

2023 ALZHEIMER'S DISEASE ADVISORY COMMITTEE

● ● ● ● ● ● *Annual Report*



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FLORIDA



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FLORIDA

2023 ALZHEIMER'S STATISTICS

NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S

YEAR	TOTAL
2020	580,000
2025	720,000

ESTIMATED % INCREASE

24.1%

PREVALENCE

362

 # OF GERIATRICIANS IN 2021

277.1%

 INCREASE NEEDED TO MEET DEMAND IN 2050

76,140

 # OF HOME HEALTH AND PERSONAL CARE AIDES IN 2020

22.5%

 INCREASE NEEDED TO MEET DEMAND IN 2030

WORKFORCE

UNPAID CAREGIVERS (2022)

827,000

 # OF CAREGIVERS

1,301,000,000

 TOTAL HOURS OF UNPAID CARE

\$23,409,000,000

 TOTAL VALUE OF UNPAID CARE

CAREGIVER HEALTH (2021)

66.4%

 OF CAREGIVERS WITH CHRONIC HEALTH CONDITIONS

28.6%

 OF CAREGIVERS WITH DEPRESSION

13.6%

 OF CAREGIVERS IN POOR PHYSICAL HEALTH

CAREGIVING

HOSPICE (2017)

19,897

 # OF PEOPLE IN HOSPICE WITH A PRIMARY DIAGNOSIS OF DEMENTIA

15%

 HOSPICE RESIDENTS 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

\$31,665

 PER CAPITA MEDICARE SPENDING ON PEOPLE WITH DEMENTIA (IN 2022 DOLLARS)

HEALTH CARE

OF DEATHS FROM ALZHEIMER'S DISEASE (2019)

6,539

MORTALITY



More than **6 million Americans** are living with Alzheimer's, and over **11.5 million** provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$345 billion** in 2023, increasing to nearly **\$1 trillion** (in today's dollars) by mid-century.

For more information, view the **2023 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. In the United States, approximately 6.2 million people are living with Alzheimer's disease, 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, vascular, and Parkinson's disease. Currently, there are no known cures for Alzheimer's disease and related dementias, or ADRD.

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, or AD, brain cells degenerate and die, destroying memory, cognitive function, and thinking skills, which affects the behavior of individuals experiencing these symptoms. Alzheimer's disease, the most common cause of dementia, 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 AD 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 AD 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 AD 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 likely will continue to lead the nation, as approximately 21 percent of its population is over 65.

AD 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, AD remains the only one without prevention or cure. In 2050, the number of people in America ages 65 and older with AD is projected to reach 12.7 million, with Florida having the highest projected rate of increase in the country. The Miami-Dade region, along with Baltimore, MD, and Bronx County, NY, currently have the highest estimated AD rates in the country¹.

The economic impact of this disease is also devastating and overwhelming. In 2023, ADRD will cost the nation \$345 billion — not including the value of unpaid caregiving. Costs of health care and long-term care for individuals living with ADRD are substantial, and dementia is one of the costliest conditions to society. These costs are reflected in all areas of health care delivery:

- People living with ADRD have twice as many hospitalizations per year as other older people.
- Medicare beneficiaries with ADRD are more likely than those without dementia to have other chronic conditions, such as heart disease, diabetes, and kidney disease;
- Older people living with ADRD have more skilled nursing facility stays and home health

1 doi.org/10.1002/alz.13081

care visits per year than other older people; and

- People living with ADRD make up a large proportion of all elderly people who receive adult day services and nursing home care².

2023 Alzheimer's Association Facts and Figures

The 2023 Alzheimer's Association Facts and Figures Report³ provides an overview of the latest national statistics and information on Alzheimer's 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 2023; by 2050, this number is projected to rise to nearly 13 million.
- Approximately 580,000 Floridians are currently living with AD.
- Florida has the second highest prevalence of AD in the nation.
- By 2025, data scientists project that there will be over 720,000 Floridians living with AD – an increase of over 24 percent.
- AD is the sixth leading cause of death in Florida.
- One in three seniors dies with ADRD; it kills more than breast cancer and prostate cancer combined.
- The lifetime risk for AD at age 45 is one in five for women and one in 10 for men.
- 73 percent of people living with AD are age 75 or older.
- Two-thirds of Americans age 65 or older living with AD (3.6 million) are women.
- Seven in 10 Americans reported that they would want to know early if they have AD if it could allow for earlier treatment.

- Only four in 10 Americans would talk to their doctor right away when experiencing early memory or cognitive loss.
- African Americans are two times more likely to develop AD than their white counterparts.
- Hispanic Americans are one-and-a-half times more likely to AD than their white counterparts.

Caregiving

- Eighty-three percent of the help provided to older adults in the U.S. comes from family members, friends, or other unpaid caregivers.
- Nearly half of all caregivers who provide help to older adults do so for someone living with ADRD
- About 30 percent of caregivers are age 65 or older.
- Nearly half of all caregivers (48 percent) who provide help to older adults do so for someone living with ADRD.
- Approximately two-thirds of caregivers are women. More specifically, over one-third of dementia caregivers are daughters.
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers – meaning that they care not only for an aging parent but also for at least one child.
- Forty-one percent of caregivers have a household income of \$50,000 or less.
- ADRD takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.
- Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families – either through out-of-pocket health and long-term care expenses or from the value of unpaid care.

² [alz.org/alzheimers-dementia/facts-figures](https://www.alz.org/alzheimers-dementia/facts-figures)

³ Alzheimer's Association Facts and Figures 2023

- Over 11 million Americans provide unpaid care for people with ADRD.
- Women make up two-thirds of those living with AD and approximately two-thirds of the caregiving population.
- There are over 827,000 Floridians providing loved ones with unpaid care.

National Cost of Care for ADRD

- In 2023, ADRD will cost the nation \$345 billion, not including the value of unpaid care. By 2050, these costs could rise to nearly \$1 trillion.
- In 2022, unpaid caregivers provided an estimated 18 billion hours of care valued at \$339.5 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 \$222 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 \$87 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.
- AD is currently the most expensive disease in America, costing more than cancer or heart disease.

Florida Costs

- In 2022, Florida caregivers of people with ADRD provided an estimated 1.3 billion hours of unpaid care, a contribution to the nation valued at \$23.4 billion.
- 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.

Workforce Shortage

Most families reach out to their valued primary care physician (PCP) with their first concerns about ADRD. However, most PCPs report they do not have the time or confidence to respond to the increasing demand of dementia-related concerns.

