

2022 ALZHEIMER'S DISEASE ADVISORY COMMITTEE

● ● ● ● ● ● *Annual Report*



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Florida

Alzheimer's Statistics



Prevalence

NUMBER OF PEOPLE
AGED 65 AND OLDER
WITH ALZHEIMER'S

Year	TOTAL
2020	580,000
2025	720,000

ESTIMATED % CHANGE

24.1%



Workforce

362

of geriatricians

277.1%

% increase needed to meet
the demand in 2050

73,130

of home health and
personal care aides

27.6%

% increase needed to meet
demand in 2028



Caregiving (2021)

806,000
Number of Caregivers

\$20,596,000,000
Total Value of Unpaid Care

16.3% % of caregivers
with depression

1,267,000,000 **47.8%** % of caregivers
Total Hours of Unpaid Care with chronic
health conditions



Health Care

HOSPICE (2017)

19,897

of people in hospice
with a primary diagnosis
of dementia

15%

% in hospice with a primary
diagnosis of dementia

HOSPITALS (2018)

1,552

of emergency department
visits per 1,000 people
with dementia

23.0%

dementia patient hospital
readmission rate

MEDICAID

\$2.689B

Medicaid costs of caring
for people with Alzheimer's
(2020)

28.4%

projected change in costs
from 2020 to 2025

MEDICARE

\$30,436 per capita Medicare spending on people
with dementia (in 2021 dollars)



Mortality

OF DEATHS FROM ALZHEIMER'S DISEASE (2019)

6,539

More than **6 million Americans** are living with Alzheimer's, and over **11 million** provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$321 billion** in 2022, increasing to nearly **\$1 trillion** (in today's dollars) by mid-century.

For more information, view the **2022 Alzheimer's Disease Facts and Figures** report at alz.org/facts.
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Section 1

Introduction to Alzheimer's Disease and Related Dementias

Worldwide, 50 million people are living with Alzheimer's disease and related dementias (ADRD). In the United States, approximately 6.2 million people are living with Alzheimer's disease (AD), and in Florida, approximately 580,000 Floridians over 65 are living with Alzheimer's disease.

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 complete everyday activities independently. Other forms of dementia include Lewy Body dementia, vascular dementia, or Parkinson's disease dementia. Alzheimer's disease and related dementias are known as ADRD. Currently, there are no known cures.

The progression of ADRD illness is characterized by years of declining mental and physical abilities, and increased dependency on caregivers. The disease eventually is fatal. In Alzheimer's disease, brain cells degenerate and die, destroying memory, cognitive function, thinking skills, and affecting the behavior of individuals experiencing these symptoms. Alzheimer's disease accounts for 60 to 80 percent of the cases of diagnosed dementia. It is irreversible and progressive. Symptoms most commonly manifest in patients during their sixties.

Current research indicates that Alzheimer's disease may begin 20 years or more before symptoms arise, with changes in the brain that are unnoticeable to the person affected. Noticeable symptoms such as memory loss and language problems do not occur until after many years of physiological brain changes.

Alzheimer's Disease in Florida

Florida has the second highest prevalence of Alzheimer's disease in the country and the highest prevalence in the country, per capita. Currently, Florida is home to approximately 580,000 individuals over 65 with AD. Researchers estimate a 24.1 percent increase in the rate of Alzheimer's Disease in Florida between 2020 – 2025, amounting to approximately 720,000 residents of the Sunshine State with this fatal disease. Since age is the most prominent risk factor for developing AD, Florida will likely continue to lead the nation, as 19 percent of its population is over 65.

Alzheimer's disease is the sixth-leading cause of death in the United States and the sixth-leading cause of death in Florida. Of the nation's top 10 leading causes of death, Alzheimer's disease remains the only one without prevention or cure. In 2050, the number of people in America age 65 and older with Alzheimer's disease is projected to reach 12.7 million.

The economic impact of this disease is also devastating and overwhelming. Costs of health care and long-term care for individuals living with Alzheimer's disease and related dementias are substantial, and dementia is one of the costliest conditions to society. In 2022, Alzheimer's disease and related dementias will cost the nation \$321 billion, including \$206 billion in Medicare and Medicaid payments combined. Unless a treatment to slow, stop, or prevent the disease is discovered, in 2050, Alzheimer's is projected to cost more than \$1.1 trillion. This dramatic rise includes more than three-fold increases in both government spending under Medicare and Medicaid and out-of-pocket spending. Groundbreaking research efforts are exploring early diagnostics and treatments that could slow the progression of the disease.

In Florida, Medicaid costs for caring for people with Alzheimer's in 2020 were \$2.689 billion.

