



# Alzheimer's Disease State Plan 2020

## INTRODUCTION

The Florida Department of Elder Affairs (DOEA/the Department), AARP, the Alzheimer’s Association, the Alzheimer’s Disease Advisory Committee (ADAC), and other partners, envision Florida as a national model providing person-centered, evidence-based, principled, and high-quality care. This is achieved through a continuum of care for Alzheimer’s disease and related dementias through an organized system geared towards meeting the needs and desires of those living with dementia, their families, friends, and caregivers. The guiding principles emphasized throughout Florida’s Alzheimer’s Disease State Plan stress the urgent and ongoing need to:

- Promote person-centered care specifically designed to individual needs
- Address the broad cultural, ethnic, racial, socio-economic, and demographic diversity in Florida
- Address the social determinants of health and incorporate medical needs of the aging population living with Alzheimer’s disease and related dementias
- Support the most direct path to prevention, treatment, and ultimately a cure through a commitment to research

This updated Florida Alzheimer’s Disease State Plan, (“the Plan”) beginning in 2020, and every third year after, on or before November 1, is a result of the facilitated coordination to improve the lives of Floridians. The last Alzheimer’s Disease State Plan, effective 2013, created by the Purple Ribbon Task Force (PRTF) included 37 recommendations comprised of legislative goals, state and federal goals, other agency goals, and national funding goals.

This Plan promotes synergy through newly formed state goals that still consider the original 2013 Plan, ADAC’s recommendations, the Healthy Brain Initiative Road Map effective 2018-2023, the State Health Improvement Plan Priority Area 9 (PA9) ADRD goals, Chapter Law 2020-45, and Livable Florida. The Department will internally evaluate this three-year strategic Plan annually, allowing the flexibility to adapt to any widespread changes within the state. The goals were chosen after considering all recommendations, ultimately focusing on the newly edited, comprehensive, strategically driven goals, strategies, and objectives being recommended to the Steering Committee for PA9 2021. The CDC’s Healthy Brain Initiative Roadmap, Livable Florida, ADAC’s eight recommendations and original SHIP PA9 goals all played a critical role in formulating the final four. The four goals are identified below:

- Increase concern and awareness of ADRD in Florida by promoting early detection/early diagnosis, brain health and ADRD support services in Florida
- Assure a competent ADRD workforce in Florida through education and training
- Develop policies and mobilize partnerships in Florida that support ADRD
- Monitor and evaluate outcomes



I have recently been told that I am one of the millions of Americans who will be afflicted with Alzheimer's Disease.... I now begin the journey that will lead me into the sunset of my life. I know that for America there will always be a bright dawn ahead.

— *Ronald Reagan* —

AZ QUOTES



You learn something out of everything, and you come to realize more than ever that we're all here for a certain space of time, and, and then it's going to be over, and you better make this count.

— *Nancy Reagan* —

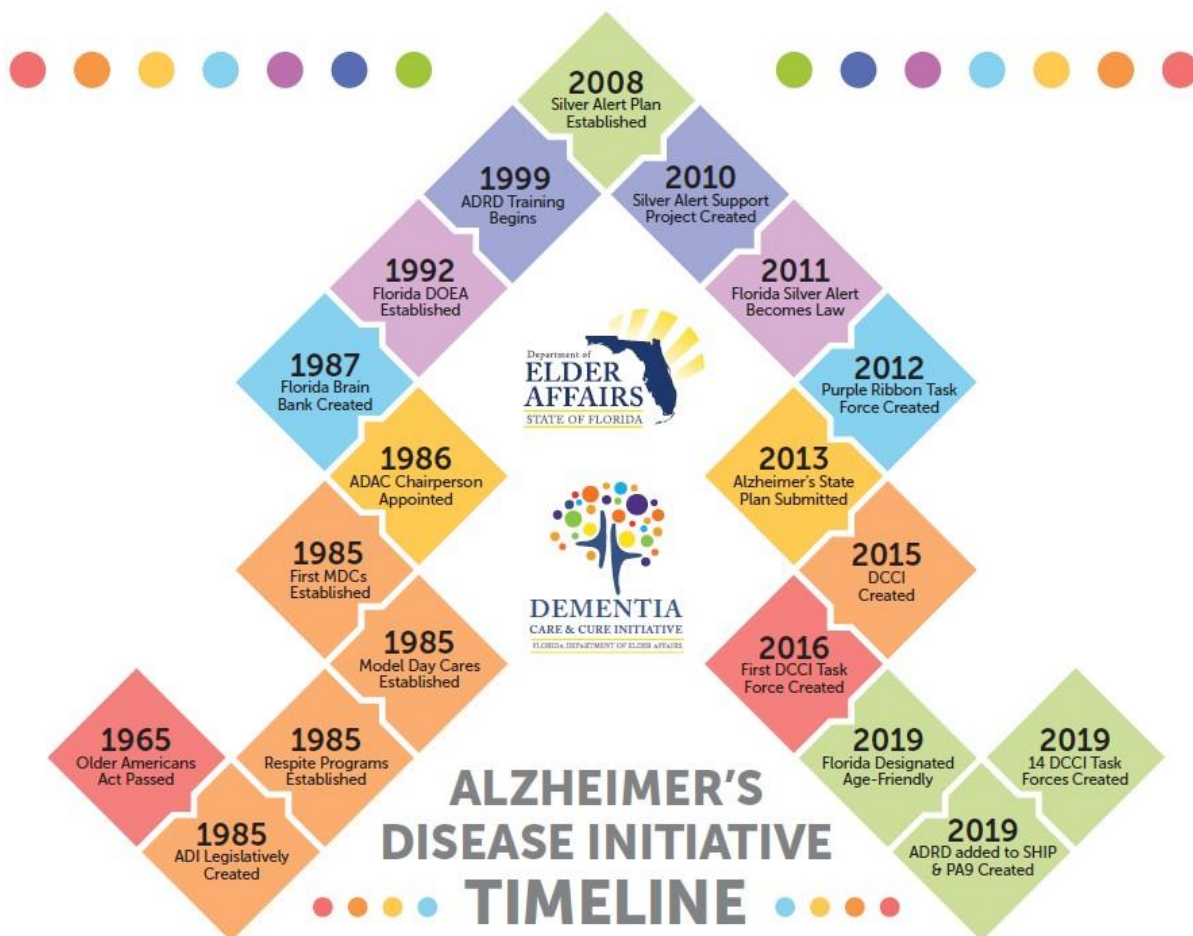
AZ QUOTES

## 1985 - CREATION OF ALZHEIMER'S DISEASE INITIATIVE AND ALZHEIMER'S DISEASE ADVISORY COMMITTEE - THE BEGINNING

The 1985 Florida Legislature realized the continued growth of our state's older population and their increasing rates of Alzheimer's disease and related dementias (ADRD). They created the Alzheimer's Disease Initiative (ADI) and the Alzheimer's Disease Advisory Committee (ADAC), both housed administratively in the Department of Elder Affairs. ADI was developed to meet the needs of individuals and Florida families living with ADRD. The 10-member ADAC was created to advise DOEA on matters relating to individuals, families, and caregivers impacted by ADRD.

## 2013 - THE PURPLE RIBBON TASK FORCE

In 2013, The Florida State Plan for Alzheimer's Disease was created by the Purple Ribbon Task Force (PRTF) formed by the Florida Legislature, and housed within DOEA. The PRTF was charged with devising a comprehensive state plan to address the growing public health impact of ADRD in Florida. The plan was created specifically to address persons living with the disease and their caregivers. Through this plan, 37 recommendations were provided addressing a variety of areas ranging from research to caregiver support, from strengthening of infrastructure, to training and beyond.



## Recommendations from 2013 Final Report - Purple Ribbon Task Force

Revise Waitlist Screening Tool to include ADRD	Oversee guardianship procedures
Conduct a Survey of ADRD Caregivers	Create system of acute crisis care for individuals with ADRD (alternative to Baker or Marchman Act)
Create a Statewide Buying Cooperative	Develop an Alzheimer's Disease Initiative (ADI)
Establish a tax credit to businesses who support families with ADRD	Create regulations for ADRD respite program
Ensure access to services for minorities and those disproportionately affected by ADRD	Increase ADI funding for respite
Ensure families have better access to ADRD memory screening and support	Replace model day care with ADRD specialized adult day care
Assess current and future impact of ADRD	Amend statute relating to Adult Day Care for assisted living facilities, hospices, and nursing homes
Create ADRD Family Caregiver Week	Update dementia training requirements for employees in care settings
Support research to compete for national ADRD funding	Develop a dementia capable emergency management system
Provide state funding for ADRD research	Establish a state-wide system for prevention and recovery of ADRD persons who are "lost on foot".
Support ADRD conferences in Florida	Raise the standard of care for long-term care facilities who provide services for persons with ADRD.
Create a dementia director position at the Department of Elder Affairs	Create an Alzheimer's Care designation on the ALF License
Assess existing services and resources for ADRD	Develop a protocol for ADRD residents to remain in ALFs despite a change in their condition
Ensure all families have access to respite services	Facilitate ADRD training for State/ local government staff with frequent interaction ADRD individuals.
Provide respite care vouchers for families living with ADRD.	Seek ways to keep residential costs affordable for those living with ADRD in long-term care facilities.
Provide a community-based emergency crisis intervention program	Fund the Memory Disorder Clinics
Implement additional emergency intervention in care facilities in specific situations.	Provide funding for the Florida Brain Bank
Standardize ADRD training for law enforcement.	Design a domestic violence shelter for those living with ADRD
Increase funding for senior service type law enforcement unit	

[Source: 2013 Purple Ribbon Task Force Final Report and Recommendations](#)

## 2019 – HOUSE BILL 449

The 2019 Florida Legislature passed House Bill 449 (Chapter Law 2019-147), Section 430.501 F.S., which increased the membership of ADAC to 15 members with the addition of a first responder and appointees from the Governor, President of the Senate, and Speaker of the House of Representatives. This directed state agencies to assist ADAC, required ADAC to submit an annual report including recommendations on Alzheimer's disease policy, all state-funded Alzheimer's disease efforts, and proposed updates to the Alzheimer's Disease State Plan.