- Between 2020 and 2030, 1.2 million additional direct-care workers will be needed to care for the growing population of people living with dementia — the largest worker gap in the U.S.
- Even though most initial diagnoses are made by PCPs, nearly 40 percent reported that they were “never” or “only sometimes” comfortable making a diagnosis of Alzheimer's or another dementia.
- Half of PCPs reported that they do not feel adequately prepared to care for individuals with ADRD, and more than 25 percent reported being “only sometimes” or “never” comfortable answering patient questions about dementia.
- The U.S. will have to nearly triple the number of geriatricians to effectively care for the number of people projected to have AD in 2050.
- Data from 2021 shows there were 362 geriatricians in Florida; this number must increase by more than 277% to meet the anticipated demand in 2050.
- In 2020, Florida had approximately 76,000 Home Health and Personal Care aides. This number must increase by 22.5 percent to meet the anticipated demand in 2050⁴.

⁴ alz.org/alzheimers-dementia/facts-figures

Section 2

Alzheimer’s and Related Dementias Infrastructure

Governor DeSantis has made AD a priority in the state due to the disease’s overwhelming impact across so many areas of infrastructure. Florida is positioned as a national leader in this space by integrating efforts into programs that promote research, address risk reduction, support workforce enhancement, and improve caregiver support.

The Alzheimer’s Disease Initiative (ADI) is Florida’s signature piece of infrastructure that outlines support for caregivers in the following areas: clinical services, diagnosis, support services, education, research,

and most importantly, bringing together community partners to identify gaps and make recommendations. These comprehensive services have received significant funding increases under Governor DeSantis’s leadership.

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

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.

BOLD grant, the Ed and Ethel Moore Research Grant provides 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 designated in Florida that serve as ADRD hubs. They are funded by the federal government.

Treatment Breakthroughs

The field of Alzheimer's research saw important breakthroughs across multiple treatment domains in 2023. In February 2023, the first Alzheimer's patient in Florida was treated in with MRI-guided Focused Ultrasound Technologies at Delray Medical Center, one of the state's Memory Disorder Clinics⁵. In early July, the FDA converted the new treatment option Leqembi from trial status to traditional use and approval⁶. Prior to the FDA approval, Secretary Branham and Florida Surgeon General Dr. Joseph Ladapo co-signed a letter urging the Centers of Medicare Services (CMS) to grant coverage for use of this treatment,⁷ which was granted in July for Medicare recipients who meet criteria. Additionally, the Department continued to participate in the Brain State Initiative, which represents Florida's commitment to be a global leader in a connected healthcare economy. Through that effort, a network of state universities, hospitals, and institutions work in a public-private partnership to advance novel therapies, diagnostics, and understanding of neurologic diseases. The 2023 Brain State consortium took place in May in Miami.

The Role 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 below highlights the key milestones covered by ADI.

In December 2021, Governor Ron DeSantis appointed Secretary Michelle Branham as the agency head for the Florida Department of Elder Affairs. Under Secretary Branham's leadership, the Department serves Florida's 6.1 million seniors age 60 and older, providing services and supporting initiatives through Florida's Aging Network to help seniors live well and age well in the state.

Caregiver Support and Respite Services

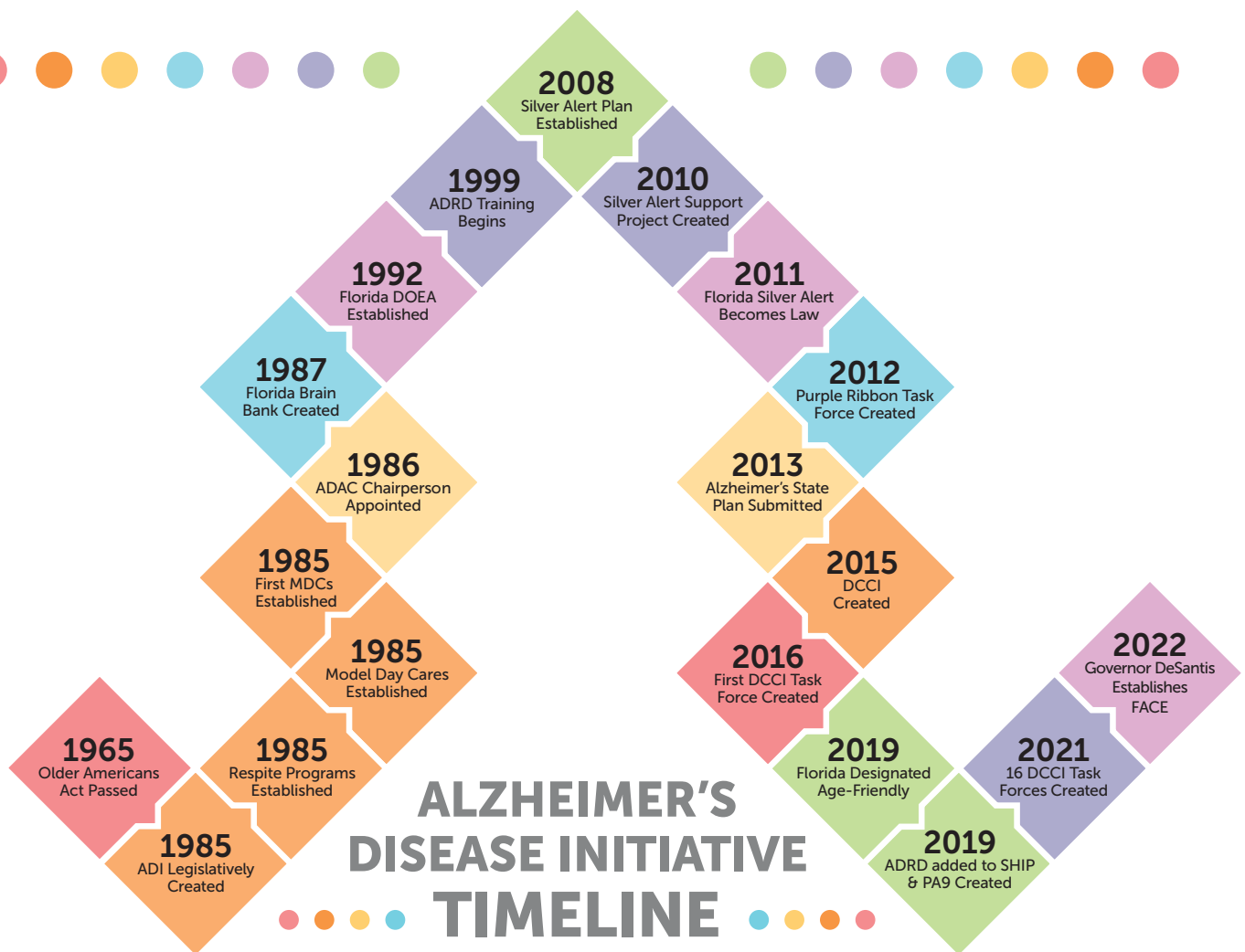
The Alzheimer's Disease Initiative (ADI) is a statewide program within the Department of Elder Affairs that provides services to individuals and families affected by ADRD. ADI includes three components:

- 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, and
- The Florida Brain Bank to support research.

