better manage their diabetes . Evidence-based content components include nutrition, prevention of both chronic and acute complications, blood glucose monitoring, insulin pump program, and individual goals which include quality and length of life.	Episodes	OAA	19

Service	Description	Unit Type	Program(s)	Units of Service
Diabetes Self-Management Program	Diabetes self-management training services .	Hours	SMMC LTC	44
	Developed by Stanford University, individuals with Type 2 Diabetes attend workshops in a community setting . Subjects covered include techniques to deal with the symptoms of diabetes, fatigue, pain, hyper/hypoglycemia, stress, and emotional programs such as depression, anger, fear, and frustration; appropriate exercise for maintaining and improving strength and endurance; healthy eating; appropriate use of medication; and working more effectively with health care providers . Participants make weekly action plans, share experiences, and help each other solve problems they encounter while creating and carrying out their self-management program .	Episodes	OAA	22
Education	Speaking to groups or distributing materials to individuals at public gatherings about services and opportunities available to them within their communities. Providing formal or informal opportunities for individuals or groups to acquire knowledge, experience, or skills; increasing awareness in areas like crime or accident prevention; promoting personal enrichment; and enhancing skills in aspecific craft, trade, job, or occupation . Other options include training individuals or groups in guardianship proceedings for older individuals if other adequate representation is unavailable .	Episodes	LSP, OAA	Group: 11,529 Individual: 1,722
Emergency Alert Response (EAR) – Installation	Community-based electronic surveillance service that monitors frail homebound elders at high risk of institutionalization. EAR monitors by means of an electronic communication link to a response center with an electronic device that enables the elder to secure help in an emergency . The recipient can also wear a portable “help” button to allow for mobility . The system is connected to the person’s phone and programmed to signal a response center once the “help” button is activated .	Episodes	CCE, OAA, SMMC LTC	426

Service	Description	Unit Type	Program(s)	Units of Service
Emergency Alert Response (EAR) – Maintenance	Maintenance of EAR system, as explained above .	Days	CCE, LSP, OAA	1,044,765
		Months	SMMC LTC	156,243
Employment and Job Training	Average of 20 hours per week of paid part-time community service work for unemployed low-income persons who are age 55 and older . Assists with transition to unsubsidized employment .	Participants Served	SCSEP	829
Energy Assistance	Assistance to low-income households (with at least one individual age 60 or older in the home) experiencing a home energy emergency .	Households Served	EHEAP	12,022
Enhance Fitness	Group exercise program developed by the University of Washington, in collaboration with Senior Services, that focuses on stretching, flexibility, balance, low-impact aerobics, and strength training exercises .	Hours	OAA	1,634
Enhance-Wellness	Evidenced-based program developed by the University of Washington, in collaboration with Senior Services, that shows participants how to lower the need for drugs that affect thinking or emotions, lesson symptoms of depression and other mood problems, and develop a sense of greater self-reliance .	Hours	OAA	4
Escort	Personal accompaniment and assistance to a person who has physical or cognitive difficulties using regular vehicular transportation . The accompaniment and assistance is provided to individuals to or from service providers, medical appointments, or other destinations needed by the client . Escort is essential during travel to provide safety, security, and support .	Trips	CCE, OAA	383
Financial Risk Reduction – Assessment	Assessment of problem area(s) and guidance for managing income, assets, liabilities, and expenditures .	Hours	CCE	9
Financial Risk Reduction – Maintenance	Maintenance of problem area(s) and guidance for managing income, assets, liabilities, and expenditures .	Hours	CCE	115

Service	Description	Unit Type	Program(s)	Units of Service
Health Promotion	Individual and/or group sessions to help participants understand how lifestyle affects physical and mental health and develop personal practices that enhance total well-being . Services are provided at multipurpose senior centers, congregate meal sites, and other appropriate places that target elders who are low-income, minorities, or medically underserved . Services include the following: health risk assessments; routine health screenings; physical activity; home injury control services; mental health screenings for prevention and diagnosis; medication management, screening and education; gerontological counseling; and distribution of information concerning diagnosis, prevention, treatment, and rehabilitation of age- related diseases and chronic disabling conditions such as osteoporosis and cardiovascular diseases .	Episodes	LSP	60
Health Risk Assessment	Assessment utilizing one tool or a combination of tools to test older persons for certain risk factors that are known to be associated with a disease or condition . Many factors can be modified, including diet, risk-taking behaviors, coping styles, and lifestyle choices (such as smoking and overeating), and can be measured or identified through risk appraisal questionnaires . The health risk assessment helps the individual determine the addictive nature of many factors in their life . This can be done on a one-on-one or group basis .	Episodes	LSP	770
Health Support	Helps individuals secure and utilize necessary medical treatment, as well as preventive, emergency, and health maintenance services .	Hours	LSP, OAA	Group: 15,074
		Episodes	LSP, OAA	Individual: 9,280
Healthy Eating Every Day	Helps individuals establish healthy eating habits . Participants identify the reasons for their poor eating choices, learn management skills, and improve their eating habits . Healthy Eating Every Day follows the USDA Nutrition Guidelines.	Episodes	OAA	4