The 2019 bill required DOEA to utilize the ADAC Report and collaborate with other Alzheimer's disease organizations to review the Alzheimer's Disease State Plan and to submit an updated Alzheimer's Disease State Plan to the Governor, the President of the Senate, and the Speaker of the House of Representatives every three years, beginning November 1, 2020.

This three-year plan represents a collaborative effort to bring together state agencies, private and non-profit organizations, caregivers, advocates, healthcare professionals, and universities to work together to improve the quality of care for people living with ADRD and their families.

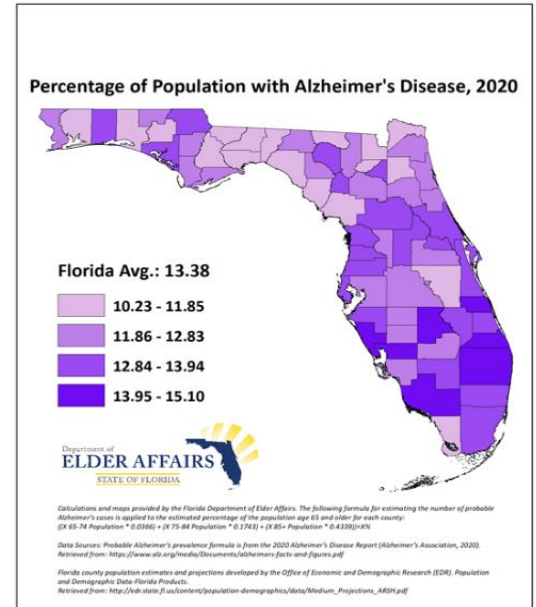
## 2020 - ADRD: WHERE WE ARE TODAY IN FLORIDA

The [2020 Alzheimer's Disease Facts and Figures](#) Report provides an overview of the latest national statistics and information on Alzheimer's prevalence, incidence, mortality and morbidity, costs of care, and caregiving.

# ASSESSING THE CURRENT AND FUTURE IMPACT OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN FLORIDA

## Prevalence, Incidence, and Mortality:

- Approximately 5.8 million Americans age 65 and older are living with Alzheimer's disease in 2020.
  - 80% are age 75 or older
- Two-thirds of Americans over age 65 with Alzheimer's disease (3.6 million) are women
- Alzheimer's disease is the sixth-leading cause of death in the U.S., and the fifth-leading cause of death for those ages 65 and older
- Approximately 580,000 Floridians currently living with Alzheimer's disease
- Florida has the 2nd highest prevalence for Alzheimer's disease in the nation
- Alzheimer's disease is the 6th leading cause of death in Florida
- African Americans are two times more likely to get Alzheimer's disease
- Hispanic Americans are 1.5 times more likely to get Alzheimer's disease
- There is less access to diagnosis and support services for culturally diverse communities, who are disproportionately affected by ADRD
- By 2025, it is projected that there will be over 720,000 Floridians living with Alzheimer's disease
  - An increase of 24% from current statistics



## Caregiving:

- Nearly half of all caregivers (48%) who provide help to older adults do so for someone with ADRD
- There are over 1.2 million Floridians providing loved ones with unpaid care
- Approximately two-thirds of caregivers are women, more specifically, one-third of dementia caregivers are daughters

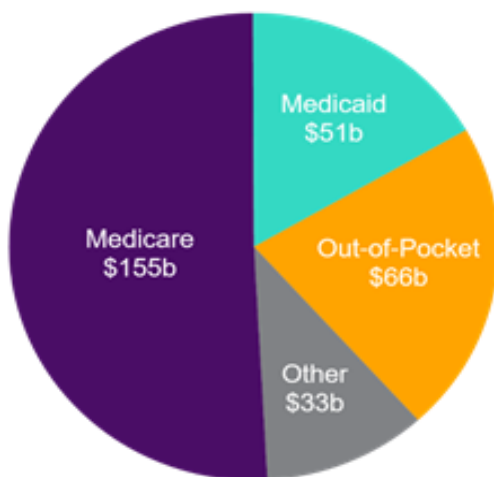
## COSTS OF CARE FOR ADRD IN FLORIDA

- In 2019, caregivers of people with ADRD provided an estimated 18.6 billion hours of unpaid care, a contribution to the nation valued at \$244 billion
- Total payments in 2020 for all individuals with ADRD are estimated at \$305 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$206 billion or 67% of the total health care and long-term care payments for people with ADRD. Out-of-pocket spending is expected to be \$66 billion.

- Total payments for health care, long-term care, and hospice care for people with ADRD are projected to increase to more than \$1.1 trillion in 2050 (Not adjusted for inflation)
- In 2019, the total lifetime cost of care for someone living with dementia was estimated at \$357,297
- Medicaid costs for people living with Alzheimer’s disease in Florida is over \$2.6 billion
- Caregivers in Florida provide over 1.3 billion hours in unpaid care

Alzheimer’s disease is currently the most expensive disease in America, more than cancer and heart disease. According to Genworth’s Cost of Care Study, the median cost of care in Florida versus national is:

2019 Average Monthly Cost of Care		National	Florida
Nursing Home	Private Room	\$8,517	\$9,384
	Semi-Private Room	\$7,513	\$8,547
Assisted Living (ALF)	Private, One bedroom	\$4,051	\$3,500
Adult Day Care Centers (ADCC)		\$1,625	\$1,473
Home Health Care	Homemaker Services	\$4,290	\$4,004
	Homemaker Health Aide	\$4,385	\$4,195



In 2020, the costs of caring for seniors with ADRD will total an estimated \$305 billion. Two-thirds of the \$305 billion will be spent by Medicare and Medicaid.

Source: Alzheimer’s Disease 2020 Facts and Figures

## EXISTING INDUSTRIES, SERVICES, AND RESOURCES ADDRESSING THE NEEDS OF PERSONS HAVING ADRD AND THEIR FAMILY CAREGIVERS IN FLORIDA

### Type, Cost, and Availability of Dementia-Specific Services

The most recent Alzheimer's Disease Advisory Committee Annual Report provided an inventory of existing services, resources, and capacity for people living with Alzheimer's disease and related dementias and their caregivers across the state. ADAC also completed a needs assessment across the state through surveys and community listening sessions with a goal of getting feedback.

Additionally, other tools are available through the Agency for Health Care Administration (AHCA), such as [FloridaHealthFinder.gov](https://www.floridahealthfinder.gov) and [Florida Health Price Finder](https://www.floridahealthpricefinder.com). Florida Health Finder was established to provide Floridians with available healthcare performance, quality data, resources, and valuable tools. The tools are available in an easy-to-use format. The Facility Locator offers basic and advanced search options allowing users to search more than 48,000 licensed providers. The provider information is updated from AHCA's electronic licensure databases. Individual provider profile pages offer direct access to important licensure, certification, and owner information along with direct linkage to relevant regulatory compliance documentation such as inspection reports and legal orders. This website also features specialized tools for users to compare quality measures and performance among hospitals, ambulatory surgery centers, emergency departments, nursing homes, assisted living facilities, home health agencies, and health insurance plans.

The companion Florida Health Price Finder was launched with multiple integration points to be used in combination with the Florida Health Finder. The website displays estimated costs for consumers at the national, state, and county level – with facility level price estimates. The published prices are calculated based on data collected from hundreds of thousands of paid health care claims in Florida. Care bundles represent the typical set of services a patient may receive for a condition.

The Department works to improve the well-being of Florida's older adults through a provision of appropriate and cost-effective home and community-based services. Additionally, programs that may not be dementia specific, work as a suite of case management services to assist caregivers, their families, and people living with ADRD. These services include:

#### 1. The Alzheimer's Disease Initiative (ADI)

ADI provides specialized services to meet the needs of caregivers and individuals with ADRD. Supporting caregivers is an essential part of Alzheimer's disease and related dementias. In Florida, there are approximately 1.2 million caregivers with over 1.3 billion hours of unpaid care to loved ones valued at \$17.2 billion.

To be eligible to receive services funded under ADI, an individual must be 18 years of age or older and have a diagnosis of ADRD, or they must be suspected of having ADRD. The caregivers of individuals receiving services under the ADI are eligible to receive training and



related support services to assist them in caring for the person with ADRD. DOEA completed an ADI evaluation report in 2018, which provides an overview of ADI services, costs, quality assurance, and client and caregiver outcomes. The current total 2020-2021 SFY State General Revenue Budget for ADI is \$32,381,826 in accordance with Section 430.501 – 503 F.S.

Provider agencies are responsible for the collection of fees for services in accordance with Section 430.503, F.S. and DOEA policies. To help pay for services received through the ADI, functionally impaired elderly persons are charged fees based on their overall ability to pay. Funds collected are used at the provider level to expand services and serve additional clients. The total statewide co-pay collected during 2019-2020 SFY State Fiscal Year was \$622,164.