Per capita, Medicare spending was \$30,436 for people with dementia.¹

2022 Facts and Figures

The [2022 Alzheimer's Association Facts and Figures Report](#) provides an overview of the latest national statistics and information on Alzheimer's disease prevalence, incidence, mortality and morbidity, costs of care, and caregiving. These staggering numbers illustrate the importance of prioritizing this illness.

- Approximately 6.5 million Americans age 65 and older live with AD in 2022.
- 73 percent are age 75 and older.
- Two-thirds of Americans over 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.
- Women make up two-thirds of those living with Alzheimer's disease and approximately two-thirds of the caregiving population.
- There is less access to diagnosis and support services for culturally diverse communities disproportionately affected by ADRD.
- By 2025, data scientists project 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 unpaid care for loved ones.
- One-third of dementia caregivers are daughters.

National Cost of ADRD Care

- In 2022, caregivers of people with ADRD provided an estimated 16 billion hours of unpaid care, a contribution to the nation valued at \$271.6 billion.
- Total payments in 2022 for all individuals with ADRD are estimated at \$321 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$206 billion, or 64 percent, of the total health care and long-term care payments for people with ADRD. Out-of-pocket spending is expected to be \$81 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 2021, the total lifetime cost of care for someone with dementia was estimated at \$377,621.
- Medicaid costs for people living with Alzheimer's disease in Florida is over \$2.6 billion.
- Caregivers in Florida provide over 1.267 billion hours in unpaid care.
- Alzheimer's disease is currently the most expensive disease in America, costing more than cancer or heart disease.

1 Alzheimer's Association 2022 Florida Alzheimer's Statistics [alz.org/media/Documents/florida-alzheimers-facts-figures-2022.pdf](https://www.alz.org/media/Documents/florida-alzheimers-facts-figures-2022.pdf)

Section 2

Alzheimer's and Related Dementias Infrastructure in Florida

As the Alzheimer's Disease Initiative (ADI) expands, Florida's infrastructure continues to be enhanced. The state's comprehensive resources include clinical services, diagnosis, 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: Alzheimer's Disease Advisory Committee (ADAC), ADI respite and support services, Memory Disorder Clinics

(MDCs), and the Florida Brain Bank. Program advancements also include Florida's Silver Alert system, a designated ADRD Priority Area on the State Health Improvement Plan (SHIP), 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, 11 Area Agencies on Aging (AAAs) continue to provide resources and partner with the Department of Elder Affairs for ADRD concern and awareness, community resources, and more. Finally, there are two Alzheimer's Disease Research Centers (ADRCs) designated in Florida that serve as ADRD hubs, which are funded by the federal government.

Governor DeSantis' Five Point Dementia Action Plan

1

Include Alzheimer's and related dementias as a priority within the State Health Improvement Plan (SHIP).

Alzheimer's is the sixth leading cause of death in Florida but was not previously directly addressed by the SHIP.

2

Challenge local communities to expand the Dementia Care and Cure Initiative (DCCI) in their areas.

Eight out of 11 AAAs are engaged in DCCI programs, including 16 area-specific DCCI Task Forces.

3

Challenge Florida institutions to match funding for their in-house Memory Disorder Clinics (MDC).

The State of Florida has designated and funded 17 MDCs located in medical schools, teaching hospitals, and similar institutions.

4

Increase funding for the Alzheimer's Disease Initiative (ADI).

Governor DeSantis' Freedom First Budget included \$12 million in funding to support the ADI and supportive services for people living with ADRD, their families, and caregivers.

5

Governor DeSantis requests the development of a Center of Excellence pursuant to the Federal BOLD Act.

Announced the Florida Alzheimer's Center of Excellence to promote evidence-based treatment and prevention, awareness and education about ADRD, and to connect families with resources.

The Role of the Department of Elder Affairs

The Department of Elder Affairs (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 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 8 highlights the key milestones covered by ADI.

Governor Ron DeSantis appointed Secretary Michelle Branham as the agency head for the Florida Department of Elder Affairs in December 2021. Under Secretary Branham's leadership, the Department serves Florida's nearly 6 million seniors over the age of 60, providing services and supporting initiatives through Florida's Aging Network to help seniors live well and age well in the state. Secretary Branham brings more than 20 years of experience in public policy, public health, and public relations and more than a decade of senior executive experience in federal and state-level public policy initiatives.

Caregiver Support and 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:

- 1 Supportive services such as counseling, consumable medical supplies, and respite for caregiver relief

- 2 Memory Disorder Clinics (MDCs) to provide diagnosis, education, training, research, treatment, and referrals

- 3 The Florida Brain Bank to support research

Community Care for the Elderly (CCE) is a program that 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, and
- Stimulating economic activity in areas related to research on ADRD.

The Ed and Ethel Moore Alzheimer's Disease Research Program funding opportunity announcement, including priority areas and grant categories is described in detail [here](#).