⁵ delraymedicalctr.com/news/newsroom/delray-medical-center-is-first-hospital-in-florida-to-treat-alzheimer-s-patient-with-non-invasive-focused-ultrasound-technology

⁶ fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval

⁷ twitter.com/elderaffairs/status/1649125479209631754?s=20



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



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; 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 are described in detail here.

Alzheimer's Disease Research Centers

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 Research Centers in Florida: 1) Mayo Clinic Jacksonville and 2) 1Florida (an ADRD consortium of universities and health science centers).

Resources in Florida

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

Area Agencies on Aging

1 PSA 1

Northwest Florida Area Agency on Aging

5090 Commerce Park Cir.
Pensacola, FL 32505
Phone: (850) 494-7101

Elder Helpline: (866) 531-8011
nwflaaa.org

2 PSA 2

Advantage Aging Solutions

414 Mahan Dr.
Tallahassee, FL 32308
Phone: (850) 488-0055

Elder Helpline: (866) 467-4624
advantageaging.org

3 PSA 3

Elder Options

100 S.W. 75th St., Ste. 301
Gainesville, FL 32607
Phone: (352) 378-6649

Elder Helpline: (800) 262-2243
agingresources.org

4 PSA 4

ElderSource

10688 Old St. Augustine Rd.
Jacksonville, FL 32257
Phone: (904) 391-6600

Elder Helpline: (888) 242-4464
myeldersource.org

5 PSA 5

Area Agency on Aging of Pasco-Pinellas

9549 Koger Blvd.
Gadsden Bldg., Ste. 100
St. Petersburg, FL 33702
Phone: (727) 570-9696

Elder Helpline: (727) 217-8111
agingcarefl.org

6 PSA 6

Senior Connection Center

8928 Brittany Way
Tampa, FL 33619
Phone: (813) 740-3888

Elder Helpline: (800) 336-2226
seniorconnectioncenter.org

7 PSA 7

Senior Resource Alliance

3319 Maguire Blvd., Ste. 100
Orlando, FL 32803
Phone: (407) 514-1800

Elder Helpline: (407) 514-0019
seniorresourcealliance.org

8 PSA 8

Area Agency on Aging for Southwest Florida

15201 N. Cleveland Ave., Ste. 1100
North Fort Myers, FL 33903
Phone: (239) 652-6900

Elder Helpline: (866) 413-5337
aaswfl.org

9 PSA 9

Area Agency on Aging of Palm Beach/Treasure Coast, Inc.