ADI consists of the following components:

- Caregiver training and support
- Case management
- Counseling (gerontological)
- Counseling (mental health/screening)
- Education and training
- Specialized adult day care programs
- Respite: in-facility specialized Alzheimer’s services, specialized medical equipment and supplies, facility-based respite, and home-based respite
- Transportation
- Shopping assistance – COVID-19
- Telephone reassurance – COVID-19

State Fiscal Year	State Funding	Clients Served
2010-2011	\$8,362,200	2,300
2011-2012	\$9,404,262	3,348
2012-2013	\$9,554,262	**1,808
2013-2014	\$10,412,201	1,832
2014-2015	\$16,093,452	2,657
2015-2016	\$16,471,449	2,673
2016-2017	\$18,031,499	3,567
2017-2018	\$21,309,195	5,228
2018-2019	\$22,976,477	8,480
2019-2020	\$22,976,477	#9,143

*\*In previous years, this table was titled Respite/Special Projects Appropriation History and Numbers Served, though this did not represent all of the data presented. The previous title was derived from the funding streams as they are listed in the program contracts, though this funding can be used to provide all services offered through the ADI program, not only respite and expenditures funded through special projects.*

*\*\*Beginning 2012-2013, clients served is an unduplicated number.*

*#Projection*

*Source for clients served: CIRTS*

## **2. Respite Care and Support Services in Florida**

Respite care and supportive services are provided through direct contracts with the AAAs. Funds are contracted according to an allocation formula, which includes the number and proportion of the county population of individuals who are 70 years of age and older. The AAAs contract with more than 60 providers for the provision of respite care, caregiver training and support, education, counseling, specialized medical equipment, services and supplies, and case management. Services provided under these contracts benefit persons with ADRD and caregivers. The [ADAC Report](#) provided a statewide breakdown by Planning and Service Area (PSA) of current services, total number of clients being served, clients on the waiting list, and ADI allocation for 2019.

## **3. Respite for Elders Living in Everyday Families (RELIEF)**

The RELIEF Program offers family caregivers providing constant care for a frail elder and those living with ADRD a needed break. In-home respite care can increase a caregiver's ability to attend to a homebound elder without becoming ill themselves. Volunteers are carefully screened, trained, and individually matched with clients to ensure personalities, skills, interests, and abilities are a good fit with the elder and caregivers. Caregivers are eligible for up to four hours of respite services per day with an emphasis on evening and weekend hours are available.

## **4. Senior Companion Program (SCP)**

The Senior Companion Program provides socialization and assistance to elders age 60 and older at risk of institutionalization due to chronic illnesses, disabilities, or social isolation. Some of these activities include assisting with physician visits, obtaining groceries, visits to parks, and home activities such as board games and puzzles. As a direct result of program services, clients continue to live independently and avoid or delay formal care settings such as adult day care, assisted living facilities, or nursing homes. Respite services are also available to assist the caregiver of frail elders.

## **5. AmeriCorps (Legacy Corps for Veterans & Military Families)**

The Legacy Corps for Veterans & Military Families Program is a nationwide community-based caregiver support program for veteran and military families. AmeriCorps members provide in-home respite to a veteran or military family caregiver. Legacy Corps uses a highly trained volunteer member to provide a range of caregiver support services including in-home respite care, access to information, and links to other community support systems, hospital-to-home transition services, and other related services. DOEA partners with Easter Seals South Florida as the provider of services.

## **6. Area Agencies on Aging (AAAs)**

DOEA provides most of its services to Florida seniors through contracts with the state's 11 Area Agencies on Aging. These nonprofit entities advocate, plan, coordinate, and fund a system of elder support services in their perspective Planning and Service Areas (PSAs). Each AAA

contracts with one or more Community Care for the Elderly (CCE) Lead Agencies. There are currently more than 50 CCEs in Florida. Florida's toll-free Elder Helpline is also operated through the AAAs.

### **7. Memory Disorder Clinics (MDCs)**

There are 17 state-funded Memory Disorder Clinics in Florida. All 17 MDCs participate in funded research projects. Florida's MDCs are required to provide comprehensive assessments, diagnostic services, and treatment to individuals who exhibit symptoms of ADRD. MDCs are also tasked with developing training programs and materials, and conduct training for caregivers, respite service providers, and health care professionals in the care of persons with ADRD. In consultation with the memory disorder clinics, DOEA shall specify the information to be provided by the respite care programs for research purposes. The ADAC Report includes the MDC year-end data.

### **8. Dementia Care and Cure Initiative (DCCI)**

DCCI implements a statewide effort to become more dementia-caring – acting to support those living with dementia, their families, and their caregivers. In partnership with the AAAs and MDCs, participating communities organize task forces to include professionals, advocates, and community members to bring education on, awareness of, and sensitivity regarding the needs of those affected by dementia throughout their community. Participating areas work to build inclusive, respectful, and aware communities.

As of August 2020, there are 14 task forces in dementia-caring communities throughout Florida. While the initiative is a statewide effort, it is a community-driven one, and each community has the autonomy to create an action plan and engage in educational, awareness, and advocacy projects and activities that best meet the unique needs of those living with and affected by dementia in their community.

### **9. The Florida Brain Bank**

The Florida Brain Bank is the entity designated by DOEA to collect postmortem normal brains as a control group and brains of individuals who were clinically diagnosed as having ADRD. The Brain Bank conducts comparative research aimed at learning about, finding a cause, and developing a treatment or cure for the disease. The [ADAC Report](#) includes The Brain Bank year-end data.

### **10. Division of Statewide Community-Based Services (SCBS)**

Responsible for support and oversight of the Comprehensive Assessment and Review for Long-Term Care Services (CARES). Federal law mandates CARES perform an assessment or review of each individual who requests Medicaid reimbursement for nursing facility placement or home and community-based services. CARES staff, which includes registered nurses and assessors, perform the medical needs assessments of individuals. CARES staff identifies clients' long-term care needs, determine the level of care required to meet those needs, and provide information to individuals on available long-term care options. SCBS also provides oversight for the Department's non-Medicaid home and community-based programs and services, including

programs contracted to the Area Agencies on Aging and other entities. These programs are as follows:

- Older Americans Act (OAA)
- Adult Care Food Program (ACFP)
- Community Care for the Elderly (CCE)
- Emergency Home Energy Assistance Program (EHEAP)
- Home Care for the Elderly (HCE)
- Local Services Program (LSP)
- Senior Farmers' Market Nutrition Program (SFMNP)

Additionally, SCBS provides oversight of DOEA's Medicaid Long-Term Care Services for the Program of All-Inclusive Care (PACE) and manages entrance into Statewide Medicaid Managed Long-Term Care (SMMC LTC) Program. The PACE program targets individuals age 55 and older eligible for Medicaid nursing home placement and provides a comprehensive array of home and community-based long-term care services, as well as Medicare (acute care) services.

## **NEEDS OF PERSONS OF ALL CULTURAL BACKGROUNDS HAVING ADRD AND HOW THEIR LIVES ARE AFFECTED BY THE DISEASE THROUGH ALL STAGES**

### **Diverse and Underserved Populations**

The number of Floridians living with ADRD is growing. This includes people of all generations, racial and ethnic groups, educational levels, and socio-economic backgrounds. Promoting a person-centered care approach involves understanding an individual's ethnic and cultural background and learning how ADRD affects people in different ways. Some examples of the prevalence of Alzheimer's disease and related dementias include:

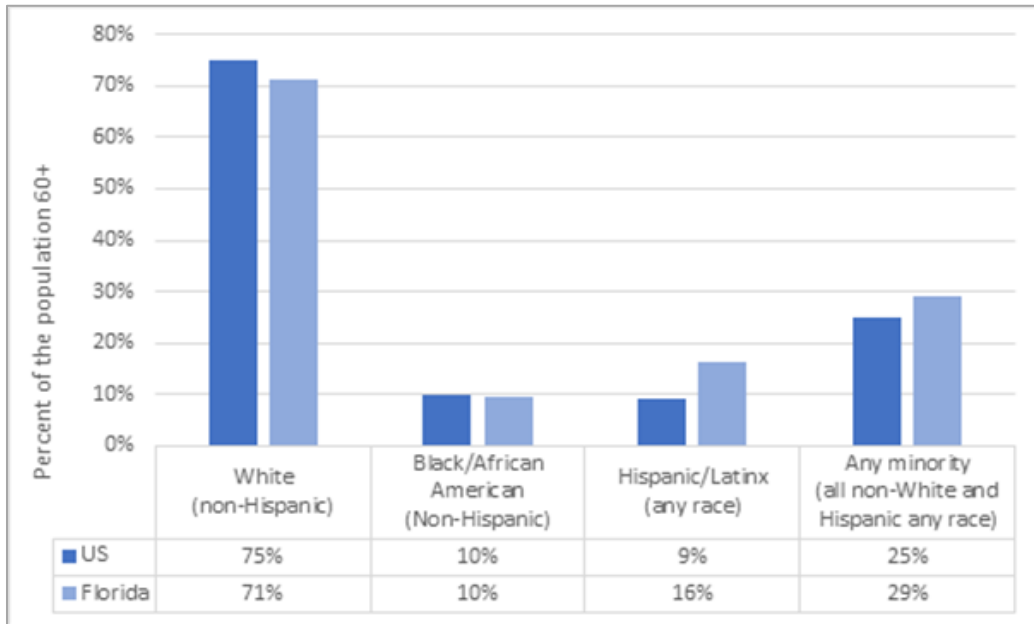
- Approximately 200,000 individuals under age 65 have younger-onset ADRD. These individuals have unique needs such as they may still be working, have young children, or they may be the primary provider for their household.
- Almost two-thirds or 3.6 million Americans with ADRD are women.
- Older African Americans are about twice as likely to have ADRD as older whites.
- Hispanics are about one and one-half times as likely to have ADRD as older whites.

The difference in the prevalence of ADRD among racial and ethnic groups is mostly attributed to health conditions such as high blood pressure or diabetes. Health conditions have more of an effect than genetics for this group. Another factor regarding ADRD among racial and ethnic groups is misdiagnosed and undiagnosed cases are more common among older African Americans and Hispanics than among older whites.

