2021
ALZHEIMER’S DISEASE
ADVISORY COMMITTEE
Annual Report
The 2020-2021 report will review the following recommendations in five topic areas outlined in the next sections. Additionally, the global pandemic prompted review of the State’s work with ADRD as it relates to COVID-19.

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2021 ALZHEIMER’S DISEASE FACTS AND FIGURES

MORE THAN
6 MILLION

Americans are living with Alzheimer’s

Between 2000 and 2019, deaths from heart disease have

DECREASED
7.3%

while deaths from Alzheimer’s disease have

INCREASED
145%

Alzheimer’s and dementia deaths have increased

16%
during the COVID-19 pandemic

IN 2021, Alzheimer’s and other dementias will cost the nation

$355 BILLION

By 2050, these costs could rise to more than

$1.1 TRILLION

OVER
11 MILLION

Americans provide unpaid care for people with Alzheimer’s or other dementias

These caregivers provided an estimated 15.3 billion hours valued at nearly

$257 BILLION

1 IN 3 seniors dies with Alzheimer’s or another dementia

DISCRIMINATION

is a barrier to Alzheimer’s and dementia care. These populations reported discrimination when seeking health care:

50% of Black Americans
42% of Native Americans
34% of Asian Americans
33% of Hispanic Americans

It kills more than

BREAST CANCER

+

PROSTATE CANCER

COMBINED

106X725

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Section 1: Introduction to Alzheimer’s Disease and Related Dementia

Worldwide, 50 million people are living with Alzheimer’s and related dementias (ADRDs). In the United States, there are approximately 6.2 million people living with Alzheimer’s; and in Florida, there are approximately 580,000 Floridians over the age of 65 living with Alzheimer’s.

Alzheimer’s disease is a degenerative brain disease and the most common type of dementia. Dementia is not a specific disease; instead, it is a general term for a decreased capacity to remember, think, or make decisions that interfere with a person’s ability to perform everyday activities. Other forms of dementia include Lewy Body Dementia, Vascular Dementia, and Parkinson’s Disease Dementia. Alzheimer’s disease and related dementias are known as ADRD. Currently, there is no known cure.

The course of ADRD illness is characterized by years of declining ability and increasing dependency and co-morbidity. Alzheimer’s disease, or AD, destroys memory, mental function, thinking skills, and affects the behavior of those living with the symptoms. Brain cells degenerate and die, which leads to decline in memory and mental function. Alzheimer’s disease, as the most common cause of dementia, accounts for between 60 to 80 percent of the cases of diagnoses of dementia. The disease is irreversible and progressive and typically begins in patients during their sixties.

Alzheimer’s disease 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.

Alzheimer’s Disease in Florida

The State of Florida has the second highest incidence of Alzheimer’s in the country. Currently, Florida is home to approximately 580,000 individuals over the age of 65 who are estimated to have AD. By the year 2025, 720,000 people are projected to have this fatal disease in the Sunshine State. Since aging is the greatest risk factor for developing AD, Florida will likely continue to lead the nation, as 19 percent of its population is over the age of 65.

Alzheimer’s is the sixth-leading cause of death in the United States; it is also the sixth-leading cause of death in Florida. Alzheimer’s disease remains the only one of the top ten leading causes of death in the nation without prevention or cure. Between 2020 and 2025, the State of Florida is predicted to have a 24.1 percent increase in AD rates. In 2050, the number of people age 65 and older in America with Alzheimer’s disease is projected to reach 12.7 million with many of these Americans retiring to Florida.

The economic impact of this disease is devastating and overwhelming. The costs of health care and long-term care for individuals living with Alzheimer’s or other dementias are substantial, and dementia is one of the costliest conditions to society.

In 2021, Alzheimer’s and other dementias will cost the nation $355 billion, including $239 billion in Medicare and Medicaid payments combined. Unless a treatment to slow, stop, or prevent the disease is developed, in 2050, Alzheimer’s is projected to cost more than $1.1 trillion (in 2021 dollars). This dramatic rise includes more than three-fold increases both in government spending under Medicare and Medicaid and in out-of-pocket spending. Currently, the research pipeline may offer treatments that could potentially slow the progression of the disease.
In the state of Florida, Medicaid costs for caring for people with Alzheimer’s in 2020 were $2.6 billion. Per capita Medicare spending was $30,106 for people with dementia (in 2020 dollars). (Citation: Florida Alz Facts and Figures)

**2021 Alzheimer’s Facts and Figures**

It is critical to assess the current and future impact of Alzheimer’s disease and related dementia in Florida. The 2021 Alzheimer’s Association Facts and Figures Report provides an overview of the latest national statistics and information on Alzheimer’s prevalence, incidence, mortality and morbidity, costs of care, and caregiving.