Service	Description	Unit Type	Program(s)	Units of Service
Home Accessibility Adaptations Services	Physical adaptations to the home required by the enrollee's plan of care that are necessary to ensure the health, welfare, and safety of the enrollee or that enable the enrollee to function with greater independence in the home and without which the enrollee would require institutionalization . Adaptations may include the installation of ramps and grab bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems to accommodate the medical equipment and supplies necessary for the welfare of the enrollee . All services shall be provided in accordance with applicable state and local building codes .	Episodes	SMMC LTC	878
Home Health Aide	Hands-on personal care services, simple procedures as an extension of therapy or nursing services, assistance with ambulation or exercises, and assistance with self-administered medication . In-home services are performed by a trained home health aide or certified nursing assistant as assigned by and under the supervision of a registered nurse or licensed therapist.	Hours	CCE, OAA	6,460
Home-Delivered Meals	Complies with the Dietary Guidelines for Americans and provides one-third of the daily Dietary Reference Intake (DRI) for a female age 70 or older (the predominant statewide demographic recipient), as established by the Food and Nutrition Board of National Academy of Sciences . May include hot, frozen, and/or emergency shelf meals .	Meals	CCE, HCE, LSP, OAA	4,636,092
			SMMC LTC	5,485,300

Service	Description	Unit Type	Program(s)	Units of Service
Homemaker	Specific home management duties including housekeeping, laundry, cleaning refrigerators, clothing repair, minor home repairs, assistance with budgeting and paying bills, client transportation, meal planning and preparation, shopping assistance, and routine household activities conducted by a trained homemaker . General household activities such as meal preparation and routine household care provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage them . Chore services, including heavy chore services and pest control, may be included in this service .	Hours	CCE, HCE, LSP, OAA	1,065,577
		Hours	SMMC LTC	9,917,979
HomeMeds	Previously known as Medication Management Improvement System (MMIS), the goal of the program is to identify, assess, and resolve medication problems that are common among frail older adults .	Hours	OAA	754
Housing Improvement	Home repairs, environmental modifications, adaptive alterations, or installing security devices .	Hours	CCE, OAA, LSP	8,917
		Episodes	HCE	25
Information	Response to inquiries from or on behalf of a person regarding public and private resources and available services.	Episodes	OAA, LSP	235,560
Intake	Completes standard intake and screening instruments to gather information about an applicant for services .	Hours	CCE, OAA, ADI	65,277
Intermittent and Skilled Nursing	Part-time or intermittent nursing care administered to an individual by a licensed practical nurse, registered nurse, or advanced registered nurse practitioner in the client's place of residence, pursuant to a plan of care approved by a licensed physician .	Hours	SMMC LTC	5,579,026
		Episodes		180
Interpreting/ Translating	Interpreting/translating is defined as explaining the meaning of oral and/or written communication to non-English speaking persons or persons with disabilities who require such assistance .	Hours	OAA, LSP	7

Service	Description	Unit Type	Program(s)	Units of Service
Legal Assistance	Legal advice and representation by an attorney (including, to the extent feasible, counseling or other appropriate assistance by a paralegal or law student under the supervision of an attorney) to older individuals with economic or social needs . Legal services include counseling or representation by a non-lawyer when permitted by law . Legal assistance protects against the loss of basic civil rights and ensures the autonomy and independence of older persons .	Hours	LSP, OAA	35,559
Long-Term Care Consumer Complaint Investigation	Investigation and resolution of complaints made by or on behalf of residents of long-term care facilities . Complaint investigations are confidential, and services have no fee. Staff and volunteers, certified as ombudsmen, work with residents and facilities to resolve complaints to the resident's satisfaction.	Assessments	LTCOP	4,182
		Facilities		4,094
		Complaint Investigations		4,653
		Visitations		4,725
Material Aid	<ul style="list-style-type: none"> • Direct distribution of commodities, surplus food, clothing, smoke detectors, eyeglasses, hearing aids, security devices, etc. • Food item(s) necessary for health, safety, or welfare . This may include condiments or paper products necessary for food consumption, as well as delivery charges. Alcohol, drug, and tobacco products are excluded . • Repair, purchase, delivery, and installation of any household appliance necessary to maintain a home or assist with household tasks necessary for the health, safety, or welfare of the person . • Purchase of materials necessary to perform chore or enhanced chore services (see Chore and Chore – Enhanced service descriptions above). • Purchase of construction materials necessary to perform housing improvements, alterations, and repairs (see Housing Improvement service description above). 	Episodes	CCE, HCE, LSP, OAA	7,407