Historically, as the U.S. population aged, the diversity in the racial and ethnic composition decreased. This decrease in diversity with age is observed in Florida and can be attributed to the migration of white retirees into Florida and the disparate life span of racial and ethnic groups within the state. Almost 29% of Floridians age 60 and older identify as a racial or ethnic

minority, but this drops to 22% for those age 85 and older. However, in large part due to the high concentration of Hispanic/Latinx residents, the portion of older adults in Florida in racial or ethnic minority groups currently exceeds that of the nation and is projected to grow.

**Contrasts the Proportions of Race And Ethnicity Of Florida Compared To The United States For Older Adults.**



Source: Annual Estimates of the Resident Population by Sex, Age, Race Alone or in Combination, and Hispanic Origin for the United States and States: April 1, 2010 to July 1, 2018, U.S. Census Bureau, Population Division <https://www.census.gov/data/tables/time-series/demo/popest/2010s-national-detail.ht>

The growing racial and ethnic diversity seen in Florida’s total population will not be notably reflected in the state’s older population for several decades. However, as the share of older minorities increases, there could be a corresponding decline in the economic well-being of these groups if the current health disparities and socioeconomic disadvantages of Hispanic/Latinx and Black/African American subpopulations continue as they age.

**CLOSING THE GAPS FOR DIVERSE AND UNDERSERVED POPULATIONS**

**Florida’s Brain Bus**

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

The Brain Bus prioritizes and targets culturally diverse and underserved, isolated, and rural families dealing with, or at risk for ADRD. The services of the Brain Bus are open to all individuals who need services and are always free of charge. The Brain Bus makes over 300 stops and provides information and services to over 2,000 people each year.



### **The Reducing Racial and Ethnic Health Disparities "Closing the Gap" Grant Program**

The Closing the Gap grant program, Section [381.7356, Florida Statutes](#), was signed into law in 2000. These grants are utilized to stimulate the development of community and neighborhood-based organizations to improve health outcomes of racial and ethnic populations and promote disease prevention activities. Projects funded through the Closing the Gap grant program help stimulate broad-based participation and the support of both public and private entities by:

- Fostering partnerships between local governments, community groups, and private sector health care organizations;
- Helping communities address their most pressing health needs through targeted health screenings, education, and awareness programs; and
- Helping communities better understand the nature of health disparities among ethnic and racial groups.

Primary benefits to the state from the Closing the Gap program include:

- Meaningful improvements in the lives of Floridians who now suffer disproportionately from disease and disability; and
- Development of tools and strategies that will enable Florida to eliminate health disparities.

Priority Areas:

- Alzheimer's disease and related dementias - added in 2019
- Adult and child immunizations
- Cancer
- Cardiovascular disease
- Diabetes
- HIV/AIDS
- Lupus

- Maternal and infant mortality
- Oral healthcare
- Sickle cell disease
- Social determinants of health (SDOH)

## **STATE TRENDS WITH RESPECT TO INDIVIDUALS LIVING WITH ADRD AND THEIR NEEDS**

### **Why Florida Is “Ground Zero” For the Alzheimer’s Public Health Crisis**

Florida is the third-most populous state in the nation with approximately 21 million residents and more than 5.5 million of them are aged 60 and older. To put that into perspective, Florida outnumbers the state senior populations of 20 other states combined. It goes without saying that because of this large proportion of older adults, Florida’s future is linked to their financial security and physical health.

One hundred years ago the average life expectancy in the US was 54; today it is 78.5. We are all living longer because 20th century medicine successfully contained infectious diseases. However, along with this increasing longevity has been a growing prominence of chronic illnesses, such as ADRD, osteoporosis, heart disease and stroke, and their associated disabilities. Age is in fact the primary risk factor for developing memory or cognitive impairment in adulthood. Given the large number of older adults in Florida, it is therefore no surprise that just over 580,000 Floridians are currently living with Alzheimer’s disease alone. (This doesn’t include the tens of thousands more with other forms of dementia like Lewy Body dementia, vascular dementia, Parkinson’s disease). Currently, Florida ranks as the state with the second-highest prevalence for this disease in the nation

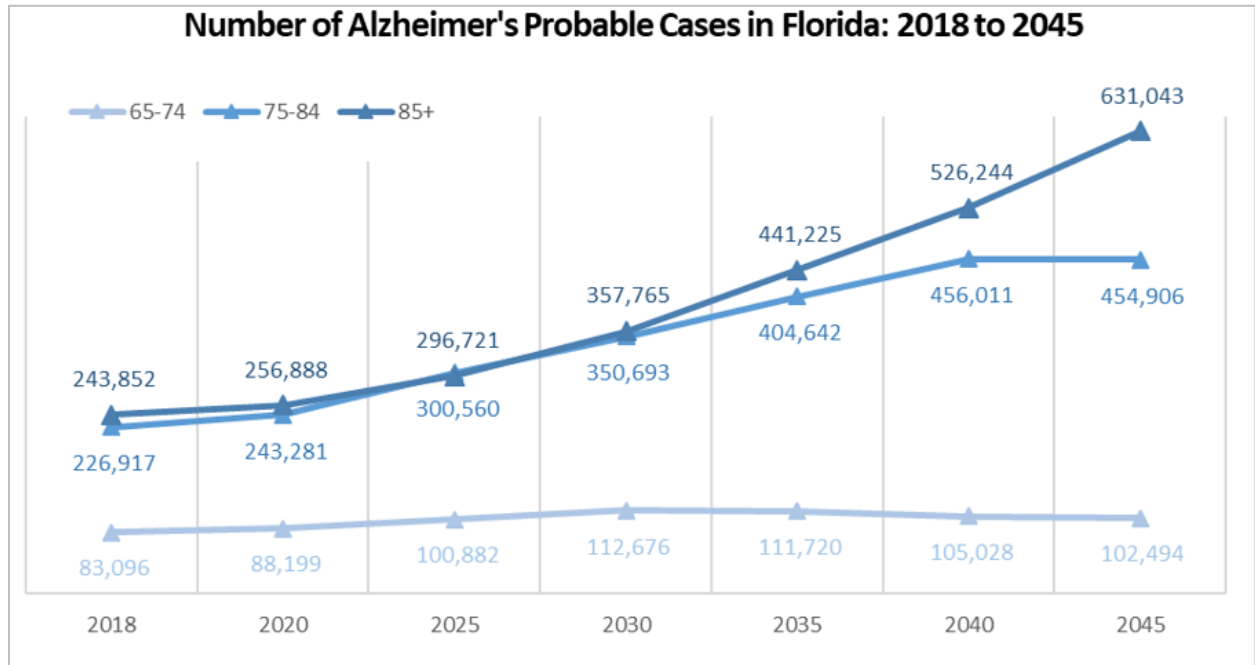
Alzheimer’s disease ranks as the 6th leading cause of death in our country, and in our state and is the only top 10 leading cause of death without any known prevention, treatment, or cure. Accordingly, Governor DeSantis has challenged DOEA and the Aging Network to take bold actions when confronting Alzheimer’s disease and related dementias.

### **Planning for Florida’s Future**

Florida is projected to continue experiencing increases in the number of older residents over the next 15 years because of migration and baby boomers who continue to age into retirement. By 2045, the older adult population is estimated to increase to 8.4 million, or over 30% of the state’s population.

Between 2030 and 2035, the most significant increase in those aged 85 years and older with ADRD is expected to occur, representing a 23% increase, or an additional 83,460 individuals in the state population. The number of older Floridians living with ADRD is projected to increase to 820,000 by 2030, a projected increase of 40% in the next ten years, and 1,190,000 by 2045, a projected increase of more than 54% in twenty-five years.

With the massive growth in the number of Floridians living with ADRD, there will be a significant increase in family caregiving demands – ranging from emotional to physical and financial. The care and support of individuals living with ADRD impacts state and federal government. The cost to Medicare of patients with ADRD is estimated to be three times the cost of enrollees without dementia.



Calculated from: Bureau of Economic and Business Research, 2010 Census Counts, and Projections of Florida Population by County and Age, Race, Sex, and Hispanic Origin, 2020-2045, With 2018 Estimates (Released June 27, 2019). Probable Alzheimer's is calculated using Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer's Disease in the United States (2010-2050) Estimated Using the 2010 Census.

The impact of ADRD is being felt across all sectors of society, but the sheer number of older adults, coupled with the aging baby boomers presents unique challenges and opportunities to address the way Florida's leaders deal with ADRD. For Alzheimer's disease and related dementias, this means addressing challenges not just among older adults, but with the wider population.

### Alzheimer's as a Public Health Priority in Florida

In Florida, addressing the burden of ADRD requires the collective action of the public health system. To provide information about this approach, the Alzheimer's Association and the Centers for Disease Control and Prevention established the Healthy Brain Initiative (HBI), State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map (Road Map). The Road Map offers an all-encompassing description of the public health approach.

Stakeholders will be able to use Florida's Alzheimer's Disease State Plan and the HBI Road Map together to see a comprehensive public health approach to inform activities; determine how to fulfill the priority needs through their organizations and available tools; encourage collaboration and partnership, and provide education.



A community-based public health approach has several intended outcomes:

- Ensure safety and quality of care for family caregivers,
- Expand early detection,
- Improve health outcomes,
- Promote quality care,
- Reduce modifiable risk factors in developing ADRD,
- Reduce stigma; and
- Respond to the needs of diverse populations.

## **STATE ADRD POLICY MEASURES - THE ROLE OF THE STATE**

### **ADRD Leadership in Florida**

Florida has strong leadership with Governor Ron DeSantis, Lieutenant Governor Jeanette Nunez, and the Florida Legislature who recognize the impact of the rising numbers of Floridians living with ADRD and the need to implement bold strategies to find innovative solutions to continue to support those with ADRD and their caregivers

Everything points to the fact that the communities that fare best in the 21st century will be those that both tackle the challenges like ADRD and embrace the positive possibilities that an aging population creates – essentially becoming livable communities. The amenities of a Livable Community help to maximize the independence and quality of life of older adults, while also enhancing the economic, civic, and social vitality of the community. Accordingly, there has been an increased emphasis on making existing systems and structures more “age-friendly”.