4400 N. Congress Ave.
West Palm Beach, FL 33407 Phone:
(561) 684-5885

Elder Helpline: (866) 684-5885
aaapbtc.org

10 PSA 10

Area Agency on Aging of Broward County

5300 Hiatus Rd.
Sunrise, FL 33351
(954) 745-9567
Phone: (954) 745-9567

Elder Helpline: (954) 745-9779
adrcbroward.org

11 PSA 11

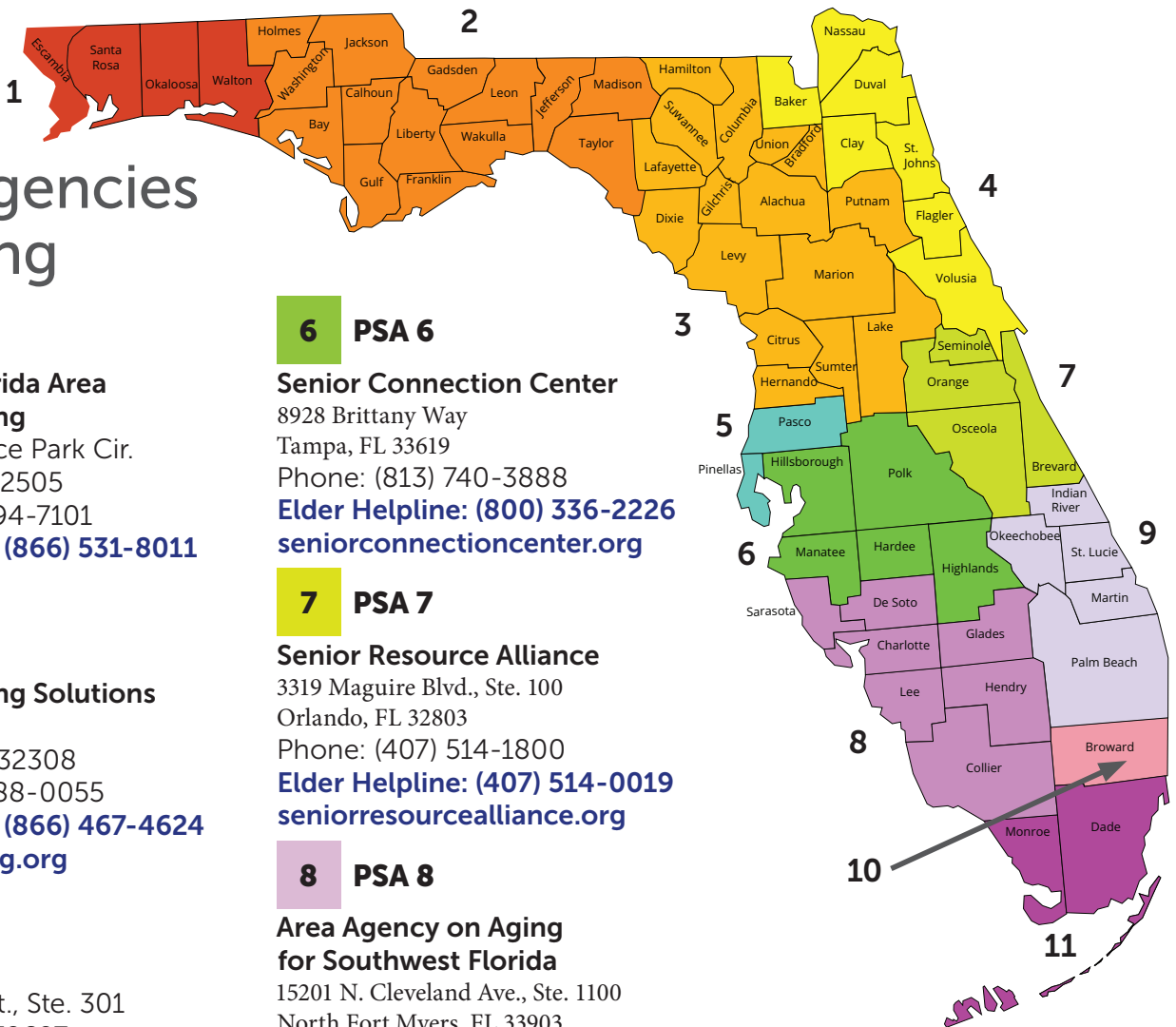
Alliance for Aging

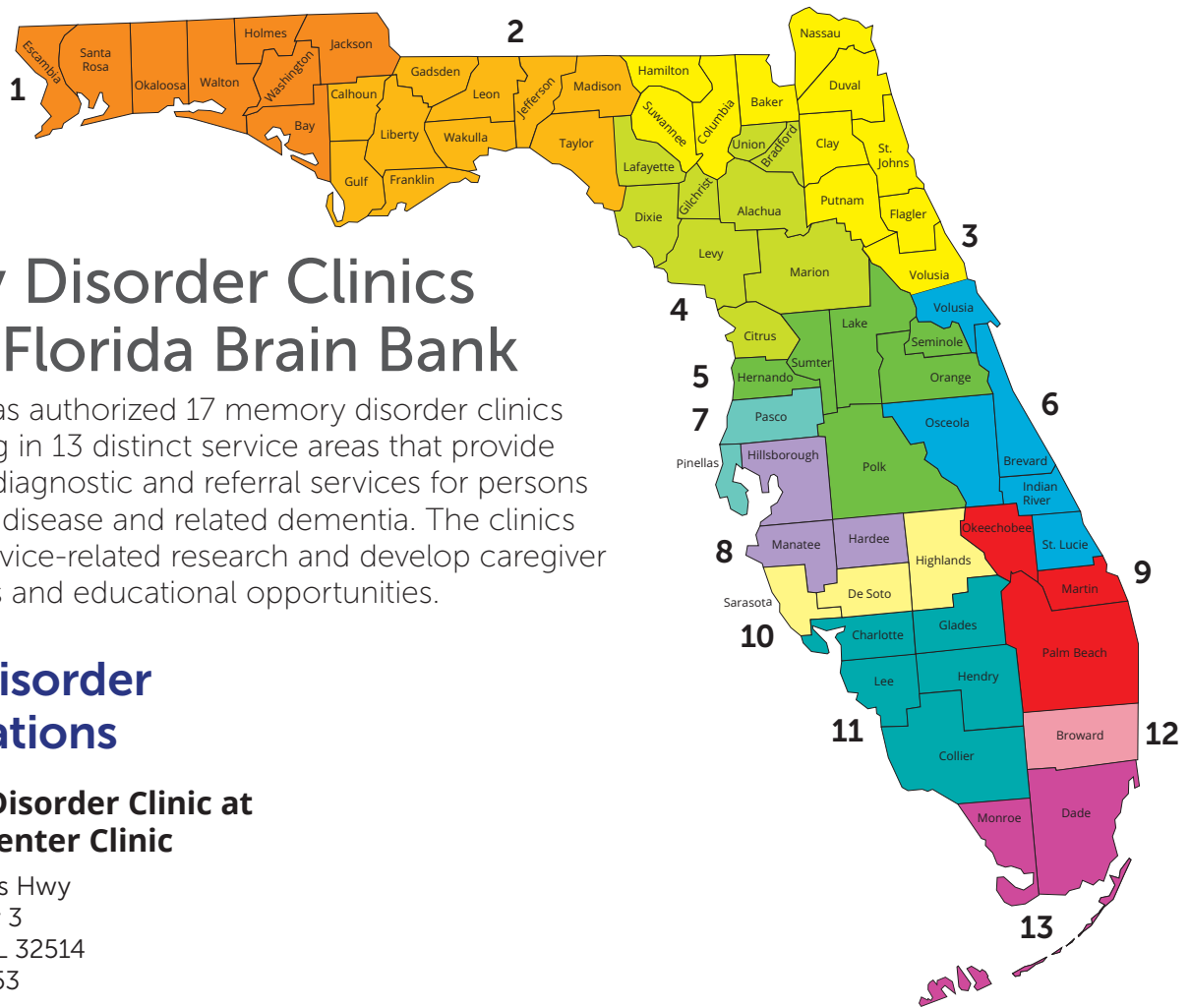
15201 N. Cleveland Ave., Ste. 1100
North Fort Myers, FL 33903
Phone: (305) 670-6500

Elder Helpline: (305) 670-4357
allianceforaging.org

County coloring represents area served by the corresponding Area Agency on Aging.

PSA - Planning and Service Area





Memory Disorder Clinics and the Florida Brain Bank

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

Memory Disorder Clinic Locations

1 Memory Disorder Clinic at Medical Center Clinic 8333 N. Davis Hwy Bldg. 1, Floor 3 Pensacola, FL 32514 850-474-8353	5 AdventHealth Memory Disorder Clinic 1573 W. Fairbanks Ave, Ste. 210 Winter Park, FL 32789 (407) 392-9237
2 Tallahassee Memorial HealthCare Memory Disorder Clinic 1401 Centerville Rd., Ste. 504 Tallahassee, FL 32308 (850) 431-5001	6 Health First Memory Disorder Clinic 3661 S. Babcock St. Melbourne, FL 32901 (321) 434-7612
3 Mayo Clinic Jacksonville Memory Disorder Clinic 4500 San Pablo Rd. Jacksonville, FL 32224 (904) 953-7103	7 Morton Plant Madonna Ptak Center for Alzheimer’s Research and Memory Disorders Clinic 430 Morton Plant St., Ste. 401 Clearwater, FL 33756 (727) 298-6025
4 University of Florida Memory Disorder Clinic 3009 SW Williston Rd. Gainesville, FL 32608 (352) 294-5400	8 University of South Florida Memory Disorder Clinic 3515 E. Fletcher Ave. Tampa, FL 33613 Phone: (813) 974-3100