- Approximately 6.2 million Americans age 65 and older are living with AD in 2021.
- 80 percent are age 75 or older.
- Two-thirds of Americans over age 65 with AD (3.6 million) are women.
- AD is the sixth-leading cause of death in the U.S. and the fifth-leading cause of death for those age 65 and older.
- Approximately 580,000 Floridians are currently living with Alzheimer’s disease.
- Florida has the second highest prevalence of Alzheimer’s disease in the nation.
- Alzheimer’s disease is the sixth leading cause of death in Florida.
- African Americans are two times more likely to develop Alzheimer’s disease.
- Hispanic Americans are one-and-a-half times more likely to develop Alzheimer’s disease.
- There is less access to diagnosis and support services for culturally diverse communities, which are disproportionately affected by ADRD.
- By 2025, it is projected that there will be over 720,000 Floridians living with Alzheimer’s disease—an increase of over 24 percent.

**Caregiving:**

- Nearly half of all caregivers (48 percent) who provide help to older adults do so for someone with ADRD.
- There are over 527,000 Floridians providing loved ones with unpaid care.
- Approximately two-thirds of caregivers are women.
- One-third of dementia caregivers are daughters.

**National Cost of Care for ADRD:**

- In 2020, caregivers of people with ADRD provided an estimated 15.3 billion hours of unpaid care, a contribution to the nation valued at $257 billion.
- Total payments in 2021 for all individuals with ADRD are estimated at $355 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover $206 billion, or 67 percent of the total health care and long-term care payments for people with ADRD. Out-of-pocket spending is expected to be $66 billion.
- Total payments for health care, long-term care, and hospice care for people with ADRD are projected to increase to more than $1.1 trillion in 2050 (not adjusted for inflation).
- In 2020, the total lifetime cost of care for someone with dementia was estimated at $373,527.
- Medicaid costs for people living with Alzheimer’s disease in Florida are over $2.6 billion.
- Caregivers in Florida provide over 685 million hours in unpaid care.

Alzheimer’s disease is currently the most expensive disease in America, costing more than cancer or heart disease.
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.

2008
Silver Alert Support Project created.

2010
Silver Alert Support Project established.

2011
Florida Silver Alert Becomes Law

2012
Purple Ribbon Task Force Created

2013
Alzheimer’s State Plan Submitted

2015
DCCI Created

2016
First DCCI Task Force Created

2019
Florida Designated Age-Friendly

2019
ADRD added to SHIP & PA9 Created

2021
16 DCCI Task Forces Created

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.

2021
16th DCCI Task force created.

*Florida Statute
Section 2: Alzheimer’s and Related Dementia Infrastructure in Florida

As the Alzheimer’s Disease Initiative (ADI) expands, Florida continues to enhance its infrastructure. The State’s comprehensive resources include clinical services, diagnoses, support services, education, research, and most importantly, community partners to identify gaps and make recommendations.

The ADI has four funded program components listed in Florida statute: ADAC, ADI respite and support services, Memory Disorder Clinics (MDCs), and the Florida Brain Bank. Program advancements also include Florida’s Silver Alert system, priority area 9 on the State Health Improvement Plan (SHIP) devoted to ADRD, and 16 Dementia Care and Cure Initiative Task Forces throughout the state. The Florida Department of Health has also committed to a continued partnership in applying for the BOLD Infrastructure for Alzheimer’s grant. Beyond the BOLD grant, the Ed and Ethel Moore Research Grant provides additional state-based research funding. Additionally, the 11 Area Agencies on Aging (AAAs) continue to provide resources and partner with the Department of Elder Affairs for ADRD concern and awareness, and community resources. Finally, there are two Alzheimer’s Disease Research Centers designated in Florida that serve as ADRD hubs. They are funded by the federal government.

The Role of the Department of Elder Affairs (DOEA)

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 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. Over the years, ADI has taken up new initiatives to be able to better serve the targeted population. The timeline on page 6 highlights the key milestones covered by ADI.

Respite Services in Florida

The Alzheimer’s Disease Initiative (ADI) is a statewide program within the Department of Elder Affairs 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 referrals
- The Florida Brain Bank to support research

Community Care for the Elderly (CCE)

Program provides community-based services organized on a continuum of care to help functionally impaired elders live in the least restrictive yet most cost-effective environment suitable to their needs.

Research in Florida

The Ed & Ethel Moore Grant Program, created in 2014, supports the development of innovative research in the prevention, assessment, and treatment of progressive dementia. The program is managed by the Department of Health. The long-term objectives include the following:
• Improving the health of Floridians through research on prevention, treatments, diagnostic tools, and cures for ADRD
• Expanding the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of Alzheimer’s disease and related dementias
• Stimulating economic activity in areas related to research on ADRD

Alzheimer’s Disease Research Centers (ADRCs) serve as hubs of translational science that focus on preventing and treating ADRD. They play a pivotal role in fostering enrollment for industry-sponsored clinical trials and for ensuring advances in evidence-based care for ADRD are efficiently and rapidly disseminated for community-based medical practices. There are two ADRCs in Florida: 1) Mayo Clinic Jacksonville and 2) 1Florida ADRD consortium of universities and health science centers.