The 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 ensuring advances in evidence-based care for ADRD are disseminated efficiently and rapidly to community-based medical practices. There are two federally funded ADRCs in Florida: 1) Mayo Clinic Jacksonville and 2) Florida ADRD consortium of universities and health science centers



ALZHEIMER'S DISEASE INITIATIVE TIMELINE

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.

2021

16th DCCI task force created.

2022

Governor Ron DeSantis highlighted record funding for Alzheimer's and related dementias and established the Florida Alzheimer's Center of Excellence (FACE).

*Florida Statute

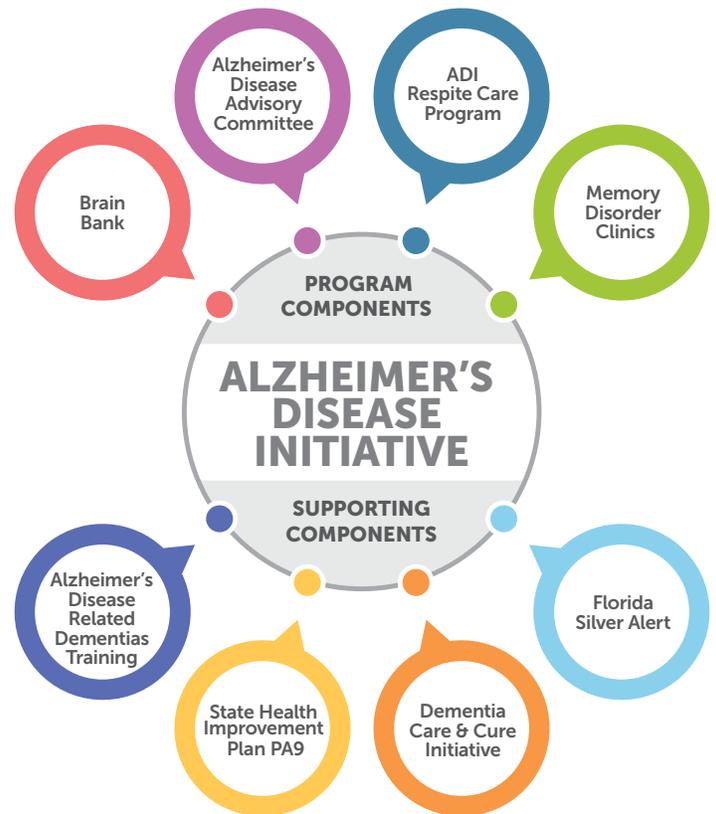
Resources in Florida

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, must 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 (CCE).

Dementia Care and Cure Initiatives (DCCIs)

Dementia Care and Cure Initiative task forces 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 services and supports are in place to make that community hospitable to those living with dementia, their caregivers, families, and loved ones. DOEA wants individuals with dementia to continue to play a vital role within their communities. Each interaction with the 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 Priority Area 9 are a collaborative effort with Florida Department of Health and Alzheimer's Association.



Section 3

Department Advances in Alzheimer's Disease and Related Dementias

Division of Elder Opportunity

Under the leadership of the newly appointed Secretary of Elder Affairs, Michelle Branham, the Department crafted a new division with the capacity to respond to new opportunities in technology and industry innovation. This division is tasked with seeking out innovative solutions to challenges seniors are facing in Florida, and to house the work of a new line of service to Floridians: the Florida Alzheimer's Center of Excellence.

Florida Alzheimer's Center of Excellence

Florida Alzheimer's Center of Excellence (FACE) supports caregivers and people with Alzheimer's and related dementias in the community using evidence-based and no-wrong-door strategies. FACE achieves a holistic care model for client and caregiver to address two primary goals: to allow Floridians living with Alzheimer's disease and related dementias to age-in-place, and to empower family caregivers with increased capacity and stamina. FACE makes additional advances through its integration into all of Florida's spheres of influence, including a peer-review component that engages the members of Alzheimer's Disease Advisory Committee (ADAC).

The FACE model's primary efforts serve people living with dementia (PLWD) and their family caregivers. Through dialogue with Care Navigators, family members can learn about helpful lifestyle interventions for brain health. Care Navigators can counsel family members who worry about the level of risk for themselves and other family members by stressing the importance of early detection and brain-healthy behaviors and encourage vital self-care techniques to help family caregivers remain healthy both physically and mentally. A second

phase of FACE efforts includes recognizing direct care settings that demonstrate excellence in staff training and support.

The third layer of FACE outlines parameters to acknowledge industry leaders in the field of ADRD clinical care and research. The model follows the framework developed by the Department of Health's Cancer Centers of Excellence by creating benchmarks and best-practice standards. The recognition as a FACE Partner allows families to seek the best professionals in the field and raises the bar of care standards.