Service	Description	Unit Type	Program(s)	Units of Service
Medication Management	Screening, education, identification, and counseling regarding the medication regimens of clients, including prescription and over-the-counter medications, vitamins, and home remedies . These services also help to identify any dietary factors that may interact with the medication regimen. This can be done on a one-on-one or group basis .	Episodes	CCE	124
Medical Equipment and Supplies	Medical equipment and supplies specified in the plan of care, including devices, controls, or appliances that can withstand repeated use and enable the enrollee to increase the ability to perform activities of daily living; devices, controls, or appliances that enable the enrollee to perceive, control, or communicate with and be appropriate for the environment in which he or she lives; items necessary for life support or to address an enrollee's physical conditions, along with ancillary supplies and equipment necessary to the proper functioning of such items; such other durable and non-durable medical equipment not available under the Medicaid State Plan that is necessary to address enrollee needs, including consumable medical supplies, such as adult diapers; and repair of such items or replacement parts .	Items	SMMC LTC	26,870,285
		Hours		12,079
		Episodes		1,264
Nursing Home Applicant Assessment	Evaluation of the medical necessity for nursing facility care, the level of care required by the individual, and pre-admission screening of all nursing facility applicants to determine serious mental illness or intellectual disabilities .	Assessments	CARES	103,742
Nutrition Assistance	Bundled produce or coupons provided to low-income elders living in targeted service counties . Coupons can be exchanged for locally grown fresh produce at area farmers' markets .	Clients Served	SFMNP	3,817

Service	Description	Unit Type	Program(s)	Units of Service
Nutrition Counseling – Individual	One-on-one individualized advice and guidance to persons who are at nutritional risk because of poor health, nutritional history, current dietary intake, medication use, or chronic illnesses . Nutrition counseling includes options and methods for improving a client’s nutritional status .	Hours	CCE, OAA, LSP	1,878
Nutrition Education	Accurate, scientifically sound, practical, and culturally sensitive nutrition information and instruction to participants in a group or individual setting consistent with their needs and food resources . Nutrition education is the process by which individuals gain the understanding, skills, and motivation necessary to promote and protect their nutritional well- being through their food choices and food preparation methods .	Clients Served	OAA, LSP	205,755
Nutritional Assessment/ Risk Reduction Services	Assessment, hands-on care, and guidance to caregivers and enrollees with respect to nutrition . This service teaches caregivers and enrollees to follow dietary specifications that are essential to the enrollee’s health and physical functioning, prepare and eat nutritionally appropriate meals, and promote better health through improved nutrition . This service may include instructions on shopping for quality food and food preparation .	Episodes	SMMC LTC	11
		Hours		132
Occupational Therapy	Provided to produce specific functional outcomes in self-help, adaptive and sensory motor skill areas and assist the client to control and maneuver within the environment . The service shall be prescribed by a physician . It may include an occupational therapy assessment that does not require a physician’s prescription . In addition, this service may include training direct care staff and caregivers and monitoring those clients to ensure that they are correctly carrying out therapy goals .	Episodes	SMMC LTC	21,217
		Hours		113,024
Other Services	Category for goods or services not defined elsewhere that are necessary for the health, safety, or welfare of the person .	Episodes	CCE, HCE, LSP	145

Service	Description	Unit Type	Program(s)	Units of Service
Outreach	An OAA-required access service making active efforts to reach targeted individuals face-to-face, either in a community setting or in neighborhoods with large numbers of low-income minority elders, making one-on-one contact, identifying their service needs and encouraging their use of available resources .	Episodes	OAA	20,540
Outreach	Group outreach and education activities include interactive presentations to the public, either in-person or via electronic means, and may include forums, speaking engagements, seminars, exhibits, conferences, or other public events . The purposes of the outreach activities are to increase public awareness, inform the public about the availability of counseling and services in their area, educate beneficiaries, family members, and caregivers about services, or assist beneficiaries with enrollment.	Individuals Reached	SHINE, MIPPA, SMP	205,344
		Events		5,000
Outreach - Media	Media outreach and education activities where general program, services, or Medicare information is shared through media channels such as billboard, email, magazine, newsletter, newspaper, radio, social media, television, or website . Information may serve to educate individuals about health care fraud, errors, and abuse or target special beneficiary groups such as individuals with low- income or those living in rural areas .	Activities	SHINE, MIPPA, SMP	820
Personal Care	Assistance with eating, dressing, personal hygiene, and other Activities of Daily Living . This service may include assistance with meal preparation and housekeeping chores such as bed-making, dusting, and vacuuming incidental to the care furnished or essential to the health and welfare of the individual .	Hours	CCE, HCE, LSP, OAA, SMMC LTC	19,529,123
		Items	SMMC LTC	63,176
Pest Control Enhanced Initiation	Assists in ridding the environment of insects and other potential carriers of disease and enhances the safety, sanitation, and cleanliness for recipients . This service is beyond the scope of pest control initiation due to the greater effort required.	Episodes	CCE	26