Resources in Florida

Memory Disorder Clinics (MDCs) are state-funded and statutorily established to conduct research and training in a diagnostic and therapeutic setting for persons living with ADRD. The MDCs also provide an annual report. There are 17 MDCs currently in Florida. They participate in funded research projects, and as part of their contractual agreement, are required to partner with research programs focusing on dementia and dementia care.

Area Agencies on Aging (AAAs) are organizations that serve seniors and individuals with disabilities in the community. The AAAs serve as a trusted resource to advocate, educate, and empower seniors, adults with disabilities, and caregivers, which promotes independence in partnership with the community. They strive to provide seniors, adults with disabilities, and caregivers with the resources and services needed to maintain independence, promote healthy aging, and live an optimal quality of life. The AAAs are the gateway to senior services. They perform all intake assessments for home and community-based services such as the Alzheimer’s Disease Initiative (ADI) respite funding and the Community Care for the Elderly funding (CCE).

Dementia Care and Cure Initiatives (DCCIs) engage communities across Florida to be more dementia-caring, promote better care for Floridians affected by dementia, and support research efforts to find a cure. Being a dementia-caring community means there are services and supports in place to make that community hospitable to those living with dementia, their caregivers, families, and loved ones. DOEA wants those living with dementia to continue to play a vital role within their communities. Each interaction they have with their community should be a positive one, created out of respect and understanding.

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.
Section 3: The Alzheimer’s Disease Advisory Committee

ADAC - FL Statute 430.501

The Alzheimer’s Disease Advisory Committee (ADAC) was established by the Florida Legislature in 1986. The size and scope of ADAC were increased in 2019. The Legislature outlined in the statute that Alzheimer’s disease and “similar memory disorders affect an alarmingly high percentage of citizens, primarily those over 65 years of age.” A Committee was formed to advise the Florida Department of Elder Affairs in the “performance of its duties under this act … The committee shall advise the Department regarding legislative, programmatic, and administrative matters that relate to persons living with Alzheimer’s disease and their caretakers.”

New duties as of 2019 included:

- 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, and institutional, home-based, and community-based programs
- Providing input and support for the state implementation of the federal BOLD Act law

The ADAC is comprised of up to 15 active members; 11 appointed by the Governor, two by the President of the Senate, and two by the Speaker of the House of Representatives. The ADAC statute recommends representation from law enforcement, Area Agencies on Aging (AAAs), a person living with dementia, and the Florida Department of Health.

Current Committee Members:

- **Michelle Branham, Committee Chair**  
  Vice President of Public Policy, Alzheimer’s Association
- **Donna Flanagan**  
  Speech and Language Pathologist
- **Fatima Perez**  
  Regional Manager, State Government Affairs, Koch Companies Public Sector
- **Jonathan Weiss**  
  Director of Strategic Innovation, INSIGHTEC
- **Representative Matt Willhite**  
  State Legislator
- **Representative Scott Plakon**  
  State Legislator
- **Senator Audrey Gibson**  
  State Legislator, Democratic Minority Leader

ADAC Committee members meet quarterly to discuss progress and future action plans. In 2020-2021, ADAC met on the following dates:

- September 25, 2020
- December 4, 2020
- February 26, 2021
- April 29, 2021 (Interim Meeting)
- June 25, 2021
- August 13, 2021 (Interim Meeting)

Recognizing the prevalence and impact of ADRD in Florida, in 2019 the Legislature increased the committee’s membership of ADAC from 10 to 15 members.

Per section 430.501, Florida Statutes, ADAC is required to submit an annual report that 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 input from community partners and families living with ADRD across the state.

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, support services, financial needs, resource shortfalls (especially long waiting lists for services), research, ethical and legal concerns, and legislative matters.

Section 4: Executive Summary of Recommendations for 2020-2021

ADAC has three key values which are summarized 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 an asset to the care of persons with ADRD and deserve programs and services to support their efforts.

During the 2020-2021 year, Florida continued to be a leader in the nation in making our state dementia-capable and enhancing our ADRD infrastructure. We saw many of the ADAC recommendations become fulfilled even during an unprecedented pandemic that took an immense toll on those living with dementia and their caregivers, placing those living with ADRD as one of the most vulnerable populations.

Significant accomplishments for ADRD in Florida this year include the following:

Dementia Director

In 2020, the Florida legislature established a dementia director position as one of eight states to prioritize ADRD in public health. This position serves at the director level and provides ADRD support and leadership within Florida’s executive branch. The Dementia Director now serves
as the state’s liaison, building bridges among government agencies and private partnerships to solidify Florida’s dementia infrastructure and continue to prioritize ADRD in a state that has the second-highest prevalence of the disease in the country. As of July 2021, this position was filled and has begun working to support the ADAC, SHIP Priority 9, and the DCCIs. The ADAC looks forward to working closely with the dementia director to accomplish the committee’s 2021 recommendations.