State Health Improvement Plan, Priority Area ADRD

Florida is a leader in ADRD efforts and acknowledges the critical importance of ADRD through the State Health Improvement Plan (SHIP). In 2019, Governor DeSantis called on the Department of Health to add ADRD as a Priority Area, making Florida the first and only state to have ADRD as a standalone priority.

- In May 2019, ADRD became the ninth priority area of the state's 2017-2021 SHIP cycle. ADRD continues as a Priority Area for the 2022-2026 cycle. The SHIP Priority Area Workgroups address the following primary functions:
 - » Develop goals and measurable objectives for each priority area,
 - » Create implementation plans to drive action,
 - » Monitor and provide quarterly progress updates on State Health Improvement Plan objectives and activities,
 - » Compile recommended revisions to State Health Improvement Plan goals and objectives for approval by the State Health Improvement Plan Steering Committee, and
 - » Serve as champions for the State Health Improvement Plan by increasing awareness and engagement within respective networks.



- The goals of ADRD Priority Area Workgroups include the following:
 - » Strengthen the capacity to address Alzheimer’s Disease and Related Dementia,
 - » Ensure a competent ADRD workforce, and
 - » Enhance support services for those living with ADRD and their caregivers.
- The ADRD Priority Area Workgroup is a potential avenue to implement the Alzheimer’s Disease Advisory Committee recommendations and highlight best-practice guidelines.

Post Pandemic Economy

The COVID-19 pandemic brought unprecedented challenges for the ADRD population, which prompted an innovative and inspired response from the Department. These initiatives included Therapeutic Robotic Pet Companions, meal deliveries, mp3 devices, and Project VITAL (Virtual Inclusive Technology for All), a groundbreaking program to combat social isolation. The pandemic also presented a need to expand services available through the ADI:

shopping assistance and telephone reassurance. These initiatives continued throughout 2021-2022. To date over 3,000 mp3 players and over 11,000 robotic pets have been shipped to home or facility-bound seniors.

Recently, the Department created an internal task force called Florida Affecting Change Today for Seniors (FACTS). This task force reviews comments and recommendations from local providers about challenges they continue to face in the field. One such change includes adjusting the current contract rate reimbursement system to increase flexibility of local providers who have continued to struggle in the post-pandemic reality.

The pandemic exacerbated challenges in Florida’s direct-care workforce. The Department of Elder Affairs’ Florida Alzheimer’s Center of Excellence aims to relieve some of the burden felt by staffing challenges at the local Area Agencies on Aging and assist family caregivers to equip themselves and their home-care environment to help their loved ones age in place.

Section 4

Policy Advancements in Alzheimer's Disease and Related Dementias

House Bill 649: Patient Care in Health Care Facilities

Authorizes unlicensed persons to assist patients with other specified tasks; revises provisions relating to medications and devices with which unlicensed persons may assist patients in self-administration; specifies staffing requirements for advanced life support ambulances during inter-facility transfers; provides certain persons occupying such ambulances are in charge of patient care during transfers; revises list of medications that registered nurses may delegate administration to certified nursing assistants or home health aides; authorizes certified nursing assistants to administer certain medication to patients in county detention facilities under certain circumstances.²

Senate Bill 806: Alzheimer's Disease and Related Forms of Dementia Education and Public Awareness

Creates the "Ramping up Education of Alzheimer's Disease and Dementia for You (READY) Act." The bill requires the Department of Health (DOH) to use preexisting, relevant public health, and community outreach programs to educate medical doctors, osteopathic physicians, and nurses on Alzheimer's disease and dementia-related disorders. Specifically, the bill requires the Department of Health to provide education on the following topics:

- The importance of early detection and timely diagnosis of Alzheimer's disease and related forms of dementia.
- Using a validated cognitive assessment tool.
- The value and effectiveness of the Medicare annual wellness visit in detecting Alzheimer's disease and related forms of dementia.
- Using Medicare advance care planning billing codes for persons with Alzheimer's disease and related forms of dementia.
- Reducing the risk of cognitive decline, particularly among persons in diverse communities who are at greater risk of developing Alzheimer's disease and related forms of dementia.³

Senate Bill 988: Patient Visitation Rights

This act is known as the "No Patient Left Alone Act"; requiring certain providers to establish visitation policies and procedures within a specified timeframe; authorizing the resident, client, or patient to designate an essential caregiver; requiring in-person visitation in certain circumstances; authorizing providers to suspend in-person visitation of specific visitors under certain circumstances, etc.⁴

House Bill 1239: Modernization of Nursing Home Facility Staffing

Specifies functions that do not constitute direct care staffing hours for purposes of required nursing home staffing ratios; requires facilities to determine their direct care staffing needs based on certain assessment and resident care plan; revises nursing home staffing requirements; revises provisions relating to applications for change of ownership; revises provisions relating to facility's failure to comply with minimum staffing requirements⁵.