Service	Description	Unit Type	Program(s)	Units of Service
Pest Control Initiation	Addresses insects and other potential carriers of disease and enhances safety, sanitation, and cleanliness for recipients. Initiation covers start-up costs .	Episodes	CCE	238
Pest Control Maintenance	Addresses insects and other potential carriers of disease and enhances safety, sanitation, and cleanliness for recipients .	Episodes	CCE	2,215
Pest Control – Rodent	Addresses rodents and other potential carriers of disease and enhances safety, sanitation, and cleanliness for recipients . Rodent service consists of trapping, baiting, or other treatments or applications that result in the elimination of the rodent(s) .	Episodes	CCE	26
Physical Therapy	Provided to produce specific functional outcomes in ambulation, muscle control and postural development and to prevent or reduce further physical disability . The service shall be prescribed by a physician . It may also include a physical therapy assessment, which does not require a physician's prescription . In addition, this service may include training direct care staff and caregivers and monitoring those individuals to ensure that they are correctly carrying out therapy goals .	Hours	SMMC LTC	36,273
Powerful Tools for Caregivers	Evidence-based education program using a train-the-trainer method of dissemination . It provides individual strategies to handle unique caregiver challenges and develop a wealth of self-care tools to: reduce personal stress; change negative self-talk; communicate needs to family members and health care or service providers; communicate more effectively in challenging situations; recognize the messages in emotions; deal with difficult feelings; and make tough caregiving decisions .	Episodes	OAA	22

Service	Description	Unit Type	Program(s)	Units of Service
Program to Encourage Active, Rewarding Lives for Seniors (PEARLS)	PEARLS is designed to reduce depressive symptoms and improve quality of life in older adults . The depression intervention takes place in the client's home over a six-month period and includes problem-solving treatment, behavioral activation, pleasant activities scheduling, and ongoing clinical supervision provided by a psychiatrist . PEARLS is designed to be deliverable by staff typically available in an Area Agency on Aging or in senior centers .	Episodes	OAA	91
Programa de Manejo Personal de la Diabetes	Community workshops designed for Spanish-speaking individuals with Type 2 Diabetes . Participants make weekly action plans, share experiences, and help each other solve problems they encounter in creating and carrying out their self-management program .	Episodes	OAA	27
Public Guardianship	Protection of the personal and property rights of an individual who lacks the capacity to make decisions on their own behalf and in their own best interest, has limited financial means, and has no able or willing family members or friends to serve as guardian .	Wards	OPPG	3,816
Recreation	Planned leisure events such as games, sports, arts and crafts, theater, trips, and other relaxing social activities .	Hours	LSP, OAA	143,540
Referral and Assistance	Resources provided via telephone or face-to-face contact related to an individual's needs . Information is obtained about a person's needs; these needs are assessed; and the person is directed to the appropriate resources most able to meet the need . Contact with the resource is made for the person, as needed . Follow-up is a mandatory part of referral/assistance and is conducted with the referred person and/or the resource to determine the outcome .	Episodes	LSP, OAA	106,640
Respiratory Therapy	Treatment of conditions that interfere with respiratory functions or other deficiencies of the cardiopulmonary system . Services include evaluation and treatment related to pulmonary dysfunction .	Episodes	SMMC LTC	15,375
		Hours		6,242

Service	Description	Unit Type	Program(s)	Units of Service
Respite	Provision of relief or rest for a primary caregiver from the constant, continued supervision and care of functionally impaired individuals of all ages in an approved facility-based environment or in the home for a specified period of time.	Hours	SMMC LTC	1,635,727
Respite – In-Facility	Provision of relief or rest for a primary caregiver from the constant, continued supervision and care of functionally impaired individuals of all ages by providing care in an approved facility-based environment for a specified period of time.	Hours	ADI, CCE, HCE, OAA	665,139
Respite In-Facility - Specialized Alzheimer's Services	Provision of relief or rest for a primary caregiver from the constant supervision and care of functionally impaired individuals of all ages by providing care in an approved specialized Alzheimer's services facility-based environment for a specified period of time.	Hours	ADI	278,966
Respite – In-Home	Provision of relief or rest for a primary caregiver from the constant supervision and care of functionally impaired individuals of all ages by providing care in the home for a specified period of time.	Hours	ADI, AC, CCE, HCE, LSP, OAA, RELIEF	1,527,871
Screening and Assessment	Administration of standard assessment instruments to gather information and prioritize clients at the time of active enrollment or to re-assess currently active clients to determine need and eligibility for services .	Hours	LSP, OAA	35,091
Shopping Assistance	Helps a client get to and from stores or shops on behalf of a client. Includes proper selection of items to purchase, as well as storing purchased items upon return to the client's home . A shopping aide may assist more than one client during a shopping trip.	Trips	OAA, CCE	8,710
Sitter	Services provided to a minor child no older than 18 or a child with a disability who resides with a grandparent age 55 or older or another related caregiver age 55 or older . Sitter services may be carried out in the home or in a facility during the day, at night, or on weekends.	Hours	OAA	7,955