State Health Improvement Plan – Priority 9 (ADRD)

Florida has also continued leading the nation in the establishment of Alzheimer’s Disease and Related Dementias (ADRD) as a distinct priority in the SHIP. In 2019, Governor DeSantis called on the Department of Health to add ADRD as a separate priority to the SHIP. In March of 2019, ADRD became the ninth priority area of the state. Florida is the only state to have ADRD as a standalone priority. In late 2020, the SHIP Priority Area 9 recalibrated to ensure its strategies, goals, and objectives aligned with the Healthy Brain Initiative (HBI) public health roadmap. The ADAC has worked closely with the SHIP committee to assist each workgroup. SHIP workgroups have worked to strengthen the capacity to address ADRD, ensure a competent workforce, and enhance support services for those living with ADRD and their caregivers.

COVID-19 Response

The COVID-19 pandemic brought unprecedented challenges for the ADRD population, which led to an innovative and inspired response from the Department. These initiatives included distribution of Therapeutic Robotic Pet Companions, meal deliveries, mp3 devices, and, finally, the implementation of Project VITAL (Virtual Inclusive Technology for All), a groundbreaking program to combat social isolation.

Enhanced Research Funding and Respite Funding in Florida

The ADAC has always prioritized the need for Florida to be a leader in cutting-edge research within ADRD. Florida is one of the only states with a state-owned research grant program—The Ed and Ethel Moore Alzheimer’s Research Program. In 2021, the Florida legislature allocated over $5 million to new members of ADAC and the exploration of innovative research, including Biogen’s Aduhelm and INSIGHTEC’s Blood-Brain Barrier trials in ADRD.

In 2021, the ADAC hosted research presentations for members and the public. These presentations were provided by new ADAC members like Dr. Jonathan Weiss of INSIGHTEC and from community members such as Mike McBrierty of Biogen on the recently FDA-approved drug, Aduhelm.
Section 5: ADAC Recommendations

Pillar 1: Alzheimer’s Disease Policy

As previously noted, Florida has the second-highest prevalence of Alzheimer’s disease in the country, and Alzheimer’s remains the sixth-leading cause of death in our nation and our state. Therefore, with the Governor’s Dementia Action Plan, outlined in March 2019, the state began to expand its ADRD infrastructure by applying to be a BOLD Infrastructure for Alzheimer’s state, ensuring that the MDCs provided the full range of required services, increasing funding for community-based programs and research, and creating a separate Priority Area dedicated to ADRD on the State Health Improvement Plan.

This year, Priority Area 9 in the SHIP successfully recalibrated its annual goals to mirror the CDC’s public health roadmap, entitled the Healthy Brain Initiative (HBI). These goals are a prescription to building ADRD infrastructure in states by focusing on:

1. Early detection/early diagnosis, brain health through concern and awareness, education, and empowerment;
2. Development of, and training for, a dementia-capable workforce;
3. Monitoring and evaluation of our efforts; and

The SHIP Priority Area 9 has already achieved one strategic objective for Goal 1: Strengthen the Capacity to Address ADRD in Florida, and one strategic objective for Goal 3: Enhance Support for Those Living with ADRD and Their Caregivers in Florida. The three SHIP Priority Area 9 subcommittees continue their work—on pace and within deadline.

Recommendation 1

Support SHIP Priority 9 As Priority Area 9 appears to have secured the ADRD priority for another five-year SHIP Plan, the ADAC recommends the following:

• DOEA and DOH continue to support Priority 9 through all available SHIP resources and continue to dedicate appropriate staff and resources to that effort.
• More community partners engage on these successful SHIP Committees for Priority Area 9 and provide a quarterly Priority Area 9 update to the ADAC.
• DOEA and DOH, along with all dedicated partners, continue to monitor the success of SHIP goals and objectives as necessary going forward.
• A joint meeting with the full SHIP Priority Area 9 and ADAC occur on an annual basis.

Special note: It should be noted that last year’s ADAC recommendation about providing a single access point for education and information has been fulfilled, as well as the ADAC recommendation advising for increased concern and awareness campaigns through SHIP Priority Area 9’s new ADRD Resource Guide, provided to the public during the July 2021 SHIP Steering Committee Meeting.

BACKGROUND INFORMATION

State Health Improvement Plan (SHIP) Priority Area 9 The current DOH SHIP began in 2017 and will end on December 31, 2021. Priority Area 9 (PA9) ADRD was added in June 2019; PA9 implementation began two-and-a-half years into that plan. After one year’s progress, the subcommittee co-chairs recognized the importance of recalibrating the original goals. The 2020 plan offered more specific, achievable objectives driven by measurable metrics (“SMART goals”) presented in the CDC’s Public Health Roadmap on ADRD, called the “Healthy Brain Initiative” (HBI).

These new SMART goals positioned PA9 to continue the successful inclusion into the DOH 2022-2027 SHIP plan. These revised goals included the following:
Goal AD1: Strengthen the capacity to address Alzheimer’s disease and related dementias (ADRD) in Florida.