**St. Mary's Medical Center
Memory Disorder Clinic at Palm
Beach Neuroscience Institute**

9

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

**Florida Atlantic University
Louis and Anne Green Memory
and Wellness Center**

9

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

**Sarasota Memorial Memory
Disorder Clinic**

10

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

Lee Memorial LPG Memory Care

11

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

**Broward Health North
Memory Disorder Center**

12

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

**Mt. Sinai Medical Center Wien
Center for Alzheimer's Disease
and Memory Disorders**

13

4302 Alton Rd., Ste. 650
Miami Beach, FL 33140
(305) 674-2543 ext. 55725

**University of Miami Center for
Cognitive Neuroscience and Aging**

13

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

**The MIND Institute at
Miami Jewish Health**

13

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



Brain Bank Locations

**State of Florida Brain Bank- Satellite
Office Orlando Alzheimer's and
Dementia Resource Center**

5

1410 Gene Street
Winter Park, FL 32789
(407) 436-7755

**State of Florida Brain Bank Wien
Center for Alzheimer's Disease
and Memory Disorders**

13

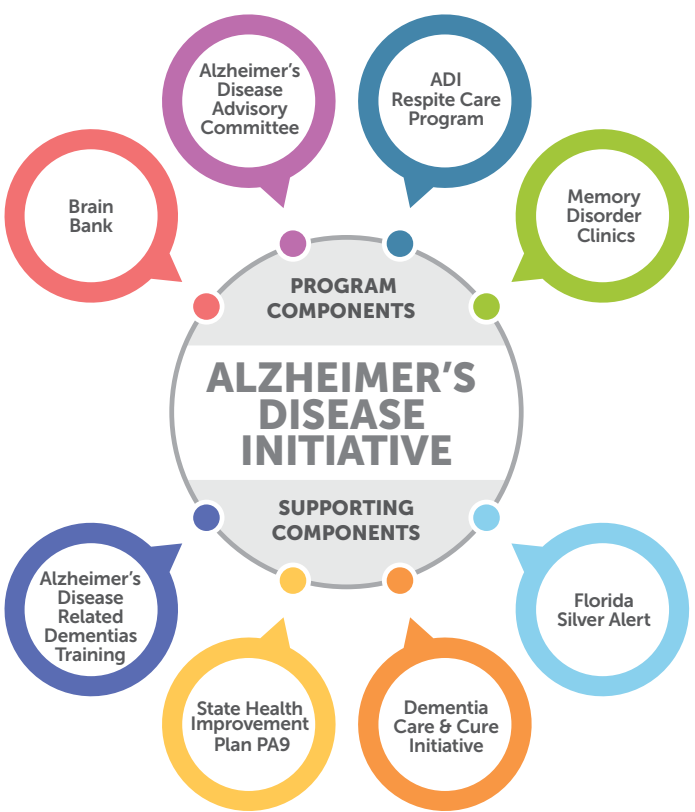
4302 Alton Road, Suite 650
Miami Beach, Florida 33140
(305) 674-2018

*NOTE: County coloring represents area served by
the corresponding Memory Disorder Clinic.*

needed to maintain independence, promote healthy aging, and live an optimal quality of life. The AAAs are considered the gateway to senior services. They perform all intake assessments for home and community-based services such as the ADI respite funding and the Community Care for the Elderly funding (CCE).

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. The recent legislative session yielded a significant increase in Memory Disorder Clinic funding. All clinics worked with the Department of Elder Affairs to develop corresponding increases to metrics that reflect their impact to the state and local communities and to the body of knowledge about Alzheimer’s disease and related dementias.

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. Each interaction with the community should be a positive one, created out of respect and understanding, with the purpose of giving individuals with dementia the opportunity to continue playing a vital role within their communities.



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 Dementia

Florida Alzheimer's Center of Excellence

Florida Alzheimer's Center of Excellence (FACE) supports caregivers and people with ADRD 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 ADRD 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 ADAC.

The FACE model's primary efforts serve people living with dementia and their family caregivers. Through dialogue with Care Navigators, family members can learn about helpful lifestyle interventions for caregiving. Care Navigators counsel family members about all elements of a successful care plan: legal and financial planning, home safety, caregiving skills, access to community resources, education, and emotional support, and more. The Care Navigators make connections to local experts for services that require professional level interventions (e.g., medical care, legal plans, etc.). The Care Navigator's primary role is to serve as a trusted resource and guide to ensure that plans evolve as the individual's needs change.

In June 2023, the FACE program began working with the Navigating Aging Needs program (NAN). NAN offers a similar care navigation program, that also includes clinical support from medical professionals⁸. The team at NAN was recently selected to present their findings at the poster

gallery of Alzheimer's Association International Conference in Amsterdam in July 2023.

The 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. Implementation of the second and third phase of the FACE model will continue over the next two years.

ADRD Curriculum and Training Provider Evaluation

In July 2023, the Department of Elder Affairs became responsible for the direct oversight of training provider certification and ADRD curriculum evaluation (previously this work was done via contract between DOEA and a third party.). The requirements for training providers and curriculum content have not changed, but the Department will work to develop a more streamlined application process and offer standardized Certificates of Completion to ease the process for the Agency for Health Care Administration team responsible for monitoring long-term care facilities that must comply with training requirements.

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.

⁸ nanforcaregivers.com/

- 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:
 - » 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.

The Department of Elder Affairs also looks for creative avenues to solve problems through 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.

Section 4

Policy Advancements in Alzheimer's Disease and Related Dementia

House Bill 299 - Education and Training for Alzheimer's Disease and Related Forms of Dementia

The bill establishes universal ADRD training requirements to be used by nursing homes, home health agencies, nurse registries, companion or homemaker service providers, health care services pools, assisted living facilities (ALF), adult family-care homes (AFCH), adult day care centers (ADCC), and ADCCs that provide specialized Alzheimer's services to replace each license type's individual training requirements on that topic.

The bill requires that all employees of covered providers receive basic written information about interacting with persons who have ADRD upon beginning employment. Employees of covered providers who provide personal care to, or have regular contact with, patients, participants, or residents, must also complete one hour of dementia-related training within 30 days of their initial employment.

This bill also makes changes to training timelines for employees at licensed facilities and charges DOEA with the responsibility to provide the one-hour training content and make educational materials available to the public⁹.