Service	Description	Unit Type	Program(s)	Units of Service
Skilled Nursing Services	Part-time or intermittent nursing care administered to an individual by a licensed practical nurse, registered nurse, or advanced registered nurse practitioner in the client's place of residence, pursuant to a plan of care approved by a licensed physician .	Hours	CCE, OAA	2,932
Specialized Medical Equipment, Services, and Supplies	<ul style="list-style-type: none"> • Adaptive devices, controls, appliances, or services that enable individuals to increase their ability to perform Activities of Daily Living. This service also includes repair of such items, as well as replacement parts; • Dentures; walkers; reachers; bedside commodes; telephone amplifiers; touch lamps; adaptive eating equipment; glasses; hearing aids; and other mechanical or non-mechanical, electronic, and non-electronic adaptive devices; • Adult briefs, bed pads, oxygen, or nutritional supplements; • Medical services paying for doctor or dental visits; and • Pharmaceutical services paying for needed prescriptions. 	Episodes	ADI, CCE, HCE, LSP, OAA	48,514
Speech Therapy	Identification and treatment of neurological deficiencies related to feeding problems, congenital or trauma-related maxillofacial anomalies, autism, or neurological conditions that affect oral motor functions. Services include the evaluation and treatment of problems related to an oral motor dysfunction when determined through a multi-disciplinary assessment to improve an enrollee's capability to live safely in the home setting .	Episodes	SMMC LTC	59,455
		Hours		519
Tai Chi: Moving for Better Balance	Developed by the Oregon Research Institute, this simplified, eight-form version of Tai Chi offered in community settings decreases the number of falls and risks associated with falling in older adults. Other program benefits include social and mental well-being, balance and daily physical functioning, self- confidence in performing daily activities, personal independence, and improved quality of life and overall health .	Episodes	OAA	53

Service	Description	Unit Type	Program(s)	Units of Service
Telephone Reassurance	Communications with designated clients by telephone on a mutually agreed schedule to determine if they are safe and to provide psychological reassurance or to implement special or emergency assistance .	Episodes	OAA	8,751
Tomando Control de su Salud	Chronic disease management education and skills for Spanish-speaking populations . The program is not a translation of the Chronic Disease Self-Management Program but was developed separately in Spanish . Subjects covered are similar, but they are presented in ways that are culturally appropriate .	Episodes	OAA	23
Transportation	Travel to or from community services and resources, health and medical care, shopping, social activities, or other life-sustaining activities .	Trips	ADI, CCE, HCE, w LSP, OAA	1,047,966
	Non-emergency transportation service offered in accordance with the enrollee's plan of care and coordinated with other service delivery systems . This non-emergency transportation service includes trips to and from services offered by the SMMC LTC Managed Care Plan and includes trips to and from the Managed Care Plan's expanded benefits.	Episodes		1,920,007
		Hours	SMMC LTC	80,840
		Miles		1,490,671
Un Asunto de Equilibrio	Adapted from Boston University Roybal Center by Maine's Partnership for Healthy Aging, this program uses practical coping strategies to reduce fear of falling and to diminish the risk of falling, including group discussions, mutual problem solving, exercises to improve strength, coordination and balance, and home safety evaluation . This is the Spanish version of A Matter of Balance . Materials and videos have been translated into Spanish .	Episodes	OAA	28
Volunteer Recruitment, Training, and Placement – AmeriCorps	Engages members (volunteers) in intensive service to meet critical community needs and provides in-home respite to elders, caregivers, and families .	Members	AC	57
		Clients Served		65

Service	Description	Unit Type	Program(s)	Units of Service
Volunteer Recruitment, Training, and Placement – Senior Companion Program	Engages elder volunteers to provide services to elders at risk of institutionalization, such as transportation to medical appointments, shopping assistance, meal preparation, companionship, respite, and advocacy .	Volunteers	SCP	63
		Clients Served		221
Volunteer Recruitment, Training, and Placement - RELIEF Program	Engages multi-generational volunteers in assisting caregivers with respite services on evenings and weekends for frail, home-bound older adults, giving the caregiver a needed break .	Volunteers	RELIEF	235
		Clients Served		421
Volunteer Training	Training for individuals interested in helping caregivers with respite services .	Hours	RELIEF	2,043
Walk with Ease	Developed by the Arthritis Foundation, this program provides services for individuals with arthritis and other ongoing health conditions to increase their level of physical activity . Research supporting this program has shown to reduce disability, pain, fatigue, and stiffness, as well as improve balance, strength, and walking pace. The program also helps build confidence to be physically active and manage ongoing health conditions .	Episodes	OAA	12

Sources for definitions and programs providing services: DOEA Programs and Services Handbook; Statewide Medicaid Managed Care Contract, Attachment II-B August 1, 2018

Sources for units of service: DOEA CIRTS; AHCA/FMMIS Medicaid Paid Claims for Medicaid Waiver Services; DOEA Division of Statewide Community-Based Services report data

Creating Dementia Capable Communities: An Interactive Community Discussion
Survey

- 1) I am a (Choose the one that best describes you)
 - A) Person with cognitive impairment
 - B) Care partner/Caregiver
 - C) Paid care partner
 - D) Family Caregiver for an Adult with Down Syndrome
 - E) Other (Please specify) _____

- 2) What County do you live in?