In April 2019, Florida became the 4th state in the nation to receive the Age-Friendly state designation from AARP’s Network of Age-Friendly States and Communities. In embracing the Age-Friendly designation last year, Governor DeSantis shared that he envisioned a Florida where older adults, and indeed all Floridians, will thrive in these supportive and engaging communities, where they not only live but live well and age well. We call it “Livable Florida”.

Becoming an Age Friendly or Livable Community essentially addresses the conditions in which people are born, grow, live, work, and age.

They include factors like socioeconomic status; education; appropriate and affordable housing; transportation options; safe streets; safe neighborhoods; protection against natural disasters and protection from abuse, neglect, and exploitation; employment; and social support networks; combatting loneliness, depression as well as access to personalized health care.

Governor DeSantis has taken important steps to ensure Florida assists these individuals in getting the care they deserve and prioritizes the advancement of research needed for this disease. The

DeSantis administration is committed to working diligently to improve the lives of Floridians living with Alzheimer's. Since taking office, Governor Ron DeSantis has:

- Directed the Department of Health to add Alzheimer's and related dementias as an additional priority area (PA) within the State Health Improvement Plan (SHIP), or PA 9. Alzheimer's is the sixth-leading cause of death in Florida, and yet it was not directly addressed by the SHIP.
  - The SHIP is a five-year plan housed in the Florida Department of Health (DOH) that sets priorities and approves goals, strategies, and objectives. Several Priority Area (PA) Workgroups are then formed to achieve the goals. The current DOH SHIP began in 2017 and will end on December 31, 2021. Priority Area 9 (ADRD) was added to this plan in June 2019. PA9 implementation began two and a half years into the plan.
- Directed the Department of Health to apply to be a Center of Excellence pursuant to the Federal Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, in order to position Florida to pursue and receive federal grants for evidence-based approaches for treatment and prevention of Alzheimer's, dementia, and cognitive decline. The Federal BOLD Act, signed in 2018, authorizes \$20 million annually over 5 years (\$100 million total) that would establish Alzheimer's Public Health Centers of Excellence to promote Alzheimer's disease and caregiving interventions and educate the public about the disease.
- Challenged institutions that house Florida Memory Disorder Clinics to provide matching funding for the clinics to allow for an increase in the number of individuals they serve with evaluation and diagnostic testing for dementia.
- Challenged local communities, who have not already done so, to expand the Dementia Care and Cure Initiative in their areas. At the time, all but three Areas Agencies for Aging (AAA) were engaged in the Dementia Care and Cure Initiative (DCCI).
- Increased funding to help those with ADRD. The 2020-21 budget contains more than \$30 million in funding to support the Alzheimer's Disease Initiative.



*DOEA Secretary Richard Prudom and Florida Governor Ron DeSantis*

The Florida Legislature also recognizes the increasing number of Floridians living with ADRD and has taken appropriate action to address the ongoing need to implement strategies that support these individuals and their caregivers.

#### **Recent legislative updates include:**

- 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.

- On June 22, 2020, House Bill 767 was signed into law. This bill amends various statutes related to the regulations of Assisted Living Facilities (ALF). A few that will have impact on those living with ADRD include:
  - Allows the use of certain physical restraints in ALFs, including any device the resident chooses to use and is able to remove or avoid independently.
  - Allows ALFs to admit residents that require 24-hour nursing care, residents that are receiving hospice services, or residents who are bedridden that meet specific criteria.
  - Requires an ALF to notify a resident's representative or designee of the need for health care services and assist in making appointments if an underlying condition of dementia or cognitive impairment is determined to exist.
    - ❖ If the resident does not have a representative or designee or the ALF cannot reach their representative or designee, the ALF must arrange for the necessary care and services to treat the condition with an appropriate health care provider.
- On June 29, 2020, Governor DeSantis approved the state's budget for SFY 2020, that included \$319,000 in funding for the Alzheimer's Association Brain Bus. The Brain Bus provides information on brain health, outreach, education, care planning, caregiver education, and community resource information about Alzheimer's disease and related dementias.

#### **Other Important Legislation Included:**

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

#### **Recent Legislative and Regulatory Updates:**

- The Alzheimer's Association will seek to establish enhanced training requirements in Florida's Long-Term Care communities including Assisted Facilities, Skilled Nursing

Homes, Adult Day Care, Hospice and Home Health Agencies. The legislation will seek to unify Florida statutes for consistent dementia training and continuing education for both direct care and indirect care staff.

- The Alzheimer's Association will seek to establish a multi-agency initiative that will focus on revisiting existing programs, develop new programs to address the workforce needs of geriatric care and professional health care providers and create a pipeline of future workers who provide geriatric care and service. This proposal will create a partnership between state agencies who provide services for older Floridians and stakeholders within the healthcare and geriatric medical care industry, as well as the state's public and private universities, state colleges and other current and potential training providers.
- The Alzheimer's Association will seek to ensure each person licensed under Chapter [458](#) and [464](#), F.S., shall be required to complete a 2-hour continuing education course, approved by the appropriate board, on Alzheimer's disease and related dementias. The course shall consist of education on ADRD, including an overview of dementia, assessment and care planning, communication with persons living with dementia, and how to recognize and be aware of the key warning signs for early stage Alzheimer's disease and related dementias.

### **Appropriations from the Florida Legislature**

During the 2020 Legislative Session, the Florida Legislature allocated \$5,000,000 for research grants sponsored by the Ed and Ethel Moore Alzheimer's Disease Research Program. They also appropriated \$319,000 in funding for the Alzheimer's Association Brain Bus.

The 2020 general revenue budget featured a new appropriation of \$1,500,000 in non-recurring dollars to the University of Florida Health Center for Operations of the Center for Translational Research in Neurodegenerative Disease.

### **Ed and Ethel Moore Grant Program**

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

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

### **Alzheimer's Disease Research Grant Advisory Board**

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

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

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

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

## **COGNITIVE AND CAREGIVER MODULES**

### **Behavioral Risk Factor Surveillance System (BRFSS)**

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Administered through the Centers for Disease Control and Prevention, BRFSS was established in 1984 with 15 states participating; BRFSS now collects data in all 50 states as well as the District of Columbia and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.

Population-based data is needed to shape programs and related policies that promote cognitive health and address cognitive decline. The number of people living with Alzheimer's disease is set to skyrocket, with over 720,000 individuals in Florida by 2025 — which is over a 24% increase. By collecting behavioral health risk data at the state and local level, BRFSS has become a powerful tool for targeting and building health promotion activities.

In addition to the core data collected through BRFSS, the CDC makes available additional modules of questions which states can add on at an additional cost. The Caregiver module is one such an add-on, which measures the extent, prevalence, and burden on caregivers — those who provide unpaid care or assistance to another person due to a health condition or disability.

Dementia caregivers, on average, face an even steeper burden. Understanding who dementia caregivers are and where they live in Florida will help state leaders design programs and policies that address caregivers' needs and health as the population continues to age.

### **State of Florida Brain Bank**

The Florida Brain Bank was created and funded by the Florida Legislature in 1986. The Brain Bank is to study the brains of individuals with progressive dementia by collecting and studying the brains of deceased individuals who were clinically diagnosed with ADRD, provide families with a definitive diagnosis, and to acquire brain tissue for research. The goals of the Florida Brain Bank are to:

- Provide a final pathological diagnosis of the cause of dementia to families and the patients' physicians,
- Provide education and feedback to health care professionals and the public about the relationship between the clinical diagnosis during life and the final pathological diagnosis,
- Provide opportunities for clinical researchers to study the frequencies of various dementias in Florida—the accuracy of clinical diagnoses and the associations between risk factors for dementia, such as a family history of dementia, medical conditions (e.g., head injury, diabetes, and hypertension) and the presence and severity of various forms of dementia.
- Conduct basic research on the biology, pathology, and genetics of ADRD. Over the last 30 years, over 3,000 brains have been studied by the Florida brain bank.

This increase in collaboration has resulted in several important discoveries about the pathology of ADRD and how it relates to the clinical presentation of the disease and the treatment of the condition. The Brain Bank year-end report is also located in the [ADAC Report](#).

### **State-Funded Memory Disorder Clinics: Research Activities**

Currently, all 17 state-funded Memory Disorder Clinics (MDC) participate in funded research projects. MDCs are established at medical schools, teaching hospitals, and public and private not-for-profit hospitals throughout the state in accordance with Section s. 430.502, F.S. MDCs served 13,105 clients in 2018-2019. MDCs receive funding based on performance measures as directed by DOEA. As part of their contractual agreement, they are required to partner with research programs focusing on dementia and dementia care. However, the scope and intensity of research activities varies considerably across 17 sites. MDCs with strong ties to academic health centers are likely to have a broader research portfolio than those who do not have such affiliations.