  
  » Objective AD1.1.1: By June 1, 2021, increase the percentage of identified partners that have distributed an approved and current Early Detection/Early Diagnosis concern and awareness campaign and a Brain Health campaign from 0% (2020) to 55%. – FULFILLED

  » Objective AD1.1.2: By November 1, 2021, increase the percentage of identified partners that have distributed an approved and current Caregiver Support Services concern and awareness campaign from 0% (2020) to 55%. – ON TARGET

Goal AD2: Assure an ADRD-competent workforce through education and training.

- Strategy AD2.1: Enhance current education/training for all staff working in Assisted Living Facilities, Skilled Nursing Facilities, Adult Day Care Programs, Specialized Adult Day Care Programs, Hospice facilities, and Home Health Agencies.
  
  » Objective AD2.1.1: By December 31, 2021, increase the percentage of facilities that have indirect staff receiving at least one hour of updated ADRD education/training on Alzheimer’s care best practices from 0% (2020) to 50%. – ON TARGET

  » Objective AD2.1.2: By December 31, 2021, increase the percentage of ADRD direct care workers who complete at least four hours of ADRD continuing education/training from 50% (2020) 100%. – RE-EVALUATING

Goal AD3: Enhance support for those living with ADRD and their caregivers in Florida.

- Strategy AD3.1: Develop and administer campaigns or policies that support those living with ADRD and their caregivers in Florida.
  
  » Objective AD3.1.1 - By June 30, 2021, increase the percentage of Area Agencies on Aging (AAAs), Dementia Care and Cure Initiatives (DCCIs), Memory Disorder Clinics (MDCs), and County Health Departments (CHDs) in Florida that provide a summary of how they plan to distribute a nationally recognized, evidence-based, standardized ADRD caregiver toolkit to their networks from 0% (2020) to 75%. – FULFILLED

  » Objective AD3.1.2 - By December 31, 2021, increase the percentage of AAAs, DCCIs, MDCs, and CHDs in Florida that disseminate evidence-based, standardized ADRD caregiver toolkits to their networks from 0% (2020) to 75%. – ON TARGET

  » Objective AD3.1.3 - By December 31, 2021, increase the number of families providing unpaid ADRD care that receive the Project VITAL “At-Home” edition from 0 (2020) to 200. – FULFILLED

Recommendation 2

Continue supporting the Governor’s Dementia Action Plan by resubmitting a BOLD application. ADAC recommends the following:

- The Department of Health re-apply for the BOLD Infrastructure for Alzheimer’s grant using committed partners when the new applications cycle is available.
- The Surgeon General or designee provide an update to the ADAC on BOLD, so the Committee can formally support the process.
Recommendation 3
Support new, re-introduced, and viable legislative priorities brought to the 2022 Session that provide for increased ADRD awareness with early detection/early diagnosis and brain health, research funding, respite funding, workforce development training, and quality of life for those living with the disease and their caregivers. ADAC recommends the following:

- Provide official letters of support to the Governor, President of the Senate, and Speaker of the House for any new legislative priorities that meet the above requirements.
- The Secretary of the Department of Elder Affairs or designee provide a series of timely updates on developing legislation throughout the 2022 Session, so that the Committee can consider voting on and providing formal support as determined.

Special Note: It should be noted that last year’s ADAC recommendation “to be consistent with national standards the ADAC will expand training requirements ...” could be fulfilled through introduced legislation that promotes training for dementia direct care workers. It also could be realized through the state’s special grant project through the DOEA Project VITAL Phase 4, which is providing 5,000 essentiALZ training and certifications to direct care workers.

Recommendation 4
Continue support of the State’s new Dementia Director. The ADAC is pleased to see the role of the Dementia Director (DD) filled with a capable and enthusiastic leader.

- ADAC supports the work of the DD and recommends that the DD provide brief updates for each ADAC meeting.
- ADAC further recommends that when the Livable Director position is filled, the Secretary of the Department of Elder Affairs introduces this person to explain roles, responsibilities, and expected partner engagement.

BACKGROUND INFORMATION
**DOEA Dementia Director** – On June 18, 2020, House Bill 835 was signed into law establishing the position of a Dementia Director within 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 Alzheimer’s disease; coordinate dementia research programs; and collect data on the impact of Alzheimer’s disease 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. As of July 2021, this position has been hired and fulfilled.

**Pillar 2: Alzheimer’s Disease Research**
The State of Florida offers a comprehensive, state-based research program for ADRD through the Ed and Ethel Moore Alzheimer’s Disease Research Program. The program awards grants for research relating to the prevention, diagnosis, treatment, and cure of Alzheimer’s disease. The legislature has established the following goals, with priority for research designed to prevent or cure Alzheimer’s disease:

- Improve the health of Floridians by researching better prevention, diagnosis, and treatments and cures for Alzheimer’s disease.
- Expand the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of Alzheimer’s disease.
- Stimulate economic activity in the state in areas related to Alzheimer’s disease research.