- 3) What type of Community do you live in?
 - A) Rural
 - B) Suburban
 - C) Urban

- 4) Who was the Health Care Practitioner who made the Dementia/ (Alzheimer's disease) diagnosis?
 - A) Primary Care Physician/Doctor
 - B) Geriatrician
 - C) Neurologist
 - D) Physician's Assistant
 - E) Nurse Practitioner
 - F) Other: Write in a response

- 5) Was the diagnosing Health Care Practitioner from the state designated Memory Disorder Clinic?
 - A) Yes (if yes, answer questions 6, 7, 8, 9, 10, 11, 12, 13a)
 - B) No (if No, answer question 7, 8, 9, 10, 11, 13b, 14)

- 6) If Yes, which state Designated Memory Disorder Clinic did you go to? (List 17 Clinics)

- 7) How long did you wait for your appointment to get an evaluation for memory loss?
 - A) 2 weeks or less
 - B) Between 3-4 weeks
 - C) Between 5-8 weeks
 - D) More than 8 weeks
 - E) More than 12 weeks

- 8) During your wait time did your loved one experience additional complications while waiting to get an evaluation at a state designated Memory Disorder Clinic?
 - A) YES
 - B) No

- 9) Did you feel your diagnosing Health Care Practitioner was capable in assessing for Alzheimer's disease/Dementia?
 - A) Yes
 - B) No

Creating Dementia Capable Communities: An Interactive Community Discussion
Survey

10) Did the diagnosing Health Care Practitioner evaluate your concerns about memory loss in the following areas?

Choose all that apply: These would be Yes/No

- a. Took a detailed history from patient?
- b. Took a detailed history from family?
- c. Performed a general physical exam?
- d. Performed memory/cognitive assessment testing?
- e. Ordered blood tests?
- f. Ordered brain imaging with Head CT? (explain CT)
- g. Ordered Brain imaging with MRI? (explain MRI)
- h. Sent for consultation?
- i. Ordered Neuropsychological testing?
- j. Prescribed medication for memory loss?
- k. Prescribed medication for other symptoms?
- l. Did the history include a complete review of the patient's medications?

11) Were you satisfied with the way the assessment was done?

- A) Yes
- B) No

12) Did the state designated Memory Disorder Clinic follow-up with your Health Care Practitioner on the results?

- A) Yes
- B) No

13a) Was your diagnosing Health Care Practitioner helpful in linking you to community support systems?

- A) Yes
- B) No

If yes, which ones:

- i. Area Agency on Aging
- ii. Alzheimer's Association
- iii. Support Groups
- iv. Respite
- v. Other: Write in a response

13b) Was your diagnosing Health Care Practitioner helpful in linking you to community support systems?

- A). Yes
- B). No

If yes, which ones:

- i.Area Agency on Aging
- ii.State designated Memory Disorder Clinic
- iii.Alzheimer's Association
- iv.Support Groups
- v.Respite
- vi.Other: Write in a response

Creating Dementia Capable Communities: An Interactive Community Discussion
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- 14) Did your diagnosing Health Care Practitioner's office follow-up to see if services were in place?
A) Yes
B) No
- 15) As a person living with dementia or as a caregiver caring for someone with Dementia/ (Alzheimer's disease), what are your most important unmet needs? Choose all that apply:
A) Medical care
B) Home Care Services
C) Meal Delivery
D) Respite services
E) Transportation
F) Financial support
G) Other (please explain) _____
- 16) Do you feel there are gaps in services that aren't available to you that you could use?
A) Yes
B) No
C) If yes, please explain what services are missing: _____
- 17) Is your loved one currently involved in any clinical trials or research studies?
A) Yes
B) No
- 18) Has your loved one been hospitalized since receiving a diagnosis Dementia/ (Alzheimer's disease)?
A) Yes
B) No
If No, move to ER Question #26
- 19) If yes, were you satisfied with the level of service related to Dementia/ (Alzheimer's disease)?
A) Yes
B) No
- 20) If no, was it a lack of training and understanding related to Dementia/ (Alzheimer's disease)?
A) Yes
B) No
If there is another reason for your dissatisfaction, please explain:
- 21) What was the primary reason your loved one was hospitalized?

Creating Dementia Capable Communities: An Interactive Community Discussion
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- A) Fall
 - B) Infection/Pneumonia
 - C) Behavior Issues, Agitation, or Confusion
 - D) Elective Surgery
 - E) Unplanned Surgery
 - F) Adverse Drug Reactions to Medications
 - G) Other:
- 22) Did the admission process include information from you as the care partner that your loved one had Dementia/(Alzheimer's disease)?
- A) Yes
 - B) No
- 23) Was there a case manager or a navigator to help coordinate services in the hospital?
- A) Yes
 - B) No
- 24) Did you feel the hospital staff was prepared to work with your loved one with Dementia/(Alzheimer's disease)?
- A) Yes
 - B) No
- 25) Were you satisfied with the discharge process in explaining the community supportive services that are available?
- A) Yes
 - B) No
- 26) Has your loved one gone to the emergency room since receiving a diagnosis of Dementia/ (Alzheimer's disease)?
- A) Yes
 - B) No
- If No, Move to question ALF Question #29**
- 27) Did you feel the Emergency Room staff were knowledgeable on understanding Dementia/ (Alzheimer's disease)?
- A) Yes
 - B) No
- 28) Do you think the staff was able to accommodate your needs in the Emergency Room?
- A) Yes
 - B) No
- 29) Has your loved one living with Dementia/ (Alzheimer's disease) ever lived in an Assisted Living Facility (ALF)?
- A) Yes
 - B) No
- If No, Move to Nursing Home question #33**