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

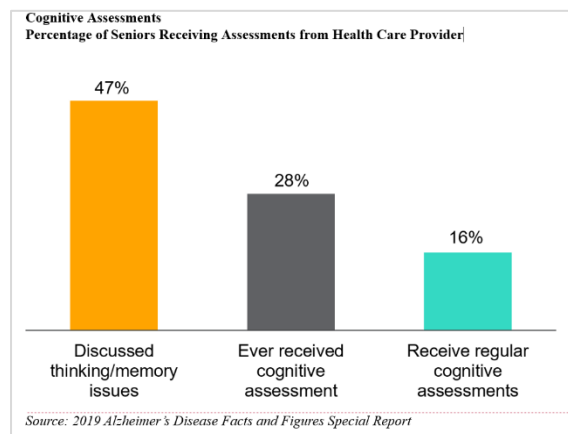
During the 2018-2019 fiscal year, MDCs referred patients living with dementia and their caregivers to 4,480 different research opportunities. Examples of types of research studies in which MDC clients participated during fiscal year 2018-2019 include:

- Pharmaceutical clinical trials to prevent onset of dementia in persons with mild cognitive impairment
- Behavioral and neuropsychological interventions to prevent or attenuate cognitive decline in adults with mild cognitive impairment
- Culturally tailored behavioral interventions to enhance caregiving skills and self-care in minority caregivers
- Treatments of psychosis and agitation in persons with Alzheimer’s disease and related dementias
- Assessing predictive power of MRI, Amyloid PET, spinal fluid, blood proteins, neurocognitive and daily functioning in the identification of Alzheimer’s disease and related dementias
- Effects of traumatic brain injury and post-traumatic stress disorder on Alzheimer’s disease and related dementias
- Longitudinal evaluation of amyloid risk and neurodegeneration
- Role of type 2 diabetes and metformin use in cognitive decline
- Delirium prevention intervention for community-dwelling older adults living with dementia

Many of those living with Alzheimer’s disease and related dementias go undiagnosed and most seniors are not even being assessed for potential memory issues at wellness checkups.

- Fewer than half of seniors have ever discussed their thinking or memory abilities with a health care provider
- Less than a third have ever been assessed for cognitive problems
- 1 in 7 seniors receives regular cognitive assessments for problems with memory or thinking during routine health checkups

Sometimes dementia-like symptoms can be caused by other conditions – mental health concerns such as depression and anxiety, vitamin deficiencies, thyroid problems, and some infections, that when treated will result in improvement of dementia-like symptoms. A key difference between these conditions and dementia is the symptoms usually appear suddenly, whereas dementia develops slowly over time. This is one reason why it is important for someone with memory changes to be seen by a health professional for a full assessment to determine a possible cause of confusion or memory loss.

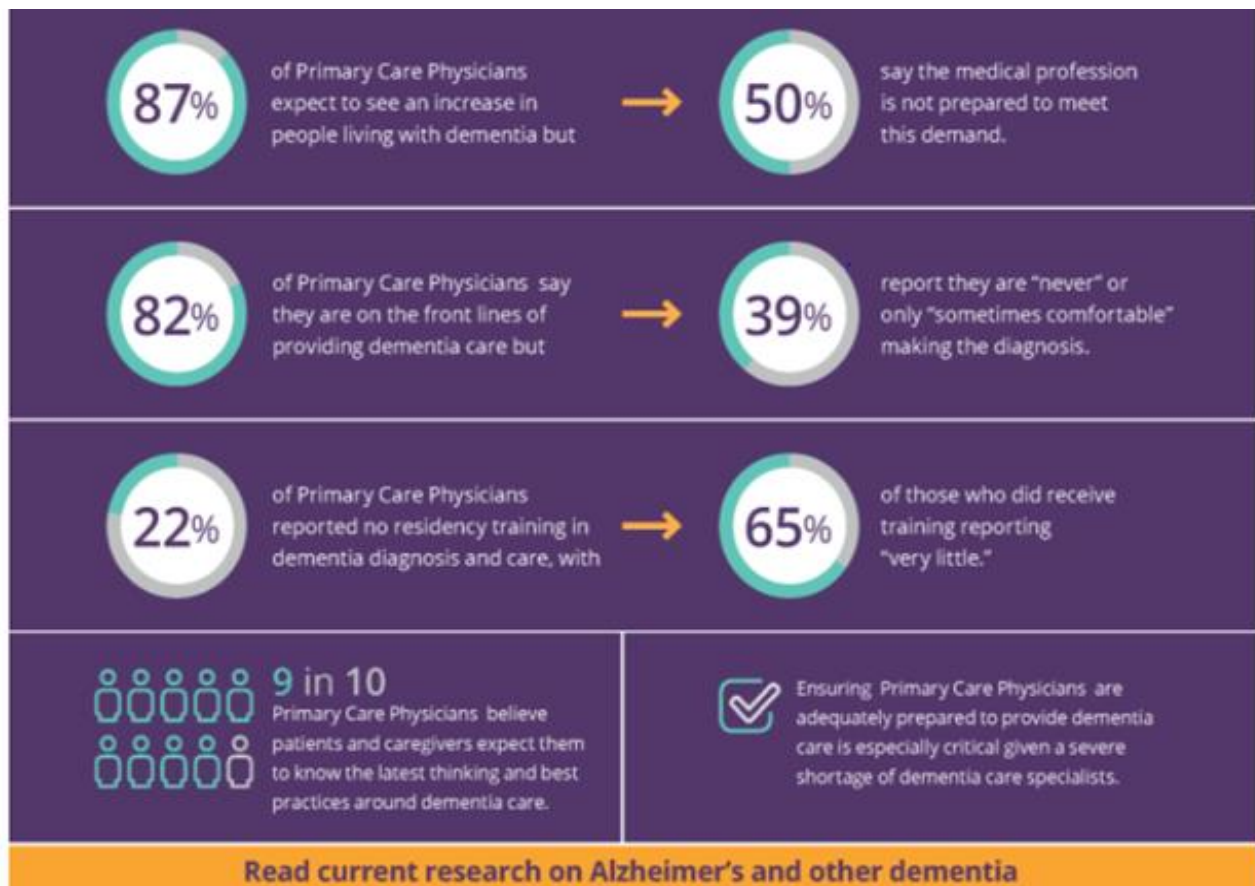


## Primary Care Physicians

The Alzheimer's Association 2020 Facts and Figures report revealed the results of a Physicians' survey which found that 82% of Primary Care Physicians (PCP) say they are on the front lines of providing dementia care, but not all are confident in their care for patients with ADRD.

- 39% report they are “never” or only “sometimes comfortable” making a diagnosis of ADRD
- 27% report they are “never” or only “sometimes comfortable” answering patient questions about ADRD
- 22% of all PCPs had no residency training in dementia diagnosis and care. Of the 78% who did undergo training, 65% reported that the amount was “very little.”

Ensuring PCPs are adequately prepared to deliver dementia care is critically important, given a shortage of dementia care specialists.





## Alzheimer's Disease Research Centers

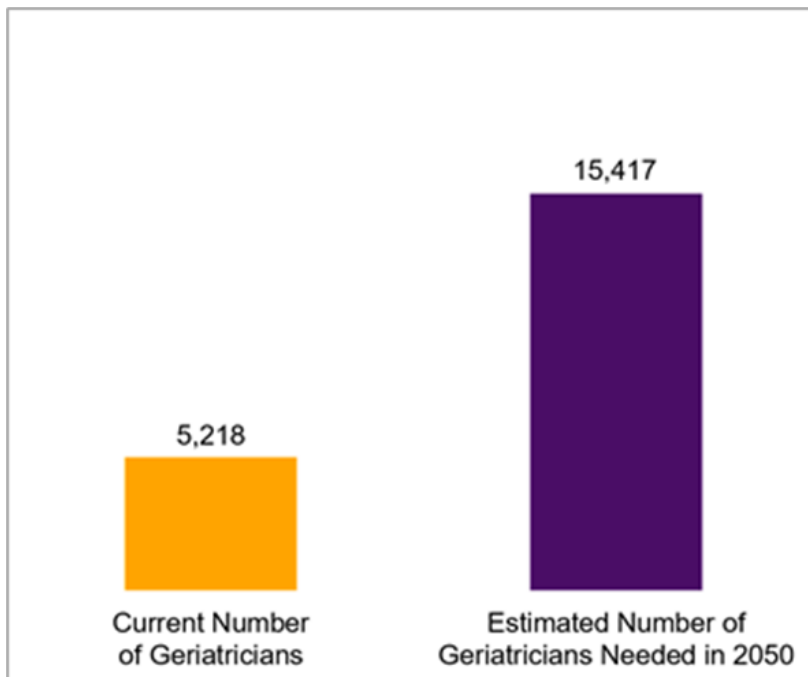
The National Institute on Aging (NIA) funds 32 Alzheimer's Disease Research Centers (ADRCs) located at medical institutions across the U.S. Two centers are sponsored by the Florida Legislature and NIA which governs through the National Alzheimer's Coordinating Center. One located at Mayo Clinic in Jacksonville and is also an MDC. The second is with the University of Florida Alzheimer's Disease Center in Gainesville. ADRC's evaluate people for diagnosis and participation in research studies. Clients may have the opportunity to try new medicines to research their effectiveness with slowing down, stopping, or preventing the disease.

## ADRD Training to Enhance Quality Care Measures in Florida

Policies and procedures are critical to ensuring high-quality care is available and delivered to the many people living with ADRD. It is equally important the guidelines take into account the range of services needed to address the many different stages of ADRD. These guidelines are presented through legislatively mandated trainings to groups such as direct care workers and medical professionals such as primary care physicians and geriatricians.

The ability of these health care professionals to provide quality ADRD care is sometimes compromised due to the high rate of turnover and possible job dissatisfaction. The National Academies of Sciences, Engineering, and Medicine have suggested changes to federal requirements for direct care worker training. The recommended focus is an increase in skills, knowledge, and abilities related to individuals living with ADRD.

## Demand for Geriatricians to Meet Needs of Alzheimer's Population



Direct care workers such as nurse aides, home health aides, and home care aides provide most of the paid long-term care to older adults. Indirect care workers, such as general services, administration, and security personnel provide indirect but interactive care to people with ADRD. There is a vital need for all staff to be appropriately trained on a consistent and frequent basis so they may stay up to date in their interactions with older individuals.