Effective Date of Legislation: July 1, 2022

2 Florida House of Representatives myfloridahouse.gov

3 The Florida Senate flsenate.gov/Committees/BillSummaries/2022/html/2728

4 The Florida Senate flsenate.gov/Session/Bill/2022/988

5 Florida House of Representatives myfloridahouse.gov/Sections/Bills/billsdetail.aspx?BillId=76097&-SessionId=93

Section 5

The Alzheimer's Disease Advisory Committee

ADAC - Section 430.501, Florida Statutes

The Florida Legislature established The Alzheimer's Disease Advisory Committee (ADAC) in 1986 under the umbrella of the Alzheimer's Disease Initiative. 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. Eleven are to be appointed by the Governor, two members appointed by the President of the Senate, and two members appointed by the Speaker of the House of Representatives. This statute outlined a committee to "advise the Department regarding legislative, programmatic, and administrative matters that relate to persons living with Alzheimer's disease and their caretakers."⁶ The ADAC statute recommends representation from law enforcement, Area Agencies on Aging (AAAs), a person living with dementia, and the Florida Department of Health.

Duties as of 2019 include the following:

- 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; and
- Providing input and support for the state implementation of the federal BOLD Act law.

Per section 430.501, Florida Statutes, ADAC must submit an annual report that includes:

- 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
- Proposed updates to the Alzheimer's Disease State Plan.

Each year, ADAC confers at quarterly meetings with many ADRD specialists and health care providers from around the state. The committee 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.

In 2021-2022, ADAC met on the following dates:

- August 13, 2021 (interim meeting)
- March 22, 2022 (Q1)
- July 14, 2022 (Q2)
- Tuesday, September 27, 2022 (Q3)
- Tuesday, December 6, 2022 (Q4)

In 2022, the ADAC hosted research presentations for members and the public. These presentations aimed to offer additional insights and information about academic progress and stimulate discussion about the current needs in ADRD services and new research opportunities. Presentation topics included the following:

- A "Dementia Friendly" Approach to African American Community Outreach by John A. Lucas, PhD, Mayo Clinic, and
- Jon Harrison and the leadership team from Vaxxinity shared research findings for an Alzheimer's vaccine – UB-311. UB-311 is an immunotherapeutic vaccine candidate

6 Online Sunshine: http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0400-0499/0430/Sections/0430.501.html



targeting toxic forms of aggregated amyloid beta in the brain to prevent and treat Alzheimer's disease⁷.

Current Committee Members:

- **Dr. Jonathan Weiss** Committee Chair, Global Head of Strategic Innovation, INSIGHTEC
- **Matt Eaton** Vice President of Communications, Florida, Alzheimer's Association
- **Samantha Ferrin** Director of the Government Law & Policy Practice, Greenberg Traurig
- **Donna Flanagan** Speech Language Pathologist
- **Senator Audrey Gibson** State Legislator

- **Dr. Jonathan Gonzalez** Primary Care Physician
- **Dr. Corrine Labyak** Associate Professor, Brooks College of Health, University of North Florida
- **Dr. Rosemary Laird** Geriatrician
- **Fatima Perez** Regional Manager, State Government Affairs, Koch Companies Public Sector
- **Representative Scott Plakon** State Legislator
- **Aileen Ruess** Geriatric Care Manager
- **Representative Matt Willhite** State Legislator

The members of ADAC have compiled and written the information in this report based on input from community partners, researchers, ADRD industry professionals, and families living with ADRD across the state.

⁷ Vaxxinity <https://ir.vaxxinity.com/node/7081/pdf>

Section 6

Executive Summary of Recommendations for 2022-2023

ADAC has three key values which are culminated below as the Priorities and Recommendations for the Year 2022-2023.

- 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.

ADAC members were asked to voice specific thoughts about progress over the past year, obstacles faced by caregivers and professionals in the field, and recommendations for the coming year. ADAC members unanimously responded that they recognize the state and ADRD industry have made some progress in this area, but still have opportunities to affect greater change. A summary of recommendations is listed below.