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- 30) If yes, was your loved one on the memory care unit?
A) Yes
B) No
- 31) Did you feel the staff in the Assisted Living Facility was effective on working with Individuals with Dementia/ (Alzheimer's disease)?
A) Yes
B) No
- 32) Did you feel the Assisted Living Facility offered effective supportive services and programs?
A) Yes
B) No
- 33) Has your loved one ever been admitted into a Nursing home?
A) Yes
B) No

If No Stop! Survey is complete

- 34) Did you feel the nursing home staff was effective on working with individuals with Dementia/ (Alzheimer's disease)?
A) Yes
B) No
- 35) Did the nursing home offer effective programs for individuals with Dementia/ (Alzheimer's disease)?
A) Yes
B) No

Thank you for your participation!

IF you aren't receiving any services but in need of assistance please call:

Alzheimer's Association at: 1.800.272.3900, 24/7 helpline.

alz.org or alz.org/care (for professionals and family members).

Area Agency on Aging Elder Helpline toll-free: 1-800-963-5337

Creating Dementia Capable Communities: An Interactive Community Discussion
Survey by the Alzheimer's Disease Advisory Committee (ADAC)

Office Use Only

EVENT: Creating Dementia Capable Communities: Interactive Community Discussion

LOCATION:

DATE:

- 1) I am a (Choose the one that best describes you)
 - A) Person with cognitive impairment
 - B) Care partner/Caregiver
 - C) Paid care partner
 - D) Family Caregiver for an Adult with Down Syndrome
 - E) Other (Please specify) _____

- 2) What County do you live in? _____

- 3) Who was the Health Care Practitioner who made the Dementia/ (Alzheimer's disease) diagnosis?
 - A) Primary Care Physician/Doctor
 - B) Geriatrician
 - C) Neurologist
 - D) Physician's Assistant
 - E) Nurse Practitioner
 - F) Other: Write in a response

- 4) Did you feel your diagnosing Health Care Practitioner was capable in assessing for Alzheimer's disease/Dementia?
 - A) Yes
 - B) No

- 5) Was your diagnosing Health Care Practitioner helpful in linking you to community support systems?
 - A) Yes
 - B) No

If yes, which ones:

 - i. Area Agency on Aging
 - ii. State Designated Memory Disorder Clinics
 - iii. Alzheimer's Association
 - iv. Support Groups
 - v. Respite
 - vi. Other: _____

Creating Dementia Capable Communities: An Interactive Community Discussion
Survey by the Alzheimer's Disease Advisory Committee (ADAC)

- 6) As a person living with dementia or as a caregiver caring for someone with Dementia/ (Alzheimer's disease), what are your most important unmet needs? Choose all that apply:
- A) Medical care
 - B) Home Care Services
 - C) Meal Delivery
 - D) Respite services
 - E) Transportation
 - F) Financial support
 - G) Other (please explain) _____
- 7) Do you feel there are gaps in services that aren't available to you that you could use?
- A) Yes
 - B) No
- If yes, please explain what services are missing: _____
- 8) Is your loved one currently involved in any clinical trials or research studies?
- A) Yes
 - B) No
- 9) Has your loved one been hospitalized since receiving a diagnosis Dementia/ (Alzheimer's disease)?
- A) Yes
 - B) No
- If yes, were you satisfied with the level of service related to Dementia/ (Alzheimer's disease)?
- A) Yes
 - B) No
- 10) Was there a case manager or a navigator to help coordinate services in the hospital?
- A) Yes
 - B) No

Thank you for your participation!



Scan the QR code using your cell phone or go to our website to fill out the survey online
<http://elderaffairs.state.fl.us/>



ALF Questions: <https://www.surveymonkey.com/r/DKVPBB>

1. What type of ALF License do you have? Standard, LMH, LNS, ECC
2. Is there a Memory Care Unit in your ALF?
3. What is your staffing ratio in the memory care unit?
4. Is there a protocol at admission to identify the patient has a possible diagnosis of dementia?
5. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
6. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
7. Do you have care policies specific to care for persons living with Dementia?
8. Is there a protocol to identify and treat adverse drug reactions in patients with dementia?
9. Is the staff trained to use visual cues from a person with dementia who can't express pain or feelings verbally?
10. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Hospital Questions: <https://www.surveymonkey.com/r/DL5W8WK>

1. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?
2. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
3. Is there an assigned and trained navigator to follow the patient with dementia during their stay and including/transition to next site of care?
4. Is there an assigned and trained navigator to follow the patient/family with dementia after discharge?
5. Is there a protocol to contact appropriate community agencies upon discharge?
 - a. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
6. Is there staff training to recognize patients with possible dementia in the emergency room or any other department?
7. Is there a protocol to address caregiver stress and/or burden while the loved one with dementia is in the hospital during and after discharge?
8. Is there a protocol to identify and treat adverse drug reactions in patients with dementia?
9. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Nursing Home Questions: <https://www.surveymonkey.com/r/D9DRNX9>

1. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?

2. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
3. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
4. Is there a protocol to train Activity Directors on appropriate activities for residents living with Down syndrome and dementia?
5. Is the staff trained to use visual cues from a person with dementia who can't express pain or feelings verbally?
6. Is there a process in place for a safe transition of care for patients returning to the facility after a hospitalization or transferring to the hospital?
7. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Home Health Care Questions: <https://www.surveymonkey.com/r/DDFML27>

1. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?
2. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
3. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
4. Do you have a protocol for risk assessments to reduce falls and other barriers within the home?
5. Do you have a protocol for working with hospitals on admissions and a discharge plan for patients with dementia?
6. Is the staff trained to use visual cues from a person with dementia who can't express pain or feelings verbally?
7. Is there a non-pharmacological protocol in treating agitated patients with dementia?

CSU Questions: <https://www.surveymonkey.com/r/DJCK3Q>

1. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?
2. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
3. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
4. Do you have training for professional staff in differentiating behaviors associated with dementia from mental health behaviors?
5. Do you have a working relationship with your local Area Agency on Aging to refer families to supportive services?
6. Do you have a protocol for engaging first responders for at-risk persons with dementia?
7. Do you have a protocol on identifying supportive services in rural communities for families caring for a loved one with dementia?

8. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Hospice Questions: <https://www.surveymonkey.com/r/YLDGHTS>

9. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?
10. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
11. Do you provide ongoing training for the staff on dementia, specifically related to challenging behaviors?
12. Do you have a protocol on grieving intervention for an individual with dementia grieving the loss of a caregiver or family member?
13. Do you have an ongoing relationship with your local Area Agency on Aging to refer families to community support services?
14. Do you have a protocol on identifying supportive services in rural communities for families caring for a loved one with dementia?
15. Do you have a protocol for working with hospitals on admissions and a discharge plan for patients with dementia?
16. Is the staff trained to use visual cues from a person with dementia who can't express pain or feelings verbally?
17. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Area Agency on Aging Questions: <https://www.surveymonkey.com/r/YVQJDVX>

18. Is there a protocol at admission to label a chart to identify the patient has a possible diagnosis of dementia?
19. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
20. Do you have a protocol to refer individuals with early onset dementia (< 65) to resources in the community?
21. Do you provide resources to local support groups for families caring for a loved one with dementia?
22. Does your ADRC have outreach in identifying the services provided in the minority aging networks on Alzheimer's disease?

MDC Questions: <https://www.surveymonkey.com/r/Y9ZY5R8>

1. Is there a protocol for a full assessment of clients with Down syndrome and dementia?
2. Do you have a protocol in working with a Florida Agency for Persons with Disability to identify community resources for family caregivers?
3. Is the inability to use Medicaid funding for medical and neuropsychological testing a barrier in assessing for dementia?

4. Is there a protocol to count home visits served (or persons evaluated) for continuity of care, timely follow-ups, access to providing home safety evaluations and the opportunity to educate (psychoeducation) the patient and the family caregiver (as well as evaluate caregiver needs)?
5. Is the staff trained to use visual cues from a person with dementia who can't express pain or feelings verbally?
6. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Agency for Persons with Disabilities Questions: <https://www.surveymonkey.com/r/Y22P5FP>

1. Is Alzheimer's disease in the Down syndrome population included in the protocol on training of Medicaid Waiver Support and Family Coordinators?
2. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
3. Is there a protocol on training the developmentally disabled support network on needs of the adult with Down syndrome who is at risk for Alzheimer's disease?
4. Is there a protocol with working with your local Area Agency on Aging for identifying services provided by the aging network for older family caregivers?
5. Is there a non-pharmacological protocol in treating agitated patients with dementia?

Veteran's Facilities: <https://www.surveymonkey.com/r/3Z2YLT9>

1. Is there a protocol to provide education on assessing for and the treatment of Alzheimer's disease and Related Disorders by the health care practitioners associated with the VA?
 - a. Yes
 - b. No
2. Is there a protocol to differentiate the symptoms of PTSD from ADRD?
3. Do you have a protocol for referring patients exhibiting dementia symptoms to a state designated Memory Disorder Clinic?
 - a. Yes
 - b. No
4. If yes, is there follow up with the MDCs on their assessment?
5. Is there a protocol to refer patients to the Area Aging on Aging Network to provide services to those diagnosed with ADRD?
 - a. Yes
 - b. No
6. Is their recognition/awareness by the VA that the older veterans may have a high incidence of ADRD?
 - a. Yes
 - b. No
7. Is there a non-pharmacological protocol in treating agitated patients with dementia?





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