For older adults with ADRD, there is a growing need for

medical personnel who specialize in the field of geriatrics. In Florida, there were 348 geriatricians in 2019. As the state's population continues to grow, Florida will need over 1,000 new providers by 2050, to meet the unique demands of the Alzheimer's disease and related dementias population. With this shortage of medical specialists, to meet the current and future needs for ADRD, primary care physicians will play an increasingly important role in caring for individuals with ADRD.

For medical professionals there is currently no mandated ADRD continuing education requirements; however, a set of standardized trainings for this particular group could help fill in the gap between now and 2050.

## **Academics**

DOEA's partnership with Florida State University (FSU) Geriatrics Workforce Enhancement Program (GWEP) has provided advancement toward improving education in the workforce. The FSU Resources and Education on Aging, Community, and Health (REACH) Project aims to offer expert education and empowering care for the aging population in Florida and the nation through a variety of products developed for healthcare professionals and student trainees, family caregivers of older adults, and older adults themselves. It is funded by the GWEP and powered by the Department of Geriatrics at the FSU College of Medicine. In collaboration with other departments at FSU, as well as community partners, The Geriatric Care Enhancement Project develops a wide range of resources intended to be freely used and shared across the spectrum of elder care professions and partners.

The Alzheimer's Association promotes free curriculum to universities and colleges. To help prepare the future public health workforce to address the growing crisis, the Centers for Disease Control and Prevention (CDC), the Alzheimer's Association, and Emory University's Rollins School of Public Health recently released an update of their curriculum [A Public Health Approach to Alzheimer's and Other Dementias](#). This free and flexible curricular resource is designed for use by faculty in schools of public health and related disciplines. [The curriculum](#) introduces students to information about ADRD, as well as public health approaches that address Alzheimer's disease and related dementias.

## **QUALITY CARE MEASURES IN FLORIDA**

[CMS quality measures](#) are tools that help measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structures that are associated with the ability to provide high-quality health care. These goals include effective, safe, efficient, patient-centered, equitable, and timely care.

The responsibility for monitoring the safety of ADRD patients in facilities rests with several state agencies and programs: AHCA, Department of Children and Families (DCF), and the Long-Term Care Ombudsman Program (LTCOP) within DOEA. AHCA conducts regular inspections of facilities to ensure regulatory compliance. In addition, the state Long-Term Care Ombudsman Program is established by the Older American Act (42 USC 3058f and 3058g), 45 CFR 1321 and 1324, and Chapter 400.0063 F.S. Representatives of the office conduct unannounced visits to

nursing homes, assisted living facilities, and adult family care homes for the purpose of resolving residents' complaints and advocating for the protection of residents' rights. Services are free.

AHCA regulates and monitors compliance of Florida's licensed health care facilities through their division of Health Quality Assurance. The Division of Health Quality Assurance protects Floridians through oversight of health care providers. The Division is funded with more than \$49 million in state and federal funds. Health Quality Assurance licenses and/or certifies and regulates 40 different types of health care providers, including hospitals, nursing homes, assisted living facilities, and home health agencies. In total, the Division licenses, certifies, regulates, or provides exemptions for more than 48,000 providers.

DOEA provides most of its services to Florida seniors through contracts with the state's 11 AAAs. DOEA regularly monitors those contracts to ensure funds are being used properly and services are being sufficiently provided to the Florida elders who need them. DOEA ensures quality of care through a designated quality assurance team.

### **Silver Alert**

The purpose of the statewide Silver Alert is to help law enforcement officers rescue missing seniors with AD/DR who became lost while driving a vehicle. The Silver Alert allows widespread broadcast of information to the public that a person is missing using message signs on highways that note the color, make, and tag number of the vehicle the missing person is driving.

State Silver Alert Statistics Overview 2008 - August 2020:

- Total activations: 2,408
- Total denials: 441
- Total recoveries prior to activation: 278
- Outcome total/percentage
- State Silver Alert recoveries: 297 (12%)
- Direct recoveries: 251 (10%)
- Indirect recoveries: 46 (2%)
- Recovered deceased: 31 (1%)

Florida is unique in that the MDCs have specific protocol in response to a Silver Alert. MDC coordinators provide follow up with local law enforcement and the primary caregivers after the missing person is found. The coordinators provide education, support and referrals to the families and establish a plan to prevent further wandering.

### **Elder Abuse and Prevention Program**

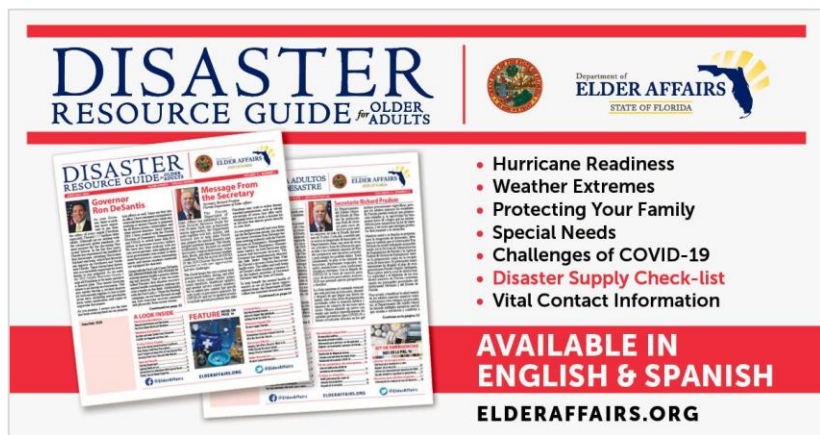
DOEA operates the Elder Abuse Prevention Program through achievement of the activities described in Title VII, Chapter III of the Older Americans Act. This Ensures that services are met through a collaborative effort and provided to any population that may need assistance with any portion or component of the elder abuse prevention program. Services may be provided, for example, by Area Agencies on Aging (AAAs), local law enforcement systems, or other state

agencies or courts of competent jurisdiction. The goal is to effectively deal with the prevention of elder abuse, neglect, exploitation, or other related matters. This program works to facilitate and remove all barriers to education, prevention, investigation, reporting, training, referrals, or any activity within the Older Americans Act for the Elder Abuse Prevention Program.

## Disaster Preparedness

The Department's Emergency Coordinating Officer (ECO) collaborates with the Florida Division of Emergency Management (DEM) on emergency preparedness issues and post-disaster response. The Department ensures that the AAAs and local service providers have Disaster and Continuity of Operations Plans (COOP) to address needs before, during, and after an emergency.

The ECO is responsible for maintaining rosters of personnel to assist in disaster operations and coordinating appropriate training for agency personnel. The ECO is responsible for ensuring each state agency and facility has a disaster preparedness plan that is coordinated with the applicable local emergency-management agency and approved by DEM.



Each year DOEA and the Florida Division of Emergency Management provide an updated disaster preparedness guide.

## Special Needs Shelters and Registry

A Special Needs Shelter (SpNS) is for "someone who during periods of evacuation or emergency, requires sheltering assistance, due to physical impairment, mental impairment, cognitive impairment or sensory disabilities." Chapter 64-3, [Florida Administrative Code](#) The Florida Department of Health, Bureau of Preparedness and Response administers a statewide Special Needs Shelter Program to assist County Health Departments in addressing the special medical needs of people in their community. These shelters are eligible for the following:

- People with special medical needs
- People whose care exceeds the basic first aid provided at general population shelters
- People with impairments or disabilities who are medically stable and do not require medical care

The 17 designated MDCs are required by contract to prepare patients and caregivers for natural disasters. MDCs provide information on emergency shelters in their areas, special needs shelters, and disaster preparedness guidebooks. MDCs evaluate if patients and caregivers may need additional assistance during a storm and guide patients and caregivers to get connected with their local Special Needs Registry. The registry is run by the Florida Division of Emergency

Management to assist residents who need transportation or shelter when alerted to evacuate their homes.

### **Elder Helpline and Information Referral Services: 1-800-963-5337**

The Elder Helpline provides information and referral services to the community. Each AAA, as part of their contract, maintains the operation of the Elder Helpline for their area (PSA). This service includes assessing the needs of the elders, evaluating appropriate resources, indicating organizations capable of meeting those needs, helping elders for whom services are unavailable by locating alternative resources and actively participating in linking elders to needed services or volunteer opportunities.

### **Emergency Generator Rule(s)**

As a result of Hurricane Irma, Florida implemented the emergency and permanent generator rules. AHCA and DOEA implemented the permanent rule making process to ensure life-saving measures included in the emergency rules were permanently codified. This action follows emergency rules for both nursing homes and assisted living facilities that requires facilities to obtain resources, including a generator and the appropriate amount of fuel, to sustain operations and maintain comfortable temperatures for at least 96-hours following a power outage. (Rules 58A-5.036 Emergency Environmental Control for Assisted Living Facilities and 59A-4.1265 Emergency Environmental Control for Nursing Homes, F.A.C.)

### **Response to COVID-19**

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

### **Meal Delivery**

DOEA worked with the state's 11 Area Agencies on Aging to provide over 13 million home-delivered meals to older adults staying safer at home from March to October. Meal delivery increased over 200% for 16 consecutive weeks from April to August. This shift was implemented within 48 hours of closings of congregate meal sites by working with the AAAs and volunteers. Part of the 13 million meals included 2.8 million meals from DOEA's launch of the Restaurant Meal Initiative. The partnership among DOEA, The Department of Business and Professional Regulation (DBPR) and the Florida Restaurant and Lodging Association (FRLA) allowed the needs of the business community and workers in the restaurant business to be matched with the needs of the elderly to continue their meal delivery during the pandemic.



## Project VITAL

While it is imperative for individuals to practice social distancing, it does not have to result in complete social isolation. To mitigate these circumstances, DOEA and the Alzheimer's Association have developed an initiative called Project: VITAL (Virtual Inclusive Technology for All).