The state has also significantly prioritized research through the executive branch and the Legislature, increasing ADRD research and respite funding to $12 million this year—this included innovative new projects with health systems such as the University of Florida and its Memory Disorder Clinic.
Recommendation 5

The State of Florida, through its governing bodies of the executive branch and legislative branch, continue to support and increase funding of research through Florida’s Ed & Ethel Moore Grant Program, the Board of Governors, and other appropriations and funding sources. ADAC recommends the following:

• An increase of ADRD research funding in Florida, including the funding and appropriations of innovative research projects through Legislative Budget Requests by the Department of Elder Affairs, the Office of the Governor, and other partnered agencies to provide funding for Alzheimer’s research, including Alzheimer’s Research using Exablate Neuro Focused Ultrasound at state universities.

• Continued research presentations at Committee meetings on Ed & Ethel Moore research projects and innovative Florida-based research projects for ADRD.

• Continued state monitoring and support of groundbreaking Alzheimer’s and ADRD research projects.

Special Note: Based on ADAC’s recommendation last year “to promote education and awareness on the availability of, purpose, and value of research and encourage participation in clinical trials and other research studies,” the Committee recommends that research campaigns be included in overall ADRD awareness campaigns that the DOH should offer.

BACKGROUND INFORMATION

University Alzheimer’s Research Using Exablate Neuro Focused Ultrasound – Presentation to ADAC by INSIGHTEC. The Board of Governors has allocated funds to research universities partnering with a hospital to conduct Alzheimer’s research through the Focused Ultrasound Neuroscience Research Institute, utilizing an Exablate Neuro (FDA-approved, proprietary technology) focused ultrasound for blood brain barrier disruption and targeted drug delivery. Funds were only granted to qualifying State University System (SUS) institutions that are utilizing a private contribution from INSIGHTEC of an Exablate Neuro focused low-frequency machine to conduct the research and trials. Between 500-1,000 patients with Alzheimer’s disease will have direct access to Exablate Neuro technology that will allow drugs, stem cells, gene therapies, and other therapeutics to traverse the blood-brain barrier and reach their intended targets deep in the brain, with the ultimate goal of reducing beta-amyloid plaques in the brain and finding the cure to Alzheimer’s disease. The target population to be served is older Floridians. The goals of this research are as follows:

• Improve physical health:
  » Alzheimer’s patients who qualify for the treatment under the FDA approved trial will exhibit improved functionality due to the deceleration of disease advancement.
Measuring method: Use INSIGHTEC’s cutting-edge technology to halt, regress Alzheimer’s plaque, and report patient and caregiver improvements.

• Improve mental health:
  » Alzheimer’s patients who qualify for the treatment under the FDA-approved trial will exhibit improved mental health and ability to make memories and interact with family and community due to decreased Alzheimer’s disease symptoms and/or a deceleration of disease advancement.
  » Measuring method: Use INSIGHTEC’s cutting-edge technology to halt, regress Alzheimer’s plaque, and report patient and caregiver improvements.

• Improve quality of education:
  » Universities and partnering health systems will receive donated, cutting-edge, state-of-the-art equipment and technology upgrades. This will cultivate the next generation of talent and researchers and will further support the attraction of top students and high-tech and medical talent to Florida from around the country.
  » Measuring method: Three Exablate Neuro low-frequency systems installed at up to three participating university health systems. (Three installs per year over six years.)

• Increase or improve economic activity:
  » This is an economic investment and job-creating strategy to attract major pharmaceutical partnerships in Florida to test their drugs. Pharmaceutical partners bring job development and massive investments into the region around trials and long-term patient follow-up. A new Alzheimer’s economy of innovation for technology, diagnostics, and therapeutics emerges from the trial.
  » Measuring method: Pharmaceutical and biotech partnerships established to test their new drugs and/or drugs that have previously failed because they were unable to cross over the blood brain barrier to reach their targets in the brain.

• Reduce substance abuse:
  » The same Exablate Neuro technology to be donated is also used in current FDA trials to treat Opioid Use Disorders. Once technology upgrades have been installed, the University/Health systems will be able to participate in the Opioid Use Disorder trials as interested.
  » Measuring method: Interested University Health Systems applying to participate in Opioid Use Disorder Trials using Exablate Neuro technology.
**Pillar 3: ADRD Clinical Care**

The term “clinical care” refers to treating patients or providing direct patient care of any type, in that way, the person’s job is considered “clinical.” Non-clinical work may support patient care, but the work does not provide direct diagnosis, treatment, or care for the patient. Clinical care is health care that encompasses the prevention, treatment and management of illness or injury, as well as the maintenance of psychosocial, mental, and physical wellbeing.