Recommendations from ADAC members align with five pillars:

<p>PILLAR 1 <i>Policy</i></p>	<p>1 Support SHIP Priority Area: Alzheimer’s Disease</p> <hr/> <p>2 Support the Governor’s Dementia Action Plan</p> <hr/> <p>3 Support ADRD legislative priorities</p> <hr/> <p>4 Support the State’s Dementia Director</p>
<p>PILLAR 2 <i>Research</i></p>	<p>5 Engage with Memory Disorder Clinics</p> <hr/> <p>6 Support and increase funding for research</p>
<p>PILLAR 3 <i>Clinical Care</i></p>	<p>7 Increase professional outreach and education efforts</p> <hr/> <p>8 Support and improve operations of Memory Disorder Clinics</p>
<p>PILLAR 4 <i>Institutional Care</i></p>	<p>9 Improve training for Direct Care Workforce</p> <hr/> <p>10 Improve collaboration with community partners</p>
<p>PILLAR 5 <i>Home and Community-Based Services</i></p>	<p>11 Improve and expand respite services, with a focus on under-served populations</p>

Section 7

ADAC Recommendations

Pillar 1: ADRD Policy

Florida is fortunate to have tremendous support from its Governor and state lawmakers due to the increasing prevalence of ADRD throughout the state and its impact on Florida residents and the economy. ADRD policy efforts overall have increased significantly in recent years. Detailed legislative advancements from 2021-22 are noted in Section 4.

ADAC acknowledges one of the most promising avenues to advance recommendations in this area is through the work of the State Health Improvement Plan Priority Area for Alzheimer's Disease Workgroups.

RECOMMENDATION 1 Continued Support of the State Health Improvement Plan (SHIP) Priority Area: Alzheimer's Disease.

Background Information Governor DeSantis used executive privilege to add Alzheimer's Disease as a SHIP Priority Area in 2019, midway through the 2017-2021 cycle. At that time, work in this space was known as "Priority Area 9." Alzheimer's Disease continues as a Priority Area on the 2022-2026 cycle as "Priority Area 1." For clarity, the Priority Area is written as "Priority Area AD" throughout this report.

The ADAC recommends the following:

- DOEA and DOH continue to support Priority Area AD 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 AD and provide a quarterly Priority Area AD update to the ADAC.
- DOEA and DOH, along with all dedicated partners, should continue to monitor the

success of SHIP goals and objectives as necessary going forward.

- A joint meeting with the full SHIP Priority Area AD and ADAC occur on an annual basis.

2022 Revised SHIP goals included the following:

Goal AD1: Strengthen the capacity to address Alzheimer's Disease and related dementias in Florida.

Objective AD1.1 By December 31, 2026, increase the number of identified partners that have distributed an approved and current early detection, early diagnosis concern and awareness campaign from 134 (2021) to 2,000.

Objective AD1.2 By December 31, 2026, increase the number of new identified partners that can distribute an approved and current early detection, early diagnosis concern and awareness campaign or related dementias resources, information, and toolkits from 714 (2021) to 6,000.

Objective AD1.3 By December 31, 2026, increase the outreach and education events throughout the state that share accurate, reliable, and cohesive information regarding early detection/early diagnosis of Alzheimer's disease and related dementias from 184 (2021) to 500.

Objective AD1.4 By December 31, 2026, increase the number of people reached at outreach and education events regarding early detection/early diagnosis of Alzheimer's disease and related dementias from 33,000 (2021) to 60,000.

Goal AD2: Ensure a competent Alzheimer's disease and related dementias workforce.

Objective AD2.1 By June 30, 2026, increase the percentage of facilities, support agencies or partners that provide Alzheimer's disease and related dementias training, in various formats, to its direct care employees or staff from 0 percent (2021) to 100 percent.

Objective AD2.2 By December 31, 2026, increase the number of counties in Florida having at least one business that has achieved the Department of Elder Affairs (DOEA) Age and/or Dementia Friendly Business/Employer Designation from one (2022) to 67.

Objective AD2.3 By December 31, 2026, increase the number of providers and partners who are receiving education and/or training and clinical support resources on the essentials of a clear and concise care plan (i.e., assessment, diagnosis, outcomes and planning, implementation, and evaluation) from zero (2021) to 3,000.

Goal AD3: Enhance support for those living with Alzheimer’s Disease and related dementias and their caregivers.

Objective AD3.1 By December 31, 2026, increase the number of promotions of public health campaigns discussing caregivers’ physical and mental health from 134 (2021) to 2,000.

Objective AD3.2 By December 31, 2026, increase the number of individuals participating in Alzheimer’s disease and related dementias support groups, counseling programs and education platforms from 32,000 (2021) to 100,000.

Objective AD3.3 By December 31, 2026, increase the number of caregivers who utilize respite programs, including emergency respite, from 1,569 (2021) to 3,000.

RECOMMENDATION 2

Continue Supporting the Governor’s Dementia Action Plan through the implementation of the Florida Alzheimer’s Center of Excellence.

Background Information Governor DeSantis directed the Department of Health to apply for the BOLD Infrastructure for Alzheimer’s grant using committed partners in 2019. The application was not successful, due to strains created by COVID-19.