Effective Date: July 1, 2023

⁹ [flsenate.gov/PublishedContent/Session/2023/BillSummary/Children__CF0299cf_00299.pdf](https://www.flsenate.gov/PublishedContent/Session/2023/BillSummary/Children__CF0299cf_00299.pdf)

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." The ADAC statute recommends representation from law enforcement, Area Agencies on Aging, 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 2022-2023, ADAC met on the following dates:

- October 25, 2022 (Q3)
- December 15, 2022 (Q4)
- March 24, 2023 (Q1)
- June 19, 2023 (Q2)

In 2023, 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:

- Dr. Lloyd Zucker and Dr. Arif Dalvi presented on the collaborated work of Delray Medical Center and Florida Atlantic University on Focused Ultrasound Technology.
- Travis Montera and John Walker, from uMETHOD, presented research that can streamline the process of screening, diagnosis, and treatment for dementia to create a standard of care.
- Dr. Hariom Yadav, Director of USF Center of Microbiome Research, presented on Microbiome Research and the hopes

to utilize it as a screening tool to detect cognitive decline and impairment.

- Blair Sisisky, MSW with Baptist Health and AgeWell, spoke on how the organizations are providing care to the senior population including those with dementia.

Current Committee Members:

- **Dr. Jonathan Weiss** Committee Chair, Vice President of Strategic Innovation, INSIGHTEC (G)
- **Dr. Jonathan Gonzalez** Committee Vice Chair, Primary Care Physician (G)
- **Dr. Rosemary Laird** Chief Medical Officer, My Memory Clinic and NANCares (G)
- **Dr. Corinne Labyak** Associate Professor, University of North Florida (G)
- **Samantha Ferrin** Senior Government Relations Director, Elevance Health (G)
- **Alex Anderson** Vice President of Public Policy, Florida Alzheimer's Association (G)
- **Jason Lederman** Client Care Liaison, American In-Home Care (G)
- **Stacy Plean** Broker Associate, LoKation Real Estate (G)
- **Donna Flanagan** Speech and Language Pathologist (S)
- **Senator Gayle Harrell** State Legislator (S)
- **Fátima Perez** Regional Manager, State Government Affairs, Koch Industries (H)
- **Representative Susan Plasencia** State Legislator (H)

(G) – Governor Appointee

(S) – Senate Appointee

(H) – House Appointee

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.

Section 6

Executive Summary of Recommendations for 2023-2024

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 and made some progress in this area, but still have opportunities to effect greater change. A summary of recommendations is listed on the following page.

Recommendations from ADAC members align with five pillars.

PILLAR 1
Policy

PILLAR 2
Research

PILLAR 3
Clinical Care

PILLAR 4
Institutional Care

PILLAR 5
Home and Community-Based Services

Section 7

ADAC Recommendations

Pillar 1: ADRD Policy

Recommendation 1 Continue support of the State Health Improvement Plan.

Efforts can include:

- Funding a public awareness campaign through DOH/DOEA (aligned with State Health Improvement Plan goals).
- Supporting DOH to publish data related to READY Act implementation.
- Encouraging public health education around brain health across the lifespan to include reducing stigma, such as “it’s just aging.”

Recommendation 2 Continue Supporting the Governor’s Dementia Action Plan through the implementation of the Florida Alzheimer’s Center of Excellence.

Efforts can include:

- Promoting growth through additional Care Navigators to serve more caregivers and persons living with dementia.
- Continuing growth of the program into Phase 2 and 3 with more hospitals/ institutions becoming FACE partner sites.
- Publishing organizational structure of FACE and support teams.
- Centralizing training under FACE with HB299 and accountability.
- Ensuring and measuring implementation success of HB299.
- Engaging directly with FDA and providing updates to new research and therapies being developed.

Recommendation 3 Support viable legislative priorities brought to the 2023 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.

Efforts can include:

- Providing 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 direct care workers.
- Identifying and providing more culturally-appropriate strategies designed to increase public awareness about ADRD, to decrease disease stigma, and to 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 providing a series of timely updates on developing legislation throughout the 2023 Session, so that the Committee can consider voting on and providing formal support as determined.
- Developing policies related to high-risk and special populations (e.g., Hispanic and African American populations).
- Studying Florida’s rapid population growth and its impact on infrastructure.
- Developing policy related to clinical education best-practice standards.
 - » A Continuing Medical Education (CME) course, (e.g., narcotics compliance, elder abuse, etc.) to address the need for increased clinical education. (ADAC can assist in the development of a one- to two-hour session that addresses the above issues.)



- Promoting screening and prevention protocols (policy on preventative care -- consider UMETHOD as a standardized best practice).
- Continuing funding priorities for ADRD initiatives.
- Developing a longitudinal caregiver support mandate (as a template for chronic illness caregiver support).
- Developing strategies for sharing updates and information with legislators and legislative staff.

Recommendation 4 Continue support of the Dementia Director.

Efforts can include:

- Growth of the Dementia Director's office to include a Program Administrator for FACE and implementation of Education and Training for Alzheimer's Disease and Related Forms of Dementia (HB299).

- Ensured funding for growing and expanding role and organization.
- More frequent contact with Dementia Director to share recommendations and assistance.
- More education and outreach about the FACE program through speaking events throughout the state.
- Engaging with facilities to share updates about resources that are all available to them through FACE.

Pillar 2: Research

Recommendation 5 Continue and expand support of the Memory Disorder Clinics (MDCs).

Efforts can include:

- Promotion of services, so that the local communities are more aware of them. This will allow for better recruitment of subjects for the clinic trials and for treatment.
- Increased number of clinics.
- Pathways for MDCs to raise awareness about clinical trials.
- Integrate MDC research and other Florida-based research efforts into FACE.

Recommendation 6 Encourage research across all impacts of the disease through the Ed and Ethel Moore Grant Program and other appropriations and funding sources.

Efforts can include:

- Increased research about models of care (i.e., care-delivery model).
- Increased research about diagnostic protocols and efficiency.
- Increase funding for Ed and Ethel Moore and streamline the application process so more researchers are eligible for this funding.

Recommendation 7 Continue engagement with the Brain State Initiative.

Efforts can include:

- Scale Brain State into the university classroom setting to train the next round of physicians.
- Build into medical school training the use of focused ultrasound for Alzheimer's treatment and research.
- Establish protocol to share clinical trial options with FACE and MDCs for patients.