Examples of Clinical Care Settings in Florida:

- MDCs
- Health Systems, such as the University of Florida and its MDC
- Doctor’s offices (primary care, neurology, geriatric, urology, etc.)
- ADRCs

**Recommendation 6**

Support the continued and successful improvement of operations of MDCs to provide a timely and accurate diagnosis and treatment plan for patients living with ADRD and provide support for family caregivers. ADAC recommends the following:

- MDCs continue to be included in all ADAC meetings and offer a collaborative update from a designated liaison at each ADAC meeting.
- The Dementia Director works with the Memory Disorder Specialist within DOE to ensure collaboration with the ADAC and MDCs.
- MDCs participate in all statewide ADRD concern and awareness campaigns that promote early detection/early diagnosis, brain health, community resources, and caregiver resources.
- ADAC recommends that the MDCs continue to meet all performance standards and benchmark goals.

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**Special Note:** This is also last year’s recommendation from ADAC and will continue to be a recommendation this year.

**Recommendation 7**

Support continued distribution of CPT Code: 99483 to cover ADRD-related care to hospitals and primary care providers in Florida.

- ADAC recommends that AHCA and the DOE again provide letters educating hospitals and providers on CPT Code: 99483 (a procedure code to ensure medical visits are paid by Medicare and insurance companies, where coverage applies).
- ADAC recommends that AHCA and DOE build in the potential for fraud with the CPT Code.

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**Pillar 4: Institutional Care**

Institutional care is defined as care provided in a hospital, nursing home, or other facility certified or licensed by the state, primarily affording diagnostic, preventative, therapeutic, rehabilitative, maintenance or personal care services. Thus, a generic definition of institutional long-term care is used to refer to a place of residence that provides nursing-supervised assistance with activities of daily living (ADLs), health care (such as wound dressing change or colostomy care), and rehabilitation, primarily for the aged.

Examples of Institutional Care facilities:

- Skilled nursing facilities
- Assisted living facilities
- Memory care facilities
- Adult day care facilities
- Hospice facilities
**Recommendation 8**

The ADAC recommends, in accordance with the Healthy Brain Initiative, that direct care workers receive enhanced training. This addresses the nearly 60 percent of institutional care residents living with Alzheimer’s disease or related dementias. ADAC recommends:

- Continued support of DOEA and other partners to create a more competent direct care workforce with enhanced training opportunities—especially through no-cost opportunities such as DOEA’s Project VITAL.
- Continued pursuit of designating dementia and age-friendly businesses and employers as dementia-capable.
- DOEA continues its work to amend current contracts with ADRCs and lead agencies to achieve 100 percent workforce training compliance for both direct and indirect care workers. This will ensure all employees of these agencies have obtained useful training on working with ADRD clientele and their families and caregivers.
- The state continues to create effective Alzheimer’s and ADRD training opportunities through resources such as DCCI and other viable contracts or partners.
- DOH and AHCA also support enhanced dementia training opportunities through their respective networks.
- The continued support of Priority Area 9’s strategies and goals for workforce development and training.

**Pillar 5: Home and Community Based Services Programs/Community Outreach Initiatives**

Home- and community-based services (HCBS) include a variety of medical and social services provided to individuals with functional or cognitive limitations.

These can include the following:

- Case management services (e.g., medical service coordination, referrals to local resources);
- Home meal deliveries;
- Transportation; and
- Financial and legal services.

**Recommendation 9**

Establish action plans for DCCI Task Forces that include the distribution of information about ADRD community resources, yearly goals and objectives for the task forces, and recommendations to the ADAC for further consideration. ADAC recommends the following:

- The DCCI Task Forces provide an annual update to the ADAC prior to the submission of their recommendations for an annual report (each year before August).
- To support the work of SHIP Priority Area 9’s concern and awareness campaigns, the DCCI Task Force includes long-term care communities in the distribution of statewide ADRD campaigns.
- Enhanced training for direct care workers that work in long-term care settings, mirroring Priority Area 9’s goals to create a dementia-capable workforce.
- The Dementia Director works closely with a growing number of DCCI task forces to offer collaboration and cohesiveness to goals, priorities, and action plans.
The Dementia Care and Cure Initiative (DCCI) was established in 2015 to increase awareness, education, 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 16 DCCI task forces throughout the state working to break down barriers, reduce the stigma associated with dementia, and create communities where people living with dementia feel comfortable and can live with dignity, independence, and respect.

**Recommendation 10**

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.

- ADAC will advocate for increases in funding to alleviate the state’s waitlist.
- ADAC will promote the Community Care Corps program among care providers.
- ADAC will make service providers aware of Community Care Corps grants.

**BACKGROUND INFORMATION**

The Alzheimer’s Disease Initiative (ADI) is a statewide program within the Department of Elder Affairs that provides services to individuals and families affected by ADRD. These services include counseling, access to consumable medical supplies, and respite for caregiver relief.