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

## MP3 Players

The Florida Alzheimer's Association donated pre-loaded MP3 Players and DOEA began delivering them to socially isolated seniors and adults living with ADRD in April. Studies suggest that listening to music can have numerous positive effects on health, including:

- Improving mood
- Reducing stress
- Lessening anxiety
- Improving memory
- Easing pain
- Providing comfort
- Improving cognition

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

## Therapeutic Robotic Pets



There is a 45% increased risk of mortality in seniors who report feeling lonely. Reducing the exposure of seniors to the coronavirus by social distancing and remaining isolated is imperative, but nonetheless poses its own challenge. DOEA has, and continues to, address this challenge by investing in therapeutic robotic Joy for All<sup>®</sup> Companion Pets and

distributing them to socially isolated seniors and the caregivers of individuals living with ADRD. The pets are making an immediate impact by reducing the negative health effects – physical as well as mental and emotional – associated with loneliness.

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

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

The therapeutic robotic pets have also made an immediate impact by providing some respite to family caregivers of those living with ADRD; those family caregivers are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions. Robotic pets have been utilized in many countries for over 16 years and they have become more common in the United States to supplement interactions between those living with ADRD and their caregivers. Thus far, DOEA has invested in 3,600 pets and the response has been overwhelmingly positive. Introduction letters and user guides are provided in English and in Spanish.

## Scent Kits

DOEA has partnered with Scent Evidence K9 to distribute 5,000 Scent Preservation Kits® to caregivers of those living with ADRD. As Florida seniors stay at home, they may have an increased tendency to wander and become lost. If that happens, proactive family safety measures, such as the Scent Preservation Kit®, are providing effective response systems to locate missing persons and



return them to safety. These kits provide K9 responders with uncontaminated scent articles that significantly reduce the time it takes to locate someone. Introduction letters, user guides, and now a thumb drive, are provided in English and in Spanish.

## Telehealth

DOEA's 17 designated MDCs quickly responded to establish alternative ways to continue to provide services to patients and caregivers. MDCs transitioned to provide telehealth visits, check-in calls, virtual support groups and virtual training statewide.

## A LOOK TO THE FUTURE

### Strategic Components Considered to Mobilize A State Response to ADRD Public Health Crisis

#### The Alzheimer's Disease Advisory Committee

There are currently 15 appointed positions on the ADAC, 11 of whom are appointed by the Governor, two by the President of the Senate, and two by the Speaker of the House of Representatives. ADAC Committee members meet quarterly to discuss the progress made by the committee and future action plans. Distinguished committee members of ADAC include:

- Chair Rosemary Laird; Medical Director Advent Health Maturing Minds Memory Disorder Clinic
- Michelle Branham; VP of Public Policy, Alzheimer's Association
- Peggy Connelly; National Director of Memory Care
- Donna Flanagan; Speech and Language Pathologist
- Minority Leader Senator Audrey Gibson
- Robert Glueckauf; Professor Department of Behavioral Sciences and Social Medicine
- Majority Whip Michael Grant; State Representative
- María de los Ángeles Ordóñez; Director Louis and Anne Green Memory and Wellness Center



- Fátima Perez; Regional Manager, State Government Affairs Koch Co Public Sector
- Representative Scott Plakon; State Representative
- Aileen Ruess; Owner of Ace Senior Care Management

The 2020 ADAC Report identified eight priority areas condensed from the 37 recommendations per the 2013 PRTF. These eight priorities establish goals and strategies to be accomplished through joint partnerships, identified as follows:

- Provide a single access point for all ADRD resources
- Education and awareness
- Workforce development
- Respite
- Clinical care
- Research
- Policy change
- Elder neglect and abuse prevention

## **STRATEGY TO MOBILIZE A STATE RESPONSE TO THE ADRD PUBLIC HEALTH CRISIS**

### **State Health Improvement Plan Priority Area 9 (SHIP)**

The current DOH SHIP began in 2017 and will end on December 31, 2021. Priority Area 9 (PA9) ADRD was added to this plan in June 2019. PA9 implementation began two and a half years into the plan. After one year's progress, the subcommittee co-chairs recognized the importance of recalibrating the original goals. The 2021 plan will offer more specific, achievable objectives driven through measurable metrics or SMART goals. These new SMART goals will position PA9 to continue the successful inclusion into the DOH 2022-2027 SHIP plan.

### **Priority Area 9**

#### **Educating and Empowering Florida**

- Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis
- Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the lifespan
- Increase messaging that emphasizes both the important role of caregivers in supporting people living with dementia and the importance of maintaining caregivers' health and well-being
- Promote prevention of abuse, neglect, and exploitation of people living with dementia

- Provide information and tools to help people living with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia
- Strengthen knowledge about, and greater use of, care planning and related tools for people in all stages of dementia
- Improve access to and use of evidence-informed interventions, services, and supports for people living with dementia and their caregivers to enhance their health, well-being, and independence

### **Develop Policy and Mobilize Partnerships**

- Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people living with dementia
- Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces
- Support better informed decisions by educating policymakers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem
- Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes
- Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people living with dementia and their caregivers
- Assure public health plans that guide emergency preparedness and emergency response address the special needs of people living with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people living with dementia

### **Assure a Competent Workforce**

- Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve
- Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being
- Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action
- Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management

- Strengthen the competencies of professionals who deliver healthcare and other care services to people living with dementia through interprofessional training and other strategies
- Educate healthcare professionals about the importance of treating comorbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia
- Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services

### **Monitor and Evaluate Outcomes**

- Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022
- Support national data collection on dementia and caregiving
- Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.
- Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact
- Estimate the gap between workforce capacity and anticipated demand for services to support people living with dementia and their caregivers

## **CLOSING**

### **From the Desk of the Secretary...**

The 2020 Alzheimer's Disease State Plan really begins with the narrative of where we began approximately eight years ago, and where we plan to go over the next three years.

These past few years have been critical and unprecedented in the world of ADRD in Florida. We began with the Purple Ribbon Taskforce and 37 recommendations eight years ago. Over the past two years, Governor DeSantis has challenged the state to excel via his Dementia Action Plan. In that challenge, Priority Area 9 of the State Health Improvement Plan (SHIP) was created. The State also passed important legislation to empower the Alzheimer's Disease Advisory Committee. Last year, the State also passed critical legislation to establish a Dementia Director position within DOEA. In the Governor's Dementia Action Plan, we also increased participation in the Dementia Care and Cure Initiative, Memory Disorder Clinics, and partnered with the Department of Health and the Alzheimer's Association to apply for the federal BOLD infrastructure for Alzheimer's funding.

These separate and distinct initiatives for ADRD in Florida have created a baseline infrastructure and a great deal of momentum to enhance policy, programs, services, research, and support

capacity. The outline of our plan moving forward for the next three years will be to create synergy, cohesiveness, and consistency with all of these aforementioned priority activities.

Over the next three years, we plan to:

**First**, hire a dedicated Dementia Director to continue building connections in the current state ADRD infrastructure by working in cohesion with state agencies, providing support for the ADAC and the 17 MDCs across the state, and serving as a central conduit for information and services.

**Second**, provide support to ADAC by focusing on key priorities laid out by the Committee and how those priorities plug into the public health platform.

**Third**, we have received approval to recalibrate Priority Area 9 to build upon the National Public Health Roadmap entitled, “The Healthy Brain Initiative.” The new PA9 SHIP goals that will be presented this year for next year’s implementation are:

- **Educating and Empowering Florida**
- **Develop Policies and Mobilize Partnerships**
- **Assure a Competent Workforce**
- **Monitor and Evaluate**

**Fourth**, we will continue to focus on expanding existing services and closing the gap on critical needs in our ADRD population. In this effort, we will support proposed legislation to enhance ADRD training in our nearly 4,000 long-term care communities, as well as continuing ADRD education for our medical professionals in Florida.

**Fifth**, we will continue to identify areas to enhance workforce development in ADRD professions, in order to close the gap for these critical workers in our state.

**Sixth**, we will continue to support and promote services and support programs that prioritize diverse and underserved populations that are disproportionately affected by ADRD.

**Seventh**, we will continue to offer special programs that mitigate the effects of senior isolation in our state through Project: Vital, the robotic companion pets, MP3 player program, Restaurant Meal Initiative, Scent Preservation Kits, and other innovations.

**Eighth**, we will continue our efforts to avoid overlap and consistently explore alternative funding opportunities through the BOLD Infrastructure for Alzheimer’s Act per the Governor’s request in 2019. The BOLD Act authorizes \$100 million over five years to carry out the various public health activities addressing Alzheimer’s disease and related dementias. Priority will remain on early detection and diagnosis, lifestyle interventions, brain health, and data collection.

**Finally**, this newly updated **2020 Alzheimer’s Disease State Plan** offers a collective and comprehensive historical narrative over the past 10 years for ADRD in our state, along with corresponding data. Milestones were achieved in 2013, with the advent of the 37 recommendations offered by the Purple Ribbon Task Force, the expansion of ADAC in 2019, and the designation of a dedicated Dementia Director in 2020. Prioritizing ADRD in Florida’s State Health Improvement Plan put ADRD into the public spotlight. This, in conjunction with the Governor’s five-part Dementia Action Plan of 2019, became a strong foundation and built energy and pace for our next three years.

Florida ranks as the second highest prevalence for ADRD in the nation. Florida’s acknowledgement of where we stand on the national ADRD stage has taken our state from the role of “implementer” to “innovator.” The combination of our priority ADRD initiatives, with key organizational support through the Dementia Director and Director of Livable Florida, will ensure success of this next ADRD chapter in Florida.

In short, our plan is to harness the energy and momentum created under the leadership of Governor Ron DeSantis and continue to build a highly developed ADRD infrastructure. Convening the ADRD work across the state and interlocking our initiatives with SHIP, ADAC, DOEA, and private partnerships will be key to this success.

Sincerely,

Richard Prudom  
Secretary  
Department of Elder Affairs