Recommendation 8 Facilitate improved dissemination of research findings.

Efforts can include:

- Implement FACE as a research "base" to house updates, distribute information, and centralize information related to Florida clinical trials.
- Use the DCCI task force network to share updates with community partners.
- Encourage public awareness campaigns to highlight the Florida research network.
 - » Create a specialty license plate for public awareness.
 - » Create a communication pipeline for sharing academic findings.

Pillar 3: Clinical Care

Recommendation 9 Continue and increase professional outreach and education efforts on the use of CPT code 99483 and best practice guidelines.

Efforts can include:

- Educate on CPT code 99483 and screening protocols.

- Standardize best-practice tools for screening (e.g., use of biomarkers such as Quest Diagnostics and uMETHOD technology).
- Centralize an updated standard of care under FACE, which includes recruitment into research trial.
- Continue support of the READY Act initiatives.
 - » Support the distribution of READY Act materials to physicians by ADAC members to their networks.
 - » Increase access to quality wellness checks and preventative screening through public awareness and physician readiness.
 - » Develop a method to measure clinical success of READY Act implementation.
 - » Develop a method to measure READY Act's impact on clinical outcomes on patient care.

Recommendation 10 Assess special populations and direct resources as to areas of need.

Efforts can include:

- Engage with pharmaceutical companies to direct available resources to areas of need.
- Include county health agencies in promoting and assisting caregivers with resource information. Support local dementia coordinators where available.
- Increase access to care for the indigent so they can have quality wellness checks and preventative screening.

Pillar 4: Institutional Care

Recommendation 11 Encourage increased education and training throughout institutional care settings.

Efforts can include:

- Members of ADAC can emphasize free training and resources to the communities they represent.



- Create opportunities for case managers to better understand how to access resources such as housing and ADRD education.
- Support implementation of the Alzheimer's Training Bill (HB299).
 - » Encourage ADAC members to serve as a board of advisors when developing the materials for implementation.
 - » Develop tools to measure implementation and impact of HB299.
 - » Increase accountability for training requirements.
- Centralize case management and case management training under FACE.

Recommendation 12 Support Geriatric Workforce Development Initiatives.

Efforts can include:

- Analyze the economic impact of worker shortages.

- Support best practice efforts in direct-care worker settings to encourage interest in joining the senior-care industry.

Recommendation 13 Collaborate with "young-senior" communities to promote early detection/early diagnosis and lifestyle intervention.

Efforts can include:

- Partner with independent living facilities to promote early detection and early diagnosis to at-risk individuals.
- Distribute information through all community-serving networks (e.g., DCCI task forces, Community Health Workers, etc.).

Pillar 5: Home and Community Based Services

Recommendation 14 Support use of new technologies that aid in home-health delivery.

Efforts can include:

- Provide outreach to home-health agencies and similar providers about best practice models and new innovations (e.g., personal health monitoring, Vayyar home imaging, etc.).
- Develop a technology caregiver toolkit.
- Develop a repository and centralize efforts to identify and provide a list of technologies on the market and companies with technologies that are up and coming via FACE.

Recommendation 15 Support the improvement and expansion of respite support services for people living with dementia and their caregivers with special attention to underserved service areas and populations.

Efforts can include:

- Increase funding to Home and Community Based Services/Alzheimer's Disease Initiative (ADI) programs.
- Increase access to caregiver programs to empower families to care for the loved one at home.
- Increase the number of case managers and social workers throughout the state to screen more people sooner and provide available resources quickly.

Recommendation 16 Support efforts to improve access to senior housing resources.

Efforts can include:

- Centralize resources of available county and municipal housing into FACE.

Pillar 1: ADRD Policy

INTRODUCTION Florida is fortunate to have tremendous support from Governor DeSantis 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 2022-2023 are noted above 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 Continue 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, 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 occurs 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. 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% (2021) to 100%.

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 1 (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 0 (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 people living with dementia and staff training. Governor DeSantis announced the launch of this effort on June 23, 2022, at a press conference in Broward County. The Florida Alzheimer's Center of Excellence scope of work is included as appendix XXXX.

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 viable legislative priorities brought to the 2023 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.
 - » 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 2023 Session, so that the Committee can consider voting on and providing formal support as determined.
- Develop policies related to high-risk and special populations (e.g., Hispanic and African American populations).
- Address Florida's rapid population growth and its impact on infrastructure.
- Develop a policy related to clinical education best-practice standards.
- Develop a CME course, (e.g., narcotics compliance, elder abuse, etc.) to address the need for increased clinical education. (ADAC can assist in the development of a one-to-two hour session that addresses the above issues.)
- Develop screening and prevention protocols, including a policy on preventative care (Consider uMETHOD as a standardized best practice.)
- Ensure continued funding priorities for ADRD initiatives.
- Develop a longitudinal caregiver support mandate (as a template for chronic illness caregiver support).
- Develop strategies for sharing updates and information with legislators and legislative staff.



Recommendation 4 Continue Support of the State's Dementia Director. The ADAC is pleased to see the role of the Dementia Director has been maintained with a capable and enthusiastic leader.

BACKGROUND INFORMATION On June 18, 2020, House Bill 835 was signed into law, establishing the position of a Dementia Director within DOEA. The Director position assists ADAC with the development of the annual report and development of the Alzheimer's Disease State Plan; supports the ADI, MDC, and Florida Brain Bank; facilitates public education on Alzheimer's disease; coordinates dementia research programs; and collects data on the impact of Alzheimer's disease on the state. The bill also made 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 had been hired and fulfilled.

ADAC supports the work of the Dementia Director and recommends the following:



- Dementia Director continue to provide brief updates for each ADAC meeting.
- Secretary of the Department of Elder Affairs to introduce all new leaders at the Department related to ADRD, to explain roles, responsibilities, and expected partner engagement.
- Dementia Director to develop strategies for sharing updates and information with legislators and legislative staff.
- Dementia Director's office to grow to include Program Administrator for FACE and implementation of Education and Training for Alzheimer's Disease and Related Forms of Dementia (HB299).

Pillar 2: ADRD Research

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

Recommendation 5 Continue and expand support of the Memory Disorder Clinics.

ADAC recommends:

- Promote services so that local communities are more aware of them. This will allow for better recruitment of subjects for the clinical trials and for treatment.
- Increase number of clinics.
- Provide pathways for MDCs to raise awareness about clinical trials.
- Integrate MDC research and other Florida-based research efforts into FACE.