**Community Care Corps** is a national program, administered by the Oasis Institute with support from Caregiver Action Network (CAN), the National Association of Area Agencies on Aging (N4A), and Altarum Institute with funding from the Administration for Community Living (ACL).
Pillar 6: COVID-19 Response

Individuals living with Alzheimer’s disease, along with their caregivers, face considerable challenges even when there is no pandemic. COVID-19 presented a unique set of new challenges such as receiving proper nutrition, preventing social isolation, and maintaining healthy communication among Alzheimer’s patients and their caregivers. DOEA responded to these acute needs by quickly marshalling resources and developing creative partnerships to support these highly vulnerable Floridians.

Recommendation 11
Promote vaccinations among seniors.

- ADAC recommends the continued promotion of COVID-19 vaccinations, especially among elders.

Promoting vaccines and vaccine access among seniors
ADAC recommends the continued promotion of COVID-19 vaccinations, especially among elders. DOEA initiated the “We Will Meet You at Home Campaign” as Florida made COVID-19 immunizations available to individuals 65 and over. The statewide campaign was designed to assist seniors with transportation to vaccine access sites and to help seniors receive a vaccination at home by a healthcare professional when requested. Television and radio ads targeted cities of lower vaccination rates and provided contact information for local Aging and Disability Resource Centers, or ADRCs.

The ADRCs arranged all transportation and home-delivered vaccinations. Testimonials received by DOEA showed the majority of requests were made by caregivers of homebound seniors, including those living with ADRD.

Feeding Older Floridians Restaurant Meal Initiative
In March 2020, as public health measures were put in place to slow the spread of COVID-19, Florida, like many states, closed congregate meal sites to ensure the safety of older adults and people with disabilities. Because these sites are a lifeline to so many, DOEA quickly pursued a way to continue to provide meals during the pandemic.

ADAC supported the program DOEA created called “The Feeding Older Floridians Restaurant Meal Initiative”. The program matched local restaurants and delivery services with older adults needing nutritional support. Meal deliveries were especially effective for those living with ADRD, homebound seniors, and their caregivers. The successful program continued into 2021 and has delivered over 6 million meals to homebound older adults.

Technology to prevent social isolation and improve communication

Project VITAL  DOEA and the Alzheimer’s Association developed an initiative called Project VITAL (Virtual Inclusive Technology for All). This project launched in early 2020 as nursing homes remained closed to the public. The goal of the project has been, is, and continues to be to support the well-being of seniors, their families, and caregivers by allowing them to remain virtually engaged and connected through specially designed tablets. The user-friendly technology allows
access to resources like music, ebooks, games, video calling, text, and email with friends and 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 or caregivers at home. The success of this program has allowed it to expand outside of nursing homes and into individuals’ homes through a pilot program called Uniper.

**Therapeutic Robotic Pets** Another technology solution DOEA used to break social isolation for older individuals is the therapeutic robotic companion pets initiative. DOEA partnered with Ageless Innovation’s Joy for All® Companion Pets to enhance meaningful interactions among older adults, their caregivers, and family members. DOEA began delivering therapeutic robotic pets to socially isolated seniors and adults living with Alzheimer’s disease and related dementias in April of 2020. The interactive companion pets help combat loneliness or depression by improving overall mood and quality of life. Robotic pets remain available through DOEA’s online application and are available for any older adult. DOEA has distributed over 7,000 robotic pets since the program’s launch.

The therapeutic robotic pets 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.” Robotic pets have been utilized in many countries for over 16 years, and they have become more common in the United States to supplement interactions between those living with ADRD and their caregivers. To date, DOEA has invested in 8,000 pets and the response has been overwhelmingly positive. Introduction letters and user guides are provided in English and Spanish.

**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 of 2020. Studies suggest that listening to music can have numerous positive effects on
health, including: improving mood, reducing stress, lessening anxiety, improving memory, easing pain, providing comfort, and improving cognition. While caregivers sheltered in place with their loved ones during COVID-19, the music was able to benefit both the caregiver as well as their loved ones by reducing stress or distress and enhancing their moods.

**Scent Kits** DOEPA partnered with Scent Evidence K9 to distribute 3,150 Scent Preservation Kits® to caregivers of those living with ADRD. As Florida seniors remained home to limit their risk of exposure to COVID-19, older adults with ADRD had an increased tendency to wander and become lost. If that happened, proactive family safety measures, such as the Scent Preservation Kit®, provided 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 Spanish. Florida’s Memory Disorder Clinics assisted with this initiative by distributing 1,350 of the kits.

**Memory Disorder Clinics (MDCs)** DOEPA’s 17 designated MDCs quickly responded to establish alternative methods 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. DOEPA also worked with Scent Evidence K-9 to provide MDCs with 1,350 Scent Evidence kits to distribute to their most vulnerable patients at high risk for wandering.

The collaborative partnership between the State of Florida and the Aging and Disability Resource Centers provided essential direct relief to Florida communities during COVID-19. Many of these programs emerged from immediate need, but the state-community partnerships have paved the way for future innovation and collaboration. ADAC recommends continued support of these programs, as possible, through additional partners such as philanthropic foundations, age-friendly communities, and private companies offering assistance in communications and technology.
REFERENCES