The Department of Elder Affairs took the initiative to craft a state-directed model to offer ongoing support to caregivers and recognize sites that demonstrate excellence in ADRD care for PLWD and staff training. Governor DeSantis announced the launch of this effort on June 23, 2022, at a press conference in Broward County, Florida.

Efforts in this area fulfill the final component of the Governor’s Dementia Action Plan and will address this recommendation in its entirety.

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, particularly any priorities related to:
 - » Training for direct care workers, and
 - » Identifying and providing more culturally appropriate strategies designed to increase public awareness about ADRD, to decrease disease stigma and promote more early screening and detection in these high-risk groups including African Americans and Hispanics.
- The Secretary of the Department of Elder Affairs or designee provide a series of timely updates on developing legislation throughout the 2022 Legislative Session so that the Committee can consider voting on and providing formal support as determined.

RECOMMENDATION 4

Continue Support of the State's New Dementia Director. The ADAC is pleased to see the role of the Dementia Director filled with a capable and enthusiastic leader who is exceeding expectations.

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.

ADAC supports the work of the Dementia Director and recommends:

- Dementia Director should continue to provide brief updates for each ADAC meeting.
- That the Secretary of the Department of Elder Affairs introduces all new leaders at the Department related to ADRD to explain roles, responsibilities, and expected partner engagement.

Pillar 2: ADRD Research

Florida has two significant avenues that promote the study of Alzheimer's Disease and Related Dementias: The state-mandated Memory Disorder Clinics and the Ed and Ethel Moore Grant Program (in Section 2). Individual studies address all facets of research: prevention, diagnosis, treatment, and cure.

RECOMMENDATION 5

Engage fully with the full scope of practice of the Memory Disorder Clinics.

ADAC recommends the following:

- MDCs to become more active in the State Health Improvement Plan process and better integrate into the health systems in which they sit.
- Improve the flow of information from the MDC and the ADAC, and from the MDC to the public. This can be accomplished through support to their marketing efforts.
- Continued research presentations at Committee meetings on Ed & Ethel Moore research projects and innovative Florida-based research projects for ADRD.

RECOMMENDATION 6

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 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 Executive Office of the Governor, and other partnered agencies.

RECOMMENDATION 7

Continued Engagement with the Brain State.

Background Information Brain State was created based on a recommended item in ADAC's 2021 Annual Report. Brain State is a public-private partnership bringing together



academia, government, the health care sector, and industry with the goal of discovering next generation diagnostics and treatment solutions for the world's most devastating neurological diseases, focusing on Alzheimer's disease. This cross-sector ecosystem leverages Florida's world-class clinical and academic researchers and infrastructure and convenes around the world's most cutting-edge technologies to build a more robust, interconnected network across Florida of partners who share information, knowledge, technology, resources and data to deliver translational solutions to patients in need.

ADAC supports the work of the Brain State and recommends the following:

- Continued updates to the members of ADAC and public attendees at ADAC quarterly meetings.
- Dissemination of findings through available networks (e.g., DCCI task forces, DOEA website, Memory Disorder Clinics, and *Elder Update* newspaper, as appropriate).

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.

Example of Clinical Care Settings in Florida:

- Memory Disorder Clinics
- Health Systems such University of Florida and its MDC
- Doctor's offices (primary care, neurology, geriatric, urology, etc.)
- Alzheimer's Disease Research Centers (federally funded and appointed sites)

Background Information The READY Act (see details in Section 4) requires the Department of Health to offer training and education to Primary Care Providers and other health care providers throughout Florida to ensure quality care and best-practice guidelines are implemented in all clinical care settings. The ADAC supports these efforts.

RECOMMENDATION 8

Continued and increased professional outreach and education efforts on the use of CPT code 99483 and best practice guidelines.

ADAC recommends:

- In concert with efforts born from DOH resulting from the READY Act:
 - » Increase distribution of information detailing proper use of the code and how to incorporate this type of visit into the billing framework of the health system,
 - » Increase collaboration with professional groups (e.g., Florida Academy of Family Physicians) to reach practitioners from a streamlined and trusted source,
 - » Disseminate clinical information such as integration of new biomarkers so that physicians can provide more comprehensive care in all disease stages,

- » Encourage the use of clinical algorithms that could streamline office procedures for primary care physicians, and
- » Encourage the use of culturally and linguistically appropriate screening tools to improve the effectiveness of assessments performed during annual wellness visits.

RECOMMENDATION 9

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 work with the Memory Disorder Specialist within the DOEA to insure 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; and
- ADAC recommends that the MDCs continue to meet all performance standards and benchmark goals.