Recommendation 6 Encourage research across all impacts of the disease through the Ed and Ethel Moore Grant Program and other appropriations and funding sources.

ADAC recommends the following:

- Increase 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.
- Increase research about models of care (i.e., care-delivery model).
- Increase research about diagnostic protocols and efficiency.
- Increase funding for Ed and Ethel Moore and streamline the application process so more researchers are eligible for this funding.

Recommendation 7 Continue Engagement with the Brain State Initiative.

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 representatives with the goal of discovering next generation diagnostics and treatment solutions for the world's most devastating neurological diseases, with a focus on AD. 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 are knowledge-sharing, technology-sharing, resource-sharing and data-sharing, to deliver translational solutions to patients in need.

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

- Continue to update the members of ADAC and public attendees at ADAC quarterly meetings.
- Disseminate findings through available networks (e.g., DCCI task forces, DOEA website, Memory Disorder Clinics, and the Aging Outlook publication, as appropriate).
- Scale Brain State into the university classroom setting to train the next round of physicians.
- Build into medical school training the use of focused ultrasound for Alzheimer's treatment and research.
- Establish protocol to share clinical trial options with FACE and MDCs for patient.

Recommendation 8 Facilitate improved dissemination of research findings.

BACKGROUND With new research findings about ADRD making headlines on a more regular basis, it is critical to develop a means of distributing these updates and ensuring that Florida lawmakers, residents, and the business sector can access information and understand the impact of data or new therapies and treatment.

ADAC recommends the following:

- Implement FACE as a research "base" to house updates, distribute information, and centralize information related to Florida clinical trials.
- Use the DCCI task force network to share updates with community partners.
 - » Encourage public awareness campaigns to highlight the Florida research network. Examples can include a specialty license plate for public awareness, and a communication pipeline for sharing academic findings.

Pillar 3: ADRD Clinical Care

INTRODUCTION 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:

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

Recommendation 9 Continue and increase professional outreach and education efforts on the use of CPT code 99483 and best practice guidelines.



BACKGROUND INFORMATION The READY Act 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 settings¹⁰. The ADAC supports these efforts.

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.
- » Encourage the use of culturally and linguistically appropriate screening tools to improve the effectiveness of assessments performed during annual wellness visits.

Recommendation 10 Assess special populations and direct resources to areas of need.

AD has a disproportionate impact on African American and Hispanic populations. African Americans are twice as likely to develop AD, and Hispanics are 1.5 times as likely as their white counterparts to develop AD. Both groups are also less likely to obtain a diagnosis that could aid in their care.

ADAC recommends:

- Engage with pharmaceutical companies to direct available resources to areas of need.
- Include county health agencies in promoting and assisting caregivers with resource information. Support local dementia coordinators where available.
- Increase access to care for the indigent so they can have quality wellness checks and preventative screening. Consider use of telehealth visits with partnering companies to make this goal attainable.

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

¹⁰ floridahealth.gov/provider-and-partner-resources/research/HealthyBrainInitiative1/index.html

to refer to a place of residence that provides nursing-supervised assistance with activities of daily living, health care (such as wound dressing 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

Recommendation 11 Encourage increased education and training throughout institutional care settings.

BACKGROUND Direct care workers are the single most important determinant of quality dementia care. In accordance with the Healthy Brain Initiative and House Bill 299, institutional care in Florida should provide enhanced training for direct-care workers, thereby addressing the nearly 60 percent of institutional care residents living with ADRD.

ADAC recommends:

- Members of ADAC emphasize free training and resources to the communities they represent.
- Create opportunities for case managers to better understand how to access resources such as housing and ADRD education.
- Support implementation of the Alzheimer's Training Bill (HB 299).
 - » ADAC members may serve as a board of advisors when developing the materials for implementation.
 - » Develop tools to measure implementation and impact of HB 299.
 - » Increase accountability for training requirements.

- Centralize case management and case management training under FACE.

As worker shortages are noted across all areas of the geriatric workforce, from direct care workers to geriatricians, ADAC recommends highlighting this challenge as a singular recommendation.

Recommendation 12 Support geriatric workforce development initiatives.

ADAC recommends:

- Analyze the economics of worker shortage.
- Support best practice efforts in direct-care-worker settings to encourage interest in joining the senior care industry.

Recommendation 13 Collaborate with "young-senior" communities to promote early detection/early diagnosis and lifestyle intervention.

BACKGROUND The "young-senior" communities across Florida, such as independent living facilities and age 55 and older deed-restricted and HOA communities, represent a significant network of Florida residents who can mitigate the impact of ADRD through lifestyle intervention and brain health education.

ADAC recommends engagements with these communities by:

- Partnering with independent living facilities to promote early detection and early diagnosis to at-risk individuals.
- Distributing information through all community-serving networks (e.g., DCCI task forces, community health workers, etc.).

Pillar 5: Home and Community-Based Services

INTRODUCTION Home and community-based services 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
- Financial and legal services

Recommendation 14 Support use of new technologies that aid in home health delivery.

BACKGROUND ADAC heard from industry innovators about the impact of home health delivery technologies and their positive impact to caregivers and reduced burden to traditional health systems. ADAC recognizes that these technologies will play a critical role in bridging the gap of worker shortage and reducing cost burden for crisis-driven health care consumption.

ADAC recommends:

- Provide outreach to home health agencies and similar providers about best practice models and new innovations (e.g., personal health monitoring, Vayyar home imaging, etc.).
- Develop a technology caregiver toolkit.
- Develop a repository and centralized effort to identify and provide a list of technologies on the market and companies with technologies that are up and coming through FACE.

Recommendation 15 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 The 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 (details included in Section 2).

ADAC recommends the following action:

- Increase funding to Home and Community-Based Services and ADI programs.
- Increase access to caregiver programs to empower families to care for the loved one at home.
- Increase the number of case managers and social workers throughout the state so we can screen more people more quickly and direct families to the resources they need.

Recommendation 16 Support efforts to improve access to senior housing resources.

BACKGROUND The Department of Elder Affairs observed the Department's 30th anniversary in 2022 by touring the state's 11 PSAs and hearing from local providers about challenges faced in each community. Affordable housing was a concern raised within each PSA. As AD represents an overwhelming cost to family caregivers, these two challenges faced simultaneously can be insurmountable.

ADAC recommends:

- FACE to work with county and municipality housing to make timely recommendations to caregivers about housing options in each area.
- DOEA join other public and private task forces to increase access to housing.



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