Pillar 4: ADRD Institutional Care

Introduction: Institutional care is defined as care provided in a hospital, nursing home, or other facility certified or licensed by the state, primarily affording diagnostic, preventive, therapeutic, rehabilitative, maintenance, or personal care services. Thus, a generalized 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

dressings change or colostomy care), and rehabilitation, primarily for the aged.

Examples of Institutional Care:

- Skilled nursing facilities
- Assisted living facilities
- Memory care facilities
- Adult day care facilities
- Hospice facilities

Background One of the goals of the Florida Alzheimer’s Center of Excellence includes recognizing sites that demonstrate compliance with training mandates and employ highly trained staff members. ADAC recognizes that this new initiative from the Department of Elder Affairs will be a helpful step in achieve the following recommendations.

RECOMMENDATION 10

Improved training for Direct Care Workforce.

In accordance with the Health Brain Initiative, institutional care in Florida be provided enhanced training for direct care workers, thereby addressing the nearly 60 percent of institutional care residents living with Alzheimer’s disease or related dementia. ADAC recommends the following:

- 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 the DOEA’s Project VITAL,
- Continued pursuit of designating dementia and Age-Friendly businesses and employers as dementia-capable,
- DOEA continue 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 continue 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, and
- The continued support of the SHIP Priority Area AD strategies and goals for workforce development and training.

Pillar 5: Home and Community Services

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 11 Improved Collaboration with Community Partners.

Background Information Dementia Care and Cure Initiative (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 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 (Section 2).



ADAC recommends the following:

- Continue to work on our outreach to community partners;
- ADAC and DCCI to have more of a connection, and
- Target the at-home caregiver to increase awareness of possible resources and educate on how to take care of their loved one with dementia and themselves.

Note the recommendation on the 2021 ADAC report to establish action plans for DCCI Task Forces was achieved. The task forces received direction to work toward the following goals:

- Define and complete at least two intergenerational programs in the calendar year 2022;
- Develop (or identify programming you will use) to offer business-sector ADRD sensitivity training;
- Maintain information for the annual report of all training provided;
- Develop and publish (online or hard copy) up to date list of local resources for ADRD care, caregiver support, and important contact numbers;

- Initiate conversations with local law enforcement regarding their ADRD training (can offer to provide or make connections to other providers) and local LE response to ADRD issues (e.g., Yellow Dot, Scent Evidence K-9, project Lifesaver, etc.);
- Maintain “opportunity” report to identify unmet needs and inform 2023 goal planning;
- Enhanced training for direct care workers that work in long-term care settings, mirroring SHIP Priority Area AD’s goals to create a dementia capable workforce; and
- The Dementia Director work closely with growing number of DCCI task forces to offer collaboration and cohesiveness to goals, priorities, and action plans.

RECOMMENDATION 12

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.

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 (Section 2).

ADAC recommends the following:

- ADAC to encourage growth of caregiver programs that reduce the burden experienced by caregivers and alleviate the state’s waitlist (e.g. NANCares, Tcares, etc.).

References

[i] Association, Alzheimer's. Compiled from 2021 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia, 8(2). Source: alz.org/downloads_facts_figures_2021.pdf, and download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf

[ii] Association, Alzheimer's. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia, 8(2). Source: alz.org/downloads_facts_figures_2021.pdf, and download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf

[iii] Association, Alzheimer's. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia, 8(2). Source: alz.org/downloads_facts_figures_2021.pdf, and download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf

[iv] Association, Alzheimer's. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia, 8(2). Source: alz.org/downloads_facts_figures_2021.pdf, and download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf

[v] Florida Agency for Health Care Administration (2021). floridahealthfinder.gov Sources: floridahealthfinder.gov/facilitylocator/facloc.aspx

[vi] Association, Alzheimer's. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia, 8(2). Source: alz.org/downloads_facts_figures_2021.pdf, and download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012000325.pdf

[vii] Pfizer Medical Team, 10 Health Benefits of Music, Aug. 2017. Source: gethealthystayhealthy.com/articles/10-health-benefits-of-music

[viii] The Health Resources & Services Administration, U.S. Department of Health and Human Services. Source: hrsa.gov/enews/past-issues/2019/january-17/loneliness-epidemic

[ix] Centers for Disease Control and Prevention, Alzheimer's Disease and Healthy Aging Program, citing Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. Source: cdc.gov/aging/caregiving/alzheimer.htm

[x] The Utilization of Robotic Pets in Dementia Care, Petersen, S., Houston, S., Qin, H., & Studley, J., J. of Alzheimer's Disease (2016). Source: ncbi.nlm.nih.gov/pmc/articles/PMC5181659



ELDERAFFAIRS.ORG

4040 Esplanade Way
Tallahassee, Florida 32399-7000
Phone: (850) 414-2000 | Fax: (850) 414